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Health and Human Rights

DECEMBER 2025, VOLUME 27, NUMBER 2

SPECIAL SECTION
Exploring Accountability for Health Rights

Guest Editors
Paul Hunt and Anuj Kapilashrami

SPECIAL SECTION
Institutional Corruption and Human Rights in Mental Health

Guest Editors
Alicia Ely Yamin, Camila Gianella Malca, and Daniela Cepeda Cuadrado

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Harvard FXB Center for Health and Human Rights and
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Health and Human Rights Journal (online) ISSN 2150–4113

MASTHEAD

Publisher
FXB Center for Health and
Human Rights, Harvard University
and Dornsife School of Public
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HHR's open access policy is made possible through the generous support of the FXB Center for Health and Human Rights, Dornsife School of Public Health, Drexel University, and our institutional consortium members.

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Table of Contents

SPECIAL SECTION: EXPLORING ACCOUNTABILITY FOR HEALTH RIGHTS

SPECIAL SECTION: INSTITUTIONAL CORRUPTION AND HUMAN RIGHTS IN MENTAL HEALTH

GENERAL PAPERS

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EDITORIAL

Accountability from Below

PAUL HUNT AND ANUJ KAPILASHRAMI

We are indebted to everyone who, through this collection of papers and viewpoints, is sharing their experiences and research on human rights accountability in Gaza, Tigray, Kurdistan, Uganda, Bangladesh, Nepal, South Africa, Taiwan, Maharashtra (India), Aotearoa New Zealand, New York City (United States), and globally. Some of these contributions describe intolerable suffering, the inspirational professionalism of health and human rights workers, and the indispensable dedication of allies. Most of them expose, to one degree or another, the failure of state-centered accountability and a determination to reimagine and construct people-centered accountability.

Global health is characterized by regime complexity, fragmentation, and overlapping norms. As Rosalind Turkie and Pramiti Parwani write in their contribution, human rights responsibilities are dispersed and lines of accountability are blurred across multiple and diverse stakeholders. We are grateful to those contributors who examine these challenging issues, including how to conceptualize accountability in modernity.

In this editorial, we begin with a human rights paradox and the contemporary human rights landscape within which we locate health and accountability. We then signal some of the issues that emerge from the special section's collection of experience, insights, and ideas. We close with a practical, specific, institutional proposal, as well as an agenda for future research.

A paradox and the contemporary human rights landscape

Human rights are meant to control the conduct of states. But states ratify human rights treaties. They pass national human rights laws. They implement these treaties and national laws. States adjudicate human rights disputes through their courts. In short, the state-centered human rights sphere is deeply paradoxical. Human rights are meant to regulate the conduct of states, but states control human rights.[1]

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Competing interests: None declared.

Given this human rights paradox, we envisage the contemporary human rights landscape as a state-centered human rights sphere (e.g., states and corporations); a people-centered human rights sphere (e.g., communities, peoples, and social movements); and a space where both spheres relate to each other—that is, a "relational space."

Relatively speaking, the state-centered human rights sphere is dominant and the people-centered human rights sphere is subordinate, but emergent and growing.

The relational space between the two spheres includes international human rights bodies, national human rights institutions, professionalized civil society organizations, and philanthropic organizations, which, to one degree or another, are independent from the state and corporations.

Both spheres, and the relational space lying between them, are very important and need more attention. However, a crucial way of responding to the problematic human rights paradox is by empowering the people-centered sphere. This special section gives particular (but not exclusive) attention to advancing accountability in the people-centered human rights sphere. We call this people-centered accountability or accountability from below.[2]

Emerging issues

One the most striking issues to emerge from the contributions has two interrelated dimensions: the patronizing disposition of unaccountable power and the yawning accountability gap.[3] This undemocratic disposition of power, and accountability gap, extend to subnational, national, and global levels in health.

Most contributors recognize that power and accountability are inextricably connected. Depending on their experiences, some contributors pose searching questions, while others venture some answers. Drawing from their experience in New York City, Marie-Fatima Hyacinthe, Jessica Peñaranda, and Alice Miller, for example, ask "How do we facilitate accountability when people and institutions with power abuse those who are systematically denied power?" They conclude that "conversations about accountability are conversations about power inequities." On the other hand, drawing from the experience of community-based accountability in Maharashtra, Dhanajay Kakade suggests how meaningful accountability within public health demands the interaction of "three interdependent yet distinct forms of power—mandate power, solidarity power, and knowledge power." Kakade reports that these intersecting powers, exercised by communities, together generate "a change cycle."

A second issue, solidarity, comes in multiple forms. Bilal Irfan, Kaden Venugopal, Michelle Anne Cohen, et al., for example, present three "grassroots movements" recently prominent in Gaza: Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition. These initiatives represent coalitions of health care workers, civil society, and parliamentarians who exemplify "translocal networks translating global norms into localized, insurgent institutional practices, thereby expanding who enforces human rights and how." The authors discuss the politics of coalition-building, recognize the inevitable tensions, and chart a way forward. They advise that "[people-centered accountability] requires adopting movement-level codes of conduct that safeguard the dignity of those most at risk."

Coalitions of health workers and others recur. Dawit Kassa, Zazie Huml, and Bram Wispelwey describe the recent war in Tigray, which dismantled one of Ethiopia's strongest regional health systems, leaving it in ruins. Health professionals in Tigray are constructing "an alternative, victim-led architecture of accountability." At the forefront of this effort is the Tigray Medical Association (TMA), a professional body that has "transformed into a rights-based coalition." Also, a coalition of TMA, civil society organizations, women's associations, and legal advocates has established a transitional justice working group that has received some support from civil society organizations in Canada and Ireland. These partnerships highlight "the emergence of a fragile transnational solidarity." As the contributors put it, "Tigrayan health professionals are working to advance accountability from below through grassroots, survivor-led efforts that seek justice through collective organization, legal innovation, and moral authority."

Goran Zangana, Shokh Mohammad, Baxan Jamal, et al., remind us that in fragile and conflict-affected settings, traditional accountability structures are often weak or absent. The Kurdistan Region of Iraq offers a stark illustration: electoral delays, parliamentary paralysis, and widespread corruption have eroded public trust and oversight. The contributors explain that within this vacuum "grassroots citizen committees have emerged as crucial actors in advancing the right to health and fostering people-centered accountability." Local citizens have stepped in to monitor, document, and identify breaches of the right to health. "Citizen-led health committees in the Kurdistan Region exemplify how grassroots initiatives carry the potential for sustaining accountability where formal structures fail."

In their contribution, Grady Arnott, Beatrice Odallo, Teddy Nakubulwa, et al., examine rights-based approaches to access sexual and reproductive health services, primarily at the local level, drawing from case studies in Uganda, Bangladesh, and Nepal. Collaboration, participation, accountability, and solidarity are features of the three case studies, and here we mention one of them. A consortium established a human rights-based accountability initiative in Rohingya refugee camps in Bangladesh (2022–2025), integrating legal, social, and participatory accountability mechanisms, with leadership from Rohingya women and community leaders at its core. Accountability for access to services was operationalized through four interconnected components, one of which was "community solidarity networks that provided peer support and feedback relating to [sexual and reproductive health and rights], gender, and human rights realities."

A third recurrent issue is that when addressing accountability, the focus on states and courts is necessary, but not sufficient. Contributors devote attention to holding states accountable, but they also look beyond the statist horizon. Gamze Erdem Türkelli and Rossella De Falco, for example, focus on how to hold accountable multi-stakeholder partnerships. While some authors discuss the role of the judiciary in South Africa (Lindani Mhlanga and Tamanda Kamwendo) and Taiwan (Tsung-Ling Lee and Chien-Liang Lee), several contributions (such as Kakade), look beyond the role of the courts. In short, when it comes to accountability and global health, consideration of states and courts is important, but not enough if we aspire to effective accountability.

Another theme is independence. Some, but not all, forms of accountability depend on independence. But what does independence mean? In her contribution, Alicia Ely Yamin explains that autonomy (freedom from political influence) and decision-making authority (which depends on normative and institutional legitimacy) are equally relevant to the independence of an oversight mechanism at the global level. In their viewpoint, Tania Agosti, Andrea Baldwin, Susana Fried, et al., consider how to respect the independence of an accountability mechanism while ensuring that the mechanism upholds essential features of international human rights, which are subject to the principle of non-retrogression. This conundrum is an echo of the Roman aphorism "Who guards the guards?" The authors argue that civil society should scrutinize the work of United Nations Independent Experts, and they urge the Office of the United Nations High Commissioner for Human Rights to promote good practices among independent accountability mechanisms and to call out any deviations from established human rights standards.

A fifth issue is the close relationship between advocacy, activism, and accountability. All three are interrelated and important, but they are not the same. While advocacy focuses more on shifting attitudes and aims to garner greater support for ideas or collective interests, activism involves more direct action that may involve challenging ideas, underlying structures, and social norms and values.[4]

Consider sit-ins, consumer boycotts, and shareholder activism against the privatization of health services. Advocates and activists may demonstrate and hold posters that declare "PEOPLE NOT PROFITS." Their objective may be accountability. They may even call for accountability. Demonstrations, posters, and calls for accountability are important tools and tactics for advocacy and activism, but they are different from accountability.

What is accountability? In our call for papers, we adopted a working definition of accountability and encouraged contributors to critique it. This entailed a narrative definition plus some constituent features of accountability. The narrative definition, which emphasizes a relational understanding of power, views accountability as

> *the formal and informal processes, norms, and structures, particularly in a democratic system[,] that [demand] power holders account for their decisions and actions and remedy any failures in delivering their duties.*[5]

As for the constituent features of accountability, we identify *monitoring* (e.g., data collection and interviews); *review* (e.g., assessing what is happening against human rights commitments and standards); and *remedial action* (e.g., taking necessary steps when monitoring and review reveal that human rights commitments and standards are not being kept).[6] This complementary combination of narrative and constituent features provides our working definition of human rights accountability.

Several contributors discuss the conceptualization of accountability. For example, Thana de Campos-Rudinsky and Daniel Wainstock propose "a people-centered, decolonial approach to global health governance" that reconceptualizes accountability as a moral virtue and operationalizes it through the structural principle of subsidiarity. In his contribution, Mulu Beyene Kidanemariam explores the maternal death surveillance and response (MDSR), which is a form of maternal death review. He argues that MDSR should be reconceptualized as a human rights accountability mechanism "without reducing it to blame."

In their paper, Lee and Lee reject the understanding of accountability as "an episodic event." They argue that accountability relies on multiple interactions between a range of institutions—courts, parliaments, executives, civil society organizations, the public, the media, and human rights commissions—over time. For this reason, they call for "temporal accountability"—that is, "an institutional design that builds time-bound obligations for review, disclosure, and corrective action into the accountability cycle."

In her viewpoint, Emma Rawson-Te Patu emphasizes that different worldviews conceptualize accountability differently. As she puts it, "Western models of accountability tend to be individualistic and revolve around legal responsibility, compensation, and punishment. In contrast, Indigenous worldviews tend to emphasize the interconnectedness of all beings, the importance of historical context, and the restoration and prioritization of relationships underpinned by lore, rather than law."

"In this ongoing process," she writes, "accountability demands not only reparations for the past but also a shared commitment to a future built on equity, mutual respect, and genuine partnership." She concludes that there are lessons "from this conception of accountability that resonates with the worldviews of many Indigenous peoples globally," and she offers Indigenous values as guiding principles.

Clearly, more discussion is needed on the meaning of human rights accountability in law, governance, and local contexts. However, if we wait for widespread agreement on what human rights accountability means, we are likely to be waiting a long time. Perhaps the way forward is not a one-size-fits-all definition but a broad consensus on key principles and vision. In any event, the discussion should be informed by thoughtful, inventive praxis because the undemocratic disposition of unaccountable power, and the accountability gap, are too serious to wait. This takes us to the next paragraphs.

A new accountability proposal at the global level

Some contributors raise the possibility of establishing new human rights accountability arrangements in health. In their discussion about multi-stakeholder partnerships, Türkelli and De Falco suggest that "a solution might be to devise an external, independent body that effectively holds them and their constitutive members accountable." Kidanemariam observes that another human rights approach "is to establish national, regional or global independent, transparent, non-statist bodies charged with responsibility for identifying, analyzing and publicizing the structural injustice exposed by [maternal death surveillance and response]." Irfan et al. remark that movements have turned to public hearings, civil society juries, and people's tribunals to gather testimony, apply international standards, and determine when acts and omissions are breaches of human rights and humanitarian law. Although such tribunals "lack coercive power, they have shaped public understandings of atrocity and informed subsequent legal processes."

Yamin provides a remarkable reflection on the United Nations Secretary-General's Independent Accountability Panel on Women's, Children's and Adolescents' Health (IAP). She served on the IAP throughout its short life between 2016 and 2020. Yamin observes that the story of United Nations efforts to create "an independent mechanism to foster greater accountability across global health is one of high hopes, missed opportunities, and, ultimately, planned project failure." She argues that "the deeply neoliberal and colonial architecture of global governance for health constrains possibilities for transformative accountability."

Most useful for present purposes, Yamin writes:

> *I … share four lessons as to why meaningful accountability has been so elusive in global health and how future efforts might benefit from these insights. These lessons relate to the need for (1) normative grounding; (2) institutional legitimacy; (3) genuine independence; and (4) conceptual clarity with respect to the meaning of accountability.*

We keep Yamin's lessons in mind as we briefly outline a new accountability proposal. Of course, if the proposal proceeds, we look forward to a closer examination of her insights.

We encourage communities, peoples, and social movements to devise effective accountability arrangements in health at the subnational and national levels. We hope that some of the diverse contributions—from the Middle East, Africa, Oceania, South Asia, and North America—will inspire and provide guidance. While subnational and national accountability arrangements will have to reflect their own unique historical and contemporary context, some arrangements may have features that are transferable from one context to another. In the following paragraphs, however, we confine our remarks to the global level.

If the health community is serious about accountability at the global level, we cannot depend on states and their international agencies.[7] The state-centered approach is not working. Allies in the relational space have a major role to play, but they cannot do the job by themselves. Instead, we must look to the people-centered human rights sphere—communities, peoples, and social movements—where human and collective rights belong. We propose a global health coalition of robustly independent organizations and networks that are closely aligned with these constituencies.

The global health coalition should establish a human rights accountability panel or platform. The coalition's organizations, and their constituencies of communities, peoples, and social movements, would ask the panel to consider carefully selected and defined global health issues. The panel would hold specific human rights duty bearers to account, such as a state, corporation, or multi-stakeholder initiative.

Sitting in public, the panel would provide a platform for those affected to tell their stories and tender evidence. Duty bearers, such as states and corporations, would be invited to address the panel. The panel would give particular attention to inequitable structures, their origins, and the most deprived. Human rights violations would be found, or not. The panel's findings would be as short and accessible as possible. Its follow-up recommendations would include grassroots activism and advocacy, such as boycotts where appropriate.

Of course, this people-centered approach gives rise to numerous questions. The panel's findings would not be binding, for example, but neither are the decisions of international human rights bodies. The panel would elevate the voices, perspectives, and values of communities, peoples, and social movements. Importantly, it would take account of contemporary international human and peoples' rights, as well as the epistemologies of the global health coalition and its constituencies.

Our proposal builds on numerous precedents. There are examples of public hearings, citizen forums, and peoples' tribunals. The People's Health Movement and its assemblies have extensive experience from which we can benefit.[8] *Peoples' Tribunals and International Law*, edited by Andrew Byrnes and Gabrielle Simm, is an encouraging resource.[9]

In summary, the panel's legitimacy would rest on the global health coalition and its constituencies of communities, peoples, and social movements. As Irfan et al. put it in their paper, "legitimacy comes from the people they serve, not from the podiums they reach." Building on existing practice, the panel would be a standing (i.e., permanent) body subject to review after three years. Panel membership would be chosen by the global health coalition and its constituencies; membership would vary with the topics under scrutiny and include those with lived experience. The panel's methods and standards would be grounded in human and peoples' rights, respectful of diverse worldviews, and informed by data and other evidence. Subject to the preceding sentence, the panel would find states, corporations, multi-stakeholder partnerships, and other duty bearers responsible for violations of human and peoples' rights (or not). The panel's short and accessible findings would be publicized as widely as possible.

The panel would be located in the people-centered human rights sphere and supported by suitable allies from the relational space. Aware that the proposal reflects a particular worldview, we simply place it on the table for discussion and emphasize the imperative of epistemic justice. By advancing accountability from below, the proposal aims to address the patronizing disposition of unaccountable power, as well as the wide accountability gap at the global level.

If there is sufficient support, we wish to advance this proposal in 2026. What is your view? Do you favor a global health coalition, closely aligned with communities, peoples, and social movements, which establishes a permanent panel that addresses the human rights accountability gap in global health? The coalition and panel will need time to take shape, develop, and flourish. Should we make a start? Please let us know what you think.

Conclusion

Whether or not the proposal attracts sufficient support, there is much more work to be done to broaden the scope of accountability research across multiple domains. The scope of the research should encompass empirical, conceptual, and praxis. This includes a deeper exploration of the *design* and *processes* that govern accountability mechanisms (how they are working), as well as the overarching socio-political and institutional *contexts*, and underlying *conditions*, in which they operate, especially as they relate to socially excluded and marginalized groups.

A second aspect is attending to what Anuj Kapilashrami, Neil Quinn, and Abhijit Das refer to as the "black hole" in accountability scholarship and practice. It is crucial to extend inquiries into "the corporate-state nexus and the multi-level governance in which contemporary (health) systems and states operate."[10]

A third aspect is about acknowledging and correcting power imbalances within both community dynamics and state-citizen relationships. Furthermore, decolonizing the praxis of accountability necessitates transcending mere reform within existing colonial frameworks. Instead, we must fundamentally reimagine accountability—and indeed, the world order—through the lens of decolonial principles, including sovereignty, relational epistemologies, and justice.

There are several important ways to approach this work, such as:

- Investigating how colonial legacies continue to shape contemporary judicial and non-judicial forms of accountability.
- Exploring alternative epistemologies and practices of accountability rooted in Indige-

nous, local, and marginalized (minoritized) perspectives—i.e., challenging Western-centric perspectives.

- Assessing the role of restorative justice in decolonial contexts, with an emphasis on healing, reparations, and recognition of communities affected by colonial injustices.
- Understanding how global power relations affect local accountability efforts, alongside investigating how decolonial strategies can promote genuine local sovereignty and self-determination.

This agenda not only calls for robust research and dialogue but also strives for transformative accountability that genuinely reflects the needs and voices of marginalized communities.

We close by acknowledging the irrepressibility of communities, peoples, social movements, and professional associations in the struggle for accountability from below. Despite huge challenges and powerful opposition, there are encouraging developments and a positive spirit, especially among the global majority. As Irfan et al. put it:

> *If state-centered systems remain unable or unwilling to deliver, accountability from below will proceed—counting the dead with accuracy, confirming human rights violations and violators, preserving the names and methods of those who cared, and insisting that the right to health is a claim on power exercisable by the people themselves.*

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VIEWPOINT

Fragile Gains, Shifting Mandates: Civil Society, State Synergy, and the Future of Health Accountability in Maharashtra, India

DHANANJAY KAKADE

Introduction

The Community-Based Monitoring and Planning (CBMP) initiative emerged in 2007 as a collaborative effort between the government of India and civil society organizations under the framework of the National Rural Health Mission (NRHM). Rooted in the long-standing advocacy of the People's Health Movement, CBMP seeks to institutionalize "communitization" in public health governance by creating formal spaces for citizens to monitor services and hold the health system accountable. The initiative was initially rolled out in nine states, including Maharashtra, covering 324 primary health centers across 36 districts.

Since then, Maharashtra's CBMP has gradually evolved into one of the more sustained and collaborative efforts between civil society and the state in India's health sector. It has reached approximately 1,000 villages across 17 districts. Using community scorecards, social audits, and public hearings, CBMP helps communities assess how well services are being delivered, engage directly with officials, and secure commitments to improvements, embedding a culture of accountability and community participation in the public health system.

This CBMP involves four broad interlinked elements: monitoring, review, remedial action, and local planning. Monitoring, through scorecards and social audits, has generated evidence on whether power holders (frontline doctors and outreach workers) uphold their obligations; reviews, through public hearings and facility-level dialogues, have interpreted this evidence to assess performance; remedial action, such as commitments to time-bound improvements in service delivery, has ensured that gaps and failures are acknowledged and rectified; and local planning, such as a plan to utilize village-level health funds based on

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Competing interests: SATHI is one of the state nodal organizations for the implementation of the Community-Based Monitoring and Planning (CBMP) initiative in Maharashtra, where the author is director.

local priorities, has led to community participation in local health decision-making.

Though accountability is a conceptually fuzzy term, this viewpoint aligns with the idea that power holders must justify their decisions and actions and take remedial measures when they fail to fulfill their duties.

Jonathan Fox conceptualizes multiple accountability pathways in governance: vertical accountability entails bureaucratic answerability through established hierarchies; horizontal accountability prioritizes institutional oversight among government bodies; and diagonal accountability emphasizes participatory processes that connect citizens' voices with state decision-making. Located within the broader framework of diagonal accountability, this essay illustrates how the CBMP initiative in Maharashtra, India, has combined bureaucratic compliance with citizen empowerment to develop a more effective rights-based accountability system.

For pragmatic reasons, this viewpoint does not address the element of local planning, as it requires a different analytical framework.

Foundations and enabling conditions for Maharashtra's CBMP

CBMP was designed to enable local communities to monitor health service delivery and participate in health planning at the village and the primary health center level.

Implemented across multiple districts through a network of nodal civil society organizations, the process institutionalizes community feedback as part of the functioning of health facilities. While most implementing organizations are Indian nongovernmental organizations funded under NRHM's community processes component, they vary considerably in scale and orientation—from small local groups embedded in rural communities to professionalized nongovernmental organizations that provide technical support and policy dialogue.

Several enabling factors have contributed to the effectiveness of CBMP. To start, the state has provided much-needed legitimacy and dedicated budgetary support to the program through government orders and CBMP's formal inclusion in the NRHM's Programme Implementation Plan. Further, a broadly supportive political and bureaucratic environment—shaped by reform-oriented officials and a history of rights-based activism—facilitates constructive state-civil society engagement. In addition, the presence of experienced civil society partners and state-level nodal agencies ensures that accountability dialogues are systematically implemented and scaled across districts. CBMP strategies such as systematic capacity-building through training and exposure to the functioning of the public health system enables grassroots accountability actors—including community-based organizations, village health and sanitation committees (VHSNCs), and local elected representatives—to monitor health services. They regularly engage with frontline health workers through structured accountability dialogues such as public hearings (Jan Sunwais) and social audits.

Since its inception, the CBMP initiative in Maharashtra has expanded from a 2013 pilot covering 13 districts and 615 villages to nearly 1,000 villages across 17 districts in 2018. Participatory oversight bodies such as VHSNCs and Rogi Kalyan Samitis are more active in CBMP areas, contributing to the improved resolution of problems.

Between 2014 and 2015, 2,446 community-raised concerns regarding the functioning of the local public health services—ranging from basic health service improvements to shortages of human resources—were tracked, demonstrating CBMP's growing role in institutionalizing accountability within Maharashtra's public health system.

Civil society organizations' strategies of local mobilization, combined with advocacy and the presence of a reform-oriented higher bureaucracy, have created a favorable environment for grassroots participatory spaces to thrive.

Intersecting powers: Mandate, solidarity, and knowledge

At a conceptual level, CBMP illustrates how three interdependent yet distinct forms of power—

mandate power, solidarity power, and knowledge power—intersect to generate a meaningful accountability culture within public health systems from a community perspective. Both the reach and depth of CBMP in Maharashtra are influenced by how these forms of power simultaneously operate across state and community spaces.

Mandate power

Although the social foundations of CBMP predate the NRHM, the reform-oriented environment after 2007 provided the necessary institutional mandate for participatory accountability. The bureaucratic "buy-in" and formal recognition of civil society organizations as implementing partners through budgetary provisions and government orders has given the process bureaucratic legitimacy. The mandate power works as a bulwark against administrative resistance and positions accountability as a legitimate function of health governance.

Solidarity power

Nodal organizations facilitate grassroots mobilization and solidarity among VHSNCs and local communities, catalyzing the creation of a local network of accountability seekers. These empowered accountability seekers effectively utilize civil society-led and state-sanctioned forums such as public hearings, audits, and planning dialogues to present grievances and demand redress. These forums also provide a nurturing space for community solidarity, which translates into collective voice and moral authority, thereby anchoring accountability in democratic participation rather than administrative compliance.

Knowledge power

Communities acquire key skills such as the ability to understand data generated through score cards, identify service gaps, and use evidence to seek transparency and accountability from government health functionaries through context-specific trainings. This process builds what may be termed "knowledge power": the authority that emerges when citizens can engage the health bureaucracy using its own informational logic. Knowledge thus becomes a tool not only for advocacy but for redefining relations of expertise and legitimacy within the system.

Together, these intersecting powers generate a change cycle: mandate power opens institutional space for community participation, solidarity power sustains grassroots mobilization, and knowledge power lends credibility and negotiation strength to communities. Effectively, CBMP's success is achieved through the strategic interplay and configuration of institutional sanctions, collective action, and communities' knowledge-based agency.

State-society synergy and challenges

CBMP's success is predicated on the delicate balance between state-civil society partnership and community-led oversight of public health systems. The state recognizes that community engagement and participation not only help improves service quality but also serves as an essential strategy for strengthening grassroots accountability; with this in mind, the state gives a formal mandate to nodal organizations to implement CBMP. For civil society organizations, participation provides an opportunity to institutionalize community-led accountability approaches within the health system and foreground community aspirations in health planning.

Predictably, public officials sometimes perceive community monitoring as surveillance or undue criticism, while civil society actors are cautious of being co-opted. Despite occasional flare-up tensions between the bureaucracy and civil society organizations, through years of negotiation, both sides have developed a stable operating balance. The government provides resources, a mandate, and continuity, albeit sometimes with significant delays, while civil society organizations sustain community action and the program's credibility.

Shifting policy context: From CBMP to Jan Arogya Samitis

Under the Ayushman Bharat program, a nationwide scheme for universal health care launched in 2018, the government has introduced Jan Arogya Samitis ("people's health committees") at the sub-center and health and wellness center levels. These committees are envisioned as a participatory platform to promote preventive and promotive health services. While their design is based on four core functions—quality service delivery, health promotion, grievance redressal, and social accountability—and ostensibly retains participatory elements, their underlying orientation diverges sharply from the rights-based framework that shapes CBMP.

In practice, the provider-centric composition of Jan Arogya Samitis limits the scope for independent community oversight. Civil society facilitation—a cornerstone of the CBMP program's functioning—is de-emphasized. Although community monitoring as a strategy is retained, the institutional mandate for crucial accountability tools such as scorecards, public hearings, and audits is watered down.

The evolution of Jan Arogya Samitis typifies the co-option of accountability discourse—where policies appear to promote transparency and participatory language is retained but its transformative potential is weakened. It also signals a broader policy drift toward technocratic efficiency over deliberative, rights-based governance, eroding the CBMP program's gains to date in fostering trust and downward accountability.

Conclusion

The CBMP experience in Maharashtra has demonstrated that deliberative convergence among institutional mandates, community solidarity, and community knowledge-building can profoundly impact unaccountable hierarchical health systems. Through sustained dialogue and mechanisms of interface at various levels of the health system—from the village to the state—the accountability culture within public health systems can be enhanced and nurtured.

It also illustrates that meaningful accountability requires more than participation—it demands sustained dialogue, institutional openness, and mechanisms for remedial action. CBMP's success over the years has relied mainly on sympathetic reform-oriented officials, resulting in inconsistent institutionalization and weak translation of community evidence into systemic reform. Higher-level policy issues, such as staff shortages and public health funding, have remained largely beyond the program's sphere of influence. There is limited integration of community-level evidence generated through accountability processes, such as scorecards and hearings, with state-level policy decisions and planning. The recent policy trajectory, exemplified by the rise of Jan Arogya Samitis, signals a shift from empowerment-oriented accountability to program-oriented participation. This is also indicative of a broader depoliticization of community engagement, in which citizens are repositioned as supporters rather than as watchdogs of public systems. CBMP's survival over more than 15 years underscores the resilience of collaborative models that link rights-based advocacy with institutional reform. Yet its current vulnerability reminds us that accountability, once institutionalized, is never permanently secured—it must continually be renegotiated and defended against shifts in political intent and institutional design.

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VIEWPOINT

"That's a Definition for a World That Does Not Yet Exist": Reflections on Accountability from a Participatory Action Research Project with People Engaged in the Sex Trades

MARIE-FATIMA HYACINTHE, JESSICA PEÑARANDA, AND ALICE M. MILLER

This viewpoint is a product of a long-standing set of coalitional academic-community projects, specifically dedicated to advocacy alongside people engaged in the sex trades. In this piece, we present moments of friction that have challenged our understanding of accountability. We describe the conversations we have engaged in as part of a participatory action research project with people engaged in the sex trades that explores the structural forms of accountability available to and/or built by people who are already marked by alleged "criminality" and simultaneously facing abuse, especially at the hands of state actors in the United States. We also describe our reckoning with the forms of accountability between actors engaged in research with different powers and privileges, specific to our positions as researchers in and outside of the academy who have varying relationships to the sex trades but are committed to a shared understanding of justice for sex workers.

The Global Health Justice Partnership (GHJP) is a project of Yale Law School and Yale School of Public Health that has had long-standing relationships with the Sex Work Advocacy Network (SWAN) in New Haven and the Sex Workers Project (SWP) in New York City. In 2021, SWAN had begun receiving reports that its members were being coerced for sex by a certain police officer. Police abuse of people engaged in the sex trades is well documented.[1] Furthermore, the lack of recourse to report abusive officers can compound existing hesitance to seek services, including health services.[2] SWAN used its relationships throughout

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Competing interests: None declared.

Connecticut to remove that police officer from the police force and ensure his decertification.[3]

Following this experience, both SWP and SWAN were interested in addressing the larger problem of police abuse of people engaged in sex trades, including understanding the different routes for accountability that people in the sex trades utilize or desire. Both organizations recognized that definitions of accountability might shift for individuals based on their own understanding of the harm they have experienced and what they would need to heal from that harm. Working with SWAN and SWP, GHJP team members conducted a literature review and series of interviews with subject-matter experts, developing a definition of accountability as "any process that aims to identify a harm, stop that harm, prevent its recurrence, and create some type of consequences."[4]

With this definition, our next phase of research was to talk to people in the sex trades about the accountability measures that they have used and witnessed. We committed to using participatory action research, an approach rooted in demands for scholarship that documents and challenges social injustice.[5] As its name suggests, participatory action research is conducted by a group of researchers, including those who are most affected by the social injustice in question, who work with shared power and responsibility.

Our research questions transformed again, becoming (1) What are potential routes for accountability when police and others with societal power abuse people in the sex trades? and (2) Can we coalesce a group of researchers comprising those with experience in academia and those with experience in the sex trades to answer these questions about accountability? We aimed to answer these questions through a series of focus groups with people engaged in the sex trades throughout New York City.

In late 2024, as we prepared to conduct the focus groups, the governor of New York launched "Operation Restore Roosevelt," a deployment of the National Guard to Roosevelt Avenue, a busy street in Jackson Heights, Queens. For decades, Jackson Heights has been a commercial hub for the surrounding immigrant community, often described as one of the most diverse zip codes in the city.[6] Jackson Heights also has many bars and restaurants that cater to queer and trans communities of color. Without work permits, many of the most recent immigrants support themselves as street vendors and in other aspects of the informal economy.

Jackson Heights has become a flashpoint in conversations about New York City's "migrant crisis" and street vendors, sex work, and other elements of the informal economy.[7] Some local homeowners and business owners have complained about the visibility of sex work on Roosevelt Ave, and local politicians have drawn on a conservative Christian politic to specifically target trans sex workers.[8] These narratives provided fodder for Operation Restore Roosevelt, during which the National Guard conducted arrests and delivered citations. Immediately, Decrim NY, a coalition of organizations dedicated to the decriminalization of sex work, held a protest, using the slogan "Resources, Not Raids." Our co-researchers had been attending Decrim NY meetings, and we also attended this protest and witnessed the multilingual coalition standing up for both sex workers and street vendors. Members of Decrim NY also pursued advocacy in other venues, including op-eds in local newspapers.[9]

Understanding that this increase in policing and criminalization would impact our partners' work, we spoke to members of the coalition to explore how our focus groups might support their efforts. We worked to be accountable to our partners by being transparent about our ability to participate in rapid response actions and how quickly we would be able to share data from the focus groups.

Our focus groups continued through the spring of 2025, and the questions that we had added about the increase in surveillance from the National Guard shifted to become questions about increased surveillance by Immigration Customs Enforcement (ICE). Focus group participants acknowledged the particularities of this moment: the rhetoric about "cleaning up the streets" that accompanied the National Guard, and the violence that ICE employed while wearing masks to evade identification. Yet they also contextualized these actions in a long line of abuses by agents of the state, who felt that they could act with impunity toward these communities, emboldened by discrimination related to race, gender, immigration status, and language.

When we presented the definition of accountability that we had coined from the literature review, the focus group participants told us in poignant terms that our definition "was for a world that doesn't exist yet." They felt that our idea of accountability was unattainable for many reasons: misogyny, racism, xenophobia, sexism, classism, imperialism, and transphobia created a stark power imbalance between themselves and the agents of the state who perpetuated abuse. Even among those who look to restorative justice and transformative justice processes for guidance, there was an understanding that because these police officers were not part of their community (the necessary grounding for restorative and transformative processes), there was no way to rectify these power imbalances and facilitate accountability processes.[10] Thus, our opening question reverberates: How do we facilitate accountability when people and institutions with power abuse those who are systematically denied power?

Although the speakers in our focus groups felt that our broad idea of accountability is currently inaccessible, they also shared ways in which they are working toward transforming power inequities so that they are able to actualize accountability. For example, participants took part in various modes of documenting their experiences, putting forth an analysis that counters the prevailing rhetoric about sex workers, street vendors, and immigrants. One such example comes from Red Canary Song and Centro Corona, who published a zine that clearly describes the current carceral measures and surveillance as part of a "social cleansing crisis."[11] In doing so, these organizations refused the narrative that those who participate in the informal economy deserve surveillance, criminalization, deportation, and other forms of state-sponsored violence. Instead, they demonstrated how these approaches support social inequities.

Indeed, the specter of masked agents of the state breaking into cars, homes, and workplaces has already spread beyond Jackson Heights and into communities around the nation and has impacted people beyond those who participate in the informal economy. One way to understand this moment is to recognize that traditional accountability measures—which rely on trust in the courts, agents of the state, and laws enacted by the state—have always been imperfect and have consistently offered inequitable recourse to different communities. As these measures erode, that inequitable effect is contributing to the current rise in fascism and must be combated through solidarity.

Participatory action research might be one way for academic researchers to use the power that they have to support attempts at building forms of creative and concrete accountability for those who have faced and continue to face abuse from police and other state actors. Participatory action research projects in the field of public health can go beyond describing the health inequities that result from policing and surveillance, and instead identify and analyze the power structures that enable the practices of these abusive institutions.[12] Research teams composed of those with academic experience and lived experience can put forth scholarship that supports advocacy efforts, helps rectify power imbalances, and bolsters attempts at creating just systems.[13]

Ultimately, academic researchers who are attempting to document different approaches to accountability must hold central the understanding that our interlocutors put forth: conversations about accountability are conversations about power inequities.

Acknowledgments

Thank you to our partners at Colectivo Intercultural TRANSgrediendo and Red Canary Song for their invaluable support, collaboration, and contributions.

Ethics approval

Throughout this perspective, we present generalized summaries of focus group conversations, in keeping with the commitments we made to our community partners and the Institutional Review

Board. For example, the quote in the title comes from one of the focus group conversations and is elaborated on here.

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VIEWPOINT

Voices from the Margins: Citizen-Led Health Accountability in Kurdistan

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Introduction

In fragile and conflict-affected settings, traditional accountability structures are often weak or absent. The Kurdistan Region of Iraq (KRI) offers a stark illustration: electoral delays, parliamentary paralysis, and widespread corruption have eroded public trust and oversight. Within this vacuum, grassroots citizen committees have emerged as crucial actors in advancing the right to health and fostering people-centered accountability. Drawing on lived experience and field engagement, this viewpoint examines how these committees have created space for community dialogue, monitored service delivery, and leveraged local knowledge to promote transparency in health governance. We argue that despite political constraints and institutional fragility, citizen activism can form the basis of a resilient, human rights-based approach to health governance.

Accountability—understood as the mechanisms that require those in authority to explain and justify their actions and remedy failures—is a cornerstone of human rights.[1] However, in fragile and conflict-affected settings, the literature on citizen-led accountability remains limited. Much of the focus has been on external, donor-driven interventions, while endogenous, community-based forms have been overlooked due

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Competing interests: None declared.

to their informality and slow evolution.[2] External support for accountability has largely prioritized technical advice to governments rather than the empowerment of citizens.[3]

The KRI's history of political fragility underscores the need for such endogenous responses. Cycles of conflict—from early 20th-century Kurdish uprisings to the Iran-Iraq War, Anfal Campaign, and post-2003 political instability—have shaped its governance landscape.[4] Despite the KRI's de facto autonomy after 1991, internal division between major parties and a contested independence referendum in 2017 have perpetuated political deadlock. Recent crises, including unpaid public salaries, energy shortages, and deadly protests, highlight widespread public frustration.[5] While over 6,000 nongovernmental organizations operate in the region, they remain largely constrained by party influence and corruption (hence our distinction between nongovernmental organizations and citizen committees as separate forms of civil society).[6] Press freedom is limited, and donor withdrawal—such as the termination of the US$75 million Primary Health Care Project run by the United States Agency for International Development (USAID)—has left a vacuum in community engagement.[7]

This viewpoint explores the emergence of citizen-led committees aimed at promoting health rights and accountability within this fragile governance context. The committees' work aligns with article 12 of the International Covenant on Economic, Social and Cultural Rights and the United Nations' AAAQ framework of availability, accessibility, acceptability, and quality.[8] Their activities demonstrate how informal citizen structures can uphold human rights-based principles even where formal accountability has collapsed.

Health governance in Kurdistan

Modern public health in Iraq was institutionalized under British colonial influence, embedding physicians as both healers and political actors within governance structures.[9] Subsequent decades, particularly under the Ba'ath regime, prioritized tertiary hospital expansion at the expense of primary care, creating an imbalanced system.[10] The 1991 Gulf War and sanctions exposed the fragility of this model, leading to widespread service collapse.[11]

Post-2003 reforms driven by liberalization and market-oriented policies deepened inequities.[12] Profit incentives within public facilities transformed health from a human right into a commodity. Political parties gained control over pharmaceutical procurement and health contracts, eroding regulatory oversight.[13] Conventional accountability mechanisms—such as parliamentary scrutiny, media oversight, and civil monitoring—failed to prevent corruption, while the public sector's neglect of primary care entrenched inequality. Restoring trust therefore requires reimagining accountability through citizen-led participation rooted in transparency and ethics.

Citizen-led accountability initiatives

Since 2024, the Human Network for Health and Humanitarian Affairs (HUMAN), an independent nonprofit, has initiated a grassroots accountability project across the KRI in partnership with WADI. Supported with Dutch funding, the project promotes citizen participation and monitoring to rebuild trust in public health governance. While still informal, this effort represents an early step toward participatory accountability mechanisms.

Citizen committees under this initiative include medical professionals, civil society actors, and representatives of vulnerable groups. They collect community input, engage with local institutions, and formulate recommendations addressing service gaps, such as staff shortages and lack of mental health provision. Operating voluntarily, these committees act as advisory and advocacy bodies promoting transparency, inclusion, and accountability.

Their influence extends to educational and environmental initiatives. In refugee and displacement settings such as Yazidi camps in Duhok, the committees have preserved access to education and psychosocial support following government funding cuts. The "Playbus" and "No to Violence" campaigns introduced trauma-informed learning and environmental health practices, improving student well-being and civic participation. Between September and December 2024, HUMAN conducted 10 public health seminars addressing hygiene, early disease detection, drug prevention, and the right to health, each reaching up to 50 participants. Youth engagement was central, linking awareness with social responsibility.

Workshops also tackled structural inequities in health care delivery, highlighting discrimination and mistreatment, particularly of women in maternity services. Citizen dialogue reframed health care as a human rights-based, rather than transactional, domain. Environmental activism—such as campaigns against single-use plastics—linked health awareness to climate justice and mobilized collaboration between schools, municipalities, and nongovernmental organizations. These cross-sectoral actions reinforced civic engagement and helped position health as integral to sustainable development.

Mechanisms and impact

Citizen committees have adopted several mechanisms to promote accountability. They use community-based monitoring, shadow reporting, and public forums to document service failures. Social media has become an especially effective tool, enabling the anonymous reporting of malpractice and corruption to protect individuals from retaliation. Volunteer-run platforms expose violations and amplify citizens' voices, generating pressure for official responses.

Although outcomes vary, these informal approaches have yielded tangible improvements—such as reinstated services and responsiveness to public complaints. By leveraging local networks and cultural legitimacy, committees translate abstract human rights into concrete community demands. Their participatory nature fosters collective ownership of public health, challenging entrenched hierarchies and promoting ethical governance in a politically restricted environment. They also contribute to evidence-informed policymaking in the form of local knowledge.

Challenges and power dynamics

Despite their promise, citizen committees face significant constraints. Members report surveillance, intimidation, and accusations of serving foreign agendas, particularly since the closure of initiatives backed by USAID. Such pressures deter participation and undermine trust. Sociocultural barriers, including patriarchal norms and tribal divisions, further fragment citizen engagement.

Resource scarcity and dependence on external funding leave committees vulnerable to changes in donor priorities. Without formal institutional channels or enforcement mechanisms, committees' recommendations are often ignored. Geographic diversity, while a strength, complicates coordination and reduces policy influence. These dynamics reveal persistent power asymmetries between grassroots initiatives and state institutions.

Broader reflections

The emergence of citizen-led health accountability in Kurdistan represents an organic response to systemic governance failures. As external actors retreat and donor priorities shift toward short-term interventions, local citizens have stepped in to monitor, document, and identify breaches of the right to health. Their reliance on lived experience, trust, and digital connectivity offers lessons for other fragile and conflict-affected settings through, not least, evidence-informed health policymaking.

Enduring impact requires formal recognition, pathways for redress, and integration with institutional frameworks. The challenge lies in bridging informal citizen oversight with formal governance mechanisms while safeguarding civic autonomy.

Conclusion

Citizen-led health committees in the Kurdistan Region exemplify how grassroots initiatives carry the potential for sustaining accountability where formal structures fail. They operate under political fragility, limited resources, and surveillance, yet continue to champion transparency, participation, human dignity, and the right to health. Their emergence signals a shift toward localization and community-driven governance.

As international development agendas increasingly emphasize local ownership, community empowerment must go beyond rhetoric. Genuine accountability requires recognizing and protecting the spaces in which citizens can hold authorities to account. In fragile contexts such as the KRI, these committees can become foundational to rebuilding trust and reasserting health as a human right.

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VIEWPOINT

Te Āo Māori "Accountability": Indigenous Ways Toward Partnership and Restorative Practice Globally

EMMA RAWSON-TE PATU

Different worldviews conceptualize accountability differently. Western models of accountability tend to be individualistic and revolve around legal responsibility, compensation, and punishment. In contrast, Indigenous worldviews tend to emphasize the interconnectedness of all beings, the importance of historical context, and the restoration and prioritization of relationships underpinned by lore, rather than law.[1]

Look at Te Āo Māori—the Māori worldview—as an example.[2] Rather than being punitive, Māori accountability is fundamentally about restoring harmony, seeking pathways for healing, reconciliation, and the protection of collective mana (innate human authority). Kawa and tikanga Māori (Māori values, customs, and protocols) provide the framework for this approach, focusing on reciprocity, restoration, and respect for all relationships, human and non-human alike. Accountability is both a personal commitment and a shared responsibility. It flows through whānau (family), hapū (extended families that together comprise iwi), iwi (people, tribe, or nation), and across generations. Accountability is inseparable from the land, waters, ancestors, and living community.

From the perspective of Te Āo Māori, accountability is not a finite event but a living cycle, guided by utu (reciprocity and balance) and muru (ritual redress). It always seeks to restore the well-being of whānau (family), whenua (land), and the taiao (natural environment). Another key concept or value designed to hold Māori society in balance is manaakitanga. Manaaki is the act of giving to, hosting, or caring for others, recognizing that everyone is needed and deserves care. The ultimate generosity, manaakitanga raises the mana of others because it is generosity that exists without the expectation of receiving in return. All beings are connected, and utu (reciprocity) is inbuilt; therefore, it does not need to be demanded. This is the balance that keeps society in order.

It is beyond the scope of this viewpoint to fully explore Te Āo Māori, accountability, and concepts of hauora (health), but the starting point is the settler colonization of Aotearoa (New Zealand) and Te Tiriti o Waitangi, which is the country's foundational document agreed in 1840 between many iwi and

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Competing interests: None declared.

hapū, on the one hand, and the British Crown, on the other.[3] Te Tiriti has not been honored, and while steps are being taken to hold the Crown, and its bodies, accountable, this journey has been erratic, contested and often tokenistic. Genuine accountability requires far more than apologies or symbolic reparation. True commitment is measured by sustained action and the transformation of power relationships, which is inextricably connected with honoring the holistic nature of health of ngai iwi Māori.[4] Māori health is Māori identity—culturally, physically, spiritually, and emotionally. This necessitates:

- Recognition of Te Tiriti o Waitangi: honoring Te Tiriti as a living covenant, not just a historical artifact, and actively upholding its promises of tino rangatiratanga (Māori sovereignty) and authentic partnership.
- Restoring power and authority: Māori-led decision-making in all areas that directly impact Māori lives, resources, and futures, not least health and the environment. This is not consultation; it is genuine, long-term structural change and a shift in the dynamics of relationships to reflect equitable citizenship and an understanding of First Nations guardianship.
- Addressing, preventing, and not perpetuating ongoing injustices: committing to responsibility and obligations for ongoing harms and structural inequities, including disparities in health, education, land ownership, and justice. To redress historic and contemporary wrongs, systemic reforms must be implemented and enshrined in a constitution.[5]
- Meaningful partnership: building authentic, enduring partnerships where Māori voices, leadership, and knowledge are equal in influence and resource. This involves policies, equitable co-governance, and prioritizing and embedding Te Āo Māori and expertise at the heart of decision-making processes in all areas.
- Restorative practice: proactive measures of healing such as returning land, compensating for historical wrongs, and properly resourcing and supporting the revitalization of Māori language and culture.

From the perspective of Te Āo Māori, accountability is a journey of continuous learning, reflection, and courageous action. It demands humility, patience, and openness to uncomfortable truths. Restoring balance means not only upholding justice but actively acknowledging and honoring the mana of Māori people, communities, and the land. The well-being of Aotearoa depends on nurturing these relationships now and consistently over time by reordering the social understanding of the place and mana of Indigenous peoples as First Nations rights holders and gift givers.

In this ongoing process, accountability demands not only reparations for the past but also a shared commitment to a future built on equity, mutual respect, and genuine partnership. The path forward is one of co-creation, where Māori and non-Māori work together to realize a flourishing, just, and inclusive nation, an Aotearoa where the promise of Te Tiriti o Waitangi endures in practice, not just in principle.

There are lessons to learn, beyond health and Aotearoa, from this conception of accountability that resonates with the worldviews of many Indigenous peoples globally and can be a model for a world in need of deep rebalancing.

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VIEWPOINT

When Independence Meets Accountability: Upholding Non-Retrogression in the Human Rights System

TANIA AGOSTI, ANDREA BALDWIN, SUSANA T. FRIED, JAIME M. GHER, MARIAH GRANT, ALICE M. MILLER, MINDY JANE ROSEMAN, AND NERIMA AKINYI WERE

We write this viewpoint as a collective of academics and advocates with over three decades of experience advancing sexual and reproductive rights as well as gender equality, at national, regional, and international levels. We aim to champion a resilient human rights system that secures the rights and dignity of everyone in all their diversity.

Here, we address the status of, and ongoing contestations over, accountability norms for gender-based violence. Advancing state accountability for gender-based violence requires comprehensive standards that recognize persons affected by such violence, that reflect new understandings of "harm," and that extend state obligations to prevent abuses by nonstate actors. This work is closely tied to the right to health.[1]

Independence, transparency, and ethical practices are essential for the development of human rights norms, designed to benefit individuals rather than just state interests.[2] Contestation is a key element of human rights norm-building, marked by shifts in players and voices that challenge power and abuse through

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* *This viewpoint is a shortened version of a working paper by the same authors, forthcoming in another outlet.*

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Competing interests: None declared.

new claims and disagreements among experts. While debate is essential to the process, commitment to constructive engagement and adherence to non-retrogression remains paramount.[3]

Here we raise two interrelated issues that are visible in efforts to advance gender equality and rights-based responses to gender-based violence: how to grapple with United Nations (UN) expert practices that are contributing to normative retrogressions for state accountability; and how to best promote accountability to ensure non-retrogression by experts in the human rights system, while preserving their independence. We argue that careful and constructive civil society critiques of UN experts' work are essential to guide and safeguard professional practices by experts and normative developments to which these experts contribute.

Comparing two recent statements from UN human rights expert mechanisms highlights our concerns regarding the elaboration of norms on gender and gender-based violence. One reaffirms gender as a central analytic device for achieving full equality as a cornerstone of human rights, emphasizing that gender- and sex-based discrimination must be addressed to dismantle structural inequality.[4] In contrast, the other statement warns that using the concept of gender is dangerous because it separates definitions of men and women from biological sex and undermines the recognition of women as a distinct legal category.[5]

These conflicting expert statements cannot both be correct. We argue that the second, focusing solely on biological claims to "sex," represents a normative retrogression, threatening decades of gender analysis in support of comprehensive state accountability for discrimination and gender-based violence.

As we review how norm development can be undermined by UN expert practice, we focus on a key player whose mandate has been central to accountability for gender-based violence but whose current practices threaten fragile achievements. The current UN Special Rapporteur on violence against women and girls, its causes and consequences (SRVAW) wrote the second statement cited above. Normatively retrogressive efforts by this mandate holder include narrowing the definition of who can be protected in the category of women, restricting what constitutes gendered violence, torquing the scope of state obligations for violence by nonstate actors, rejecting the purposes of gender analysis, and selectively focusing on the limits of consent to further constrain the rights of already constrained populations.[6]

The principle of non-retrogression in human rights law prohibits states from reducing established protections, thus ensuring that advances to respect, protect, and fulfill rights are irreversible.[7] Non-retrogression is linked to progressive realization, requiring states to work toward the full realization of rights while maintaining existing standards. These concepts are vital to the prevention of gender-based violence and the protection of health rights more generally.[8]

Human rights protection is not zero-sum. For instance, including trans women in the category of women does not diminish women's rights; rather, it expands human rights' remit. Rights advancement must not come at the expense of some, for nondiscrimination is a cornerstone of international human rights law.[9] In other words, as human rights norms expand, prior protections remain in place, refined and better tailored to specific contexts. Thus, the principles of non-retrogression and accountability permeate guiding norms for all actors in international human rights law. And these norms are grounded in the practices of UN expert actors' research, citation, and inclusive consultation, for example. Here we apply this dual lens on accountability to a critique of the SRVAW's current work, drawing first from her report entitled "Sex-based violence against women and girls."

The SRVAW's formulation of "sex-based" rather than "gender-based" violence is a prime example of norm regression.[10] Focusing solely on "sex" as the basis for prohibiting discrimination and violence limits protections to bio-essentialist functions assigned to "girls and women."[11]

The SRVAW's efforts to reduce state accountability for gender-based violence refers to "males who identify as women and girls"—a reversion to monolithic and binary understandings of gender, strangely echoing regressive states' efforts to undo decades of rights work at the UN and globally. As a practical matter, it also undermines the work of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity—whose mandate has extensively conceptualized and applied gender-inclusive analysis—and the gender-inclusive work of a range of UN rights-related offices, programs, and agencies over the last decade.[12]

Another SRVAW report, "Prostitution and violence against women and girls," exemplifies both lapses in professional practice and retrogression on established norms recognizing the rights of adults to do sex work.[13] The SRVAW references the 1949 Convention for the Suppression of the Traffic in Persons to justify use of the term "prostituted women and girls" instead of "sex worker." This directly negates decades of sex worker-led advocacy to have their rights and legitimacy recognized. Invoking the 1949 convention also represents a retrogression that is not aligned with calls from several UN agencies, Independent Experts, and working groups to distinguish between sexual exploitation and sex work.[14]

These reports demonstrate unprofessional practices and reveal serious failures at a moment when various factors and individuals are threatening the UN's existence and directly targeting specific Special Procedures.[15]

As advocates for independence, we recognize that its safeguards depend on policies designed to prevent coercion and undue influence. These policies must be accompanied by commitments that experts do not serve the interests of governments or specific interest groups. Principles validating independence are advanced by adhering to rigorous standards of data gathering and evidence use. Independence also requires transparency and a commitment to public conversations about expert processes, ethics, and substantive claims, without fear or favor—especially unfair reprisals—for experts and civil society.

In this spirit, we propose that the Office of the United Nations High Commissioner for Human Rights (which acts as the secretariat for the Special Procedures) take a more strategic and proactive approach to making its processes more visible, spotlight deviations from established standards, and highlight good practices among expert bodies that support the evolution of rights.[16] Moreover, in our cyber-linked world, disputed, poorly sourced, or one-sided assertions, for example, are routinely called out; we ask for discussion about how to constructively use evolving technology to similarly ensure transparency and ethical practices within the UN human rights system.

We are aware that demands for oversight can be exploited by bad-faith actors, undermining the independence of UN experts and weakening the UN system, particularly its human rights framework.[17] Nevertheless, we present our viewpoint in hopes of encouraging deeper reflection on accountability processes that protect against pressures by retrogressive actors on these vital and increasingly constrained independent experts. Their work is essential for strengthening rights and enhancing the UN human rights system's capacity to promote the rights of all.

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People-Centered Accountability amid the Gaza Genocide: Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition

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Abstract

This paper examines how people-centered accountability initiatives are operating to enforce the right to health amid Israel's genocide in Gaza. Drawing on a critical case study of Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition, we situate these actors' work within

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international human rights law, social accountability scholarship, and decolonial and abolitionist critiques. We show how these actors are able to combine clinical documentation, survivor testimony, and direct action to monitor human rights violations, generate medically literate records of the harm inflicted, and press for remedies that state-centered mechanisms have failed to deliver despite findings of war crimes and genocide by United Nations bodies and human rights groups. Across these cases, we identify some common practices and tensions surrounding coalition-building, risks to documentation, navigating a media environment of mis/disinformation, and engaging strategically with institutions that often reproduce health harms or are directly complicit. We argue that these movements treat people-centered accountability as part of their professional duty and act on a mandate to prevent mass atrocity crimes rather than being silent. We conclude by outlining some practical implications for clinicians, professional associations, and health systems seeking to align their global health practice with a people-centered approach to accountability.

Introduction

Human rights policies are effective when power—state or popular—makes them operative in practice. Often, it requires both formal state mechanisms (e.g., courts, sanctions, embargoes, administrative remedies) and people-centered accountability from below (e.g., public tribunals, boycotts, demonstrations) for enforcement. The persistence of impunity for Israel's egregious human rights violations against Palestinian patients, clinicians, health systems, and people in Gaza exposes the structural frailties of state-centered human rights enforcement. It has catalyzed a proliferation of community-led actions led by health workers themselves.[1] This paper interrogates those practices by analyzing three prominent initiatives—Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition—against the normative architecture of the right to health and emergent theories, such as "accountability from below."[2] We argue that these actors operationalize monitoring, review, and remedial action in ways that complement and unsettle the United Nations human rights treaty-based paradigm, pointing to a reconfigured, people-centered accountability ecology in global public health.[3]

Article 12 of the International Covenant on Economic, Social and Cultural Rights, as interpreted in General Comment 14, encompasses the state obligations to respect, protect, and fulfill health care and health protection, including by ensuring the availability, accessibility, acceptability, and quality of health-related facilities and services.[4] Yet enforcement of this and other human rights has been weakened by geopolitical asymmetries, jurisdictional limits, and the reluctance of powerful states to sanction allies.

Accountability is foundational in law, human rights, bioethics, and public health.[6] It includes criminal prosecutions, civil lawsuits, and non-judicial arrangements (e.g., truth and reconciliation commissions and national human rights commissions).[5] Human rights accountability encompasses state-level accountability (SLA) and people-centered accountability (PCA). Accountability to affected populations is a subset of PCA.[6] In health, SLA requires states and armed actors to uphold legal obligations and ensure minimum essential services, such as those outlined in the Geneva Conventions, the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and other instruments.[7] PCA centers affected persons through access to information—safely providing feedback and exposing human rights violations—and active participation in designing, monitoring, and adapting aid and other programs to meet people's evolving needs and remedies.[8] It aims to make aid relevant, appropriate, and effective and to shift power dynamics from one-way aid provision to bidirectional community partnerships.

SLA is concerned with state duties to citizens and the international community. PCA includes a commitment by humanitarian actors directly to affected persons, supporting or substituting when states fail. Together, SLA and PCA are theoretically complementary, where SLA reinforces a state's obligation to provide aid and the PCA ensures that such aid is delivered adequately and responsively. In practice, however, SLA often fails the victims of war and genocide.

These shortcomings are evident in the case of the genocide in Gaza, where Israeli attacks on hospitals, ambulances, and health workers, combined with siege-induced deprivation of fuel, essential medicines, drinkable water, and food, have produced an unprecedented health catastrophe and affront international law.[9] In January 2024, the International Court of Justice ordered Israel to comply with provisional measures to prevent genocide in Gaza, which was followed by another order in March and another in May to halt the Rafah ground invasion—all of which Israel disregarded.[10] In November 2024, the International Criminal Court issued warrants for the arrest of Israeli Prime Minister Benjamin Netanyahu and Israeli Minister of Defense Yoav Gallant, citing war crimes and crimes against humanity.[11] At the time of writing, despite these actions, the genocide persists with minimal state-supported military or humanitarian intervention. Instead, many governments continue arms transfers and resist enforcing international humanitarian law or International Criminal Court warrants, and in some cases have even levied sanctions against entities raising alarm, such as appointees of the United Nations (UN) and the International Criminal Court.[12]

PCA is less dependent on state action and thus less easily immobilized by such sanctions; for example, UN Special Rapporteur Francesa Albanese continues her work while the International Criminal Court's work has been delayed. PCA resists the premise that large institutions are the only path to justice. It is guided by communities in need of redress: they determine the terms of accountability and what it entails for the harms they have endured.[13] Abolitionist traditions critique institutions built on oppression as structurally incapable of centering justice.[14] From this perspective, SLA's ineffectiveness arises from inadequate design. Poet and activist Audre Lorde famously wrote, "the master's tools will never dismantle the master's house."[15] The UN has been criticized for enabling the 1948 Nakba (Zionist paramilitary-led ethnic cleansing of Palestine and violent displacement of Palestinians).[16] PCA holds that accountability for genocide cannot be dictated by those enabling it or distant from affected communities.

Against this backdrop, Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition represent coalitions of health care workers, civil society, and parliamentarians who refuse the role of passive witnesses. Their praxes exemplify human rights globalization: translocal networks translating global norms into localized, insurgent institutional practices, thereby expanding who enforces human rights and how. In this analysis, we proceed as follows: we apply a PCA lens to these three cases, distill cross-cutting lessons (e.g., coalition dynamics, engagement with legal and multilateral forums, the ethics and security of documentation, and mis/disinformation), and conclude by charting direct, practical steps for clinicians, professional bodies, and civil society.

Case studies of grassroots movements

Case study 1: Doctors Against Genocide

Founded in 2023, Doctors Against Genocide is a coalition of thousands of health care workers responding to Israel's genocide in Gaza, often claiming they are "Sick from Genocide."[17] The organization frames accountability as an explicitly preventive, clinician-led duty grounded in both legal and medical reasoning, treating genocide as a measurable public health and human rights emergency demanding early warning, triage, and intervention. It defines accountability as the obligation to avert mass death rather than merely document it, anchoring this obligation to the settled protections of humanitarian and international human rights law, which require uninterrupted access to care and categorical respect for medical personnel and facilities. A combination of clinical "signs"—including forced starvation, blockade, the systematic destruction of health care, mass deaths, child suffering, and incitement—can constitute a diagnosis of genocide.

Doctors Against Genocide blends clinical documentation, open-source investigation, and survivor testimony to meet evidentiary standards while minimizing risk. It co-designs campaigns with survivors and uses community consultation to determine advocacy priorities. Its collaborative submission to the UN Special Rapporteur on the right to health brought clinician testimonies, hospital-based observations, humanitarian field notes, satellite imagery, and time-stamped media to show recurring hospital raids, impeded evacuations, and deliberate deprivation of determinants of health.[18] The submission further illustrated how clinically anchored indicators can be organized into an accountability record that is intelligible to investigators and adjudicators, reframing physicians' retrospective witness as a sentinel for atrocity prevention.

Doctors Against Genocide couples these documentation practices with a repertoire of remedial actions that targets both professional gatekeepers and state actors, thereby attempting to shift the locus of accountability from distant courts to present harm reduction. Its advocacy includes petitions and open letters to national medical associations, public-facing campaigns that reframe complicity as a breach of professional ethics and human rights, and legislative briefings that argue for embargoes and humanitarian access as health interventions. Their organizers have frequently protested inside the United States Congress and been subject to arbitrary detention and arrests.[19] Doctors Against Genocide situates this work within the growing body of normative and policy commitments that require states and armed actors to protect health services in war, and it leverages the authority of clinicians to press for compliance and sanctions. This strategy mirrors what public health and humanitarian scholars have urged for a decade—namely, that attacks on health care demand an immediate protective response by governments, donors, and professional bodies.

Although legal outcomes remain slow and contested, the organization's campaigns have normalized a clinical vocabulary for genocide risk and delineated a predictable epidemiology of health system collapse—marked by excess deaths from trauma, sepsis, obstetric complications, and chronic disease when hospitals are targeted, ambulances obstructed, and supply chains disrupted. Doctors Against Genocide reframes "medical neutrality" as a mandate for care and prevention, rather than professional quietism. By fusing legal prohibitions, clinical evidence, and professional ethics into a single practice of accountability, the organization demonstrates how PCA can complement and pressure SLA.

Doctors Against Genocide also challenges the notion that medical neutrality requires political neutrality by recognizing that every physician advocates for a system, even if that system is a status quo. PCA can begin by identifying one's own place in the power structure and how politics is ever present in medicine.

Case study 2: Healthcare Workers Watch

Launched in 2023 by Palestinian physician Muath Alser, Healthcare Workers Watch documents attacks on Palestinian health personnel and facilities, operating in an environment of mis/disinformation propagated by state actors and international media.[20] Healthcare Workers Watch emphasizes its independence and its mandate to document human rights violations experienced by health care workers, drawing on a network of advisors skilled in Gaza's health system and in quantitative and qualitative methods. This blends rapid incident verification with clinical interpretation, positioning outputs as medically literate, people-driven evidence in relation to international humanitarian law and human rights standards protecting medical personnel and facilities. Healthcare Workers Watch triangulates direct contacts with peers and families, verified clinician social media, and formal channels. Reports are often corroborated through multiple contacts and first-person testimonies collected with informed consent in Arabic or English and translated by native speakers.

Healthcare Workers Watch has synthesized extensive primary data by documenting both direct harms to individual clinicians and the functional collapse of specialist care.[21] It corroborates hundreds of killings and widespread detention of health care workers, often with severe ill treatment and death in custody. It details the disproportionate loss of senior clinicians in key specialties that were already limited pre-genocide and analyzes the cascading impacts on pathology, nephrology, radiology, and plastic surgery, as well as the knock-on effects on triage, theater capacity, and post-operative care. Healthcare Workers Watch is able to support accountability mechanisms by substantiating reports on attacks on health care, which in turn feed international media reports, prompt further advocacy efforts, and provide a citable source for legal actions.

Case study 3: Freedom Flotillas

The Freedom Flotillas are nonviolent maritime interventions challenging Israel's naval blockade while attempting to deliver aid and spotlight siege-related harms. Originating through the Free Gaza Movement and later coordinated by the Freedom Flotilla Coalition, the flotillas combine symbolic action with cargo (food, medical supplies, and mobility devices) and rely on public documentation of at-sea encounters to shift diplomatic and legal discourse. From 2008 to 2016, 31 boats sailed.[22] The Freedom Flotilla Coalition describes itself as civil society-led, aiming to break the blockade rather than substitute state relief channels it views as structurally constrained. Cargo prioritizes medical and pediatric needs.[23] The boats function as instruments to expose SLA failures.

On May 31, 2010, Israeli forces boarded vessels in international waters, killing 10 activists on the *Mavi Marmara*, including several at point-blank range.[24] The episode prompted widespread diplomatic fallout and a temporary easing of certain blockade restrictions. The UN Human Rights Council's fact-finding mission prioritized civilian protection and documented blockade-related harms to health and welfare, concluding that the blockade and the interception were unlawful due to disproportionate harm and collective punishment.[25]

In the years that followed, flotilla strategies adjusted to the new political climate while preserving a medical-humanitarian register. In 2011, Freedom Flotilla II, involving more than 300 participants, did not sail as planned after Greek authorities imposed a ban on departures to Gaza, citing safety reasons. The move was welcomed by Israel and some international actors but criticized by organizers, who argued that state-administered alternatives diluted scrutiny of the blockade's human impact. Only the French yacht *Dignité Al Karama* reached international waters near Gaza before being intercepted and towed to Ashdod.[26] In 2015, Freedom Flotilla III launched with the Swedish-flagged *Marianne*, which was stopped by the Israeli Navy about 100 nautical miles from Gaza and brought to Ashdod. Organizers said the boat carried limited aid and a symbolic gift for Palestinian fishers, using the voyage to refocus attention on the combined effects of the blockade on livelihoods, food security, and access to care. Activists were subsequently detained and deported.

In the summer of 2018, amid the Great March of Return, two vessels, *Al Awda* and *Freedom*, and their support yachts, *Mairead* and *Falestine*, were intercepted in international waters.[27] Cargo manifests included nebulizers, surgical disposables, and mobility aids to illustrate how a chronic blockade turns routine conditions into emergencies. Documentation protocols anticipated interdiction and detention, reinforcing advocacy on the discordance between the blockade and the right to health and humanitarian access.

The 2024–2025 missions continued under harsher conditions. An April 2024 mission was delayed and rerouted after flag withdrawals and political pressure.[28] In May 2025, the Freedom Flotilla Coalition reported that its passenger vessel *Conscience* was struck by Israeli drones off Malta while at anchor awaiting additional passengers.[29] In June 2025, the small aid boat *Madleen* departed from Catania with baby formula, flour, rice, prosthetics, and medical kits. It was intercepted by Israeli naval forces in international waters and towed to Ashdod.[32] In July 2025, the trawler *Handala* was seized in international waters; the coalition's press statements framed both operations as violations of international law and of the International Court of Justice's orders on humanitarian access during the ongoing genocide.[30] The Global Sumud Flotilla, consisting of 42 vessels and 462 participants from more than 44 countries and territories, was intercepted in October 2025 in international waters, and its members were kidnapped. It marked the largest attempt to date to break Israel's naval blockade of Gaza, having reached the closest to its territorial waters. It was followed up shortly by nine vessels in the *Thousand Madleens* to Gaza.

These flotillas served as a test of civil society attempts to breach the blockade, document Israel's treatment of civilian crews and medical cargo, and inform growing scholarship and jurisprudence on the legality and health consequences of the blockade.

Tensions, ideals, and prospects for people-centered accountability

Coalition-building and accountability from below

Gaza exemplifies several tensions, ideals, and prospects of PCA and human rights from below. PCA can circumvent SLA's limits, especially when perpetrators are states. Doctors Against Genocide embodies this through its dedication "to succeeding where global governments have failed in confronting genocide."[31] Reflecting growing impatience with legacy professional bodies, Doctors Against Genocide affirms parallel, anti-genocide structures rooted in indivisible human rights and the sanctity of health, challenging the complicity of associations such as the American and Canadian Medical Associations. PCA actors address urgent needs from below: Healthcare Workers Watch documents attacks; Doctors Against Genocide raises public awareness and presses for interventions; and the International Committee of the Red Cross, Doctors Without Borders, and the Palestine Red Crescent provide medical aid.

That said, the mobilization and implementation of PCA under such an extreme and geopolitically precarious environment can be fraught with practical tensions and logistical barriers. For instance, the operational viability of PCA groups is directly undermined by deliberate state actions such as the weaponization of starvation and the systematic destruction of infrastructure and health care services. Furthermore, PCA organizations can face internal tensions relating to ideological values, the mode and degree of their interventions, and their target populations. For instance, on matters such as Israel's military assault on Iran, Syria, and Lebanon, PCA organization members may disagree on strategy, word choice, public statements, and calls to action. Cultural gaps can exist across internationally joined coalitions and social movements, especially broad-based coalitions, whose members may find discomfort, disagreement, or even radically opposed stances on a myriad of other sociopolitical issues. Consequently, a critical necessity emerges to delineate and distinguish coalition-building (inherently strategic- and issue-based) and deeper, reciprocal alliances involving mutual expectations and conditions.

Shared concerns and goals do not always imply shared belief systems and ideologies. Effective PCA coalition-building involves conscientiously avoiding conditional solidarity. Involved parties can collaborate on shared concerns for Palestinian liberation without presupposing ideological or political alignment on other, even related, matters. This approach can help prevent the instrumentalization of solidarity and can aid in preserving the autonomy and integrity of each group's core principles and priorities, ensuring that activist participation comes from genuine concern for human dignity. While other deeply interrelated matters—such as colonialism, carceralism, women's health, racial prejudice, climate harms, and threats to migrants—exist in Palestine, effective global advocacy for the genocide in Gaza cannot, and should not, be conditional on the expectation of reciprocity (even though it often emerges naturally regardless). Practical coalition-building relies on strategic commonalities, not comprehensive ideological coherence, and supports claims that participation from advantaged group allies can positively influence public perceptions of disadvantaged groups.[32] Allies need not share identical ideological frameworks or worldviews with the groups they support, as their presence alone can amplify movement legitimacy, reduce negative stereotypes, and foster greater public support.[33]

Coalition politics also introduce practical and normative tensions. The constituencies mobilized for Gaza include hospital unions, faith-based organizations, disability justice advocates, professional societies, student encampments, abolitionist groups, medical societies, human rights organizations, and others. They bring different genealogies of struggle and lines they refuse to cross. PCA must therefore clearly articulate the norms that govern its coalitions. This does not suggest a single political platform as the price of collaboration, nor does it endorse sanitizing language to appease the sensibilities of elites. Rather, PCA requires adopting movement-level codes of conduct that safeguard the dignity of those most at risk and align with ethical norms. PCA also requires clarifying inside-outside roles.

One way that social movements have historically maintained accountability when some participants engage institutions is by organizing structured relationships of answerability between those "inside" and those "outside" the room. This practice is visible in how clinicians sit with survivors before and after meetings with UN rapporteurs, in how flotilla organizers brief and debrief their crews and passengers, and in how student encampments require delegates to report decisions to their assemblies. The immediate effect is to ensure that institutional recognition does not displace movement priorities; the longer-term effect is to form cadres of practitioners who understand that legitimacy comes from the people they serve, not from the podiums they reach. Practice-based analyses of social accountability in health indicate that embedding answerability through feedback loops and downward accountability contributes to government responsiveness and, in some settings, to sustained service improvements, especially where provider-patient power asymmetries are stark.[34]

Logistical tensions, ideals, and prospects

The potential of PCA lies in its refusal to outsource judgment, evidence, and remedial action to institutions that have repeatedly failed Palestinians, while still taking those institutions seriously enough to make their evasions visible. The cases examined in this paper illustrate the strengths and strains of that posture. They often organize the accountability triptych of monitoring, review, and remedy around the clinical consequences of siege and bombardment and around the legal status of health workers and patients. They do so while navigating co-optation risks, security threats to witnesses, divergent coalition norms, and a hostile information and security risk environment. The immediate ideal is not the purity of a social movement's identity but the protection of life and the reconstruction of a community's capacity to care for itself. There is a tension between the difficulties of maintaining community leadership and epistemic authority while engaging, strategically and instrumentally, with the state-centered parties whose authority has been put in doubt. This tension is amplified by the speed and scale of destruction, the abduction and killing of senior clinicians, and the collapse of health services that make even cautious documentation a matter of clinical risk management rather than archival work. Efforts by the World Health Organization and the UN Office for the Coordination of Humanitarian Affairs to standardize incident reporting showcases both the necessity and the limits of institutional monitoring. They can agree on terms and phrasing, but they cannot, on their own, alter the pattern of impunity that renders those terms a ledger of anticipated harm rather than a trigger for prevention.

Another tension concerns engagement with formal legal and multilateral processes. Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotillas all deploy documentation practices designed to meet evidentiary thresholds familiar to international court standards and UN mechanisms, yet none of them treat juridical success as the end point of accountability. The literature on social accountability is instructive.[35] Citizen-led oversight can produce gains when it combines pressure from below with tactical openings from above, but such gains depend on the responsiveness of the target institutions and on the ability of civic actors to sustain independent power.[36] Doctors Against Genocide's decision to pair UN submissions with clinician-facing actions and direct pressure on professional bodies, and Healthcare Workers Watch's insistence on clinically literate narratives that make the health systems consequences legible beyond the courtroom, reflect an understanding that prevention requires forms of authority that do not rely on state sanction. Accountability initiatives can be effective when they build on independent community power and elicit timely responses from authorities, rather than relying on retrospective review alone.[37]

Practical and ethical tensions of reporting

Another tension within PCA is the relation between professionalized nongovernmental organizations and dynamic social movements. Professionalization can stabilize methods, secure funding, and negotiate access. It also risks reproducing deference to the authorities that generate harm, narrowing vocabularies to what funders will tolerate, and deferring to legal advice that treats the accurate naming of atrocities as a reputational hazard.[38] Actors in grassroots movements, by contrast, find it easier at times to keep the horizon clear and the language honest. Yet they must contend with fragmentation, the duplication of efforts, and uneven standards for data protection.

In Gaza, this split is not abstract. In many instances, nongovernmental organizations fear that being more outspoken, doing interviews, or using terms like "genocide" will lead to a restriction of their ability to enter Gaza.[39] Furthermore, there is the tension of the epistemic and ethical nature. People often now say "center Palestinian voices," but in practice, the costs are borne disproportionately by Palestinian clinicians and families who consent to give testimony while living under occupation, surveillance, and displacement.[40] Ethical guidance from protection and humanitarian practice has long emphasized informed consent, do no harm, the minimization of re-traumatization, and robust data security; yet these injunctions meet a uniquely difficult setting when hospital raids and mass detentions target the very identities that make these testimonies credible.

Healthcare Workers Watch's methods, which prioritize direct contact with families and peers, multisource corroboration, and careful translation into medically meaningful narratives, sit within established protection standards but raise practical questions about risk, including digital interception, intimidation, and reprisals against those who speak.[41] It is sometimes not enough to redact names. An ethical documentation program in Gaza could include security protocols for storage and transmission, an explicit risk-benefit assessment for each disclosure, and the possibility of withholding publication even where verification is achieved, if the protective environment is absent (much of which Healthcare Workers Watch considers already). Movements may need to invest in encrypted infrastructures and community-led ethics boards that can set red lines independent of funder timelines. The ideal is credible, clinically grounded, and community-controlled knowledge that travels as far as necessary and no further than is safe.

Information warfare constitutes another source of tension for PCA. Gaza has exposed the limits of faith in Western-dominated mainstream media as a mechanism of accountability.[42] The pattern is familiar from health emergencies: euphemisms for structural violence, the episodic amplification of official narratives, and the marginalization of Palestinian clinical authorities until their counts and warnings are retrofitted to match institutional sensibilities.[43] This is why Doctors Against Genocide emphasizes the importance of clinical language: it is harder to distort. The remedy is not disengagement but capacity. Movements must build their own media literacy, cultivate relationships with reporters who are committed to forensic standards, and develop internal protocols for the release of clinical data that anticipate misframing and preempt it with clear, medically anchored language. Where a headline can determine whether an intensive care unit receives diesel or not, messaging is not just a public relations task but a component of patient safety. Passive voice is too often used to deflect, diminish, and absolve Israel and its officials of their war crimes and acts of genocide in Gaza.

Charting a path forward

For effective PCA, coalitions must invest in trauma-informed, security-aware practices for clinicians and witnesses. The evidence on mental health burdens among health workers in conflict shows sustained elevations in anxiety, depression, and posttraumatic stress.[44] Programs that blend peer support, protected time away from exposure, confidential counseling, and fair remuneration are not luxuries; they are preconditions for ethical documentation and for continuity of care. Clinical networks can establish protected witness clinics, staffed by trained health care workers who can assess, document, and support colleagues who have faced harassment, been detained, or been assaulted. These clinics should function with strict confidentiality, encrypted records, and predefined referral relationships with trusted legal and protection partners. In parallel, medical schools and training programs can incorporate modules on documentation under duress, data security, and survivor-centered interviewing, with particular attention to the gendered and sexualized forms of violence that often occur in custody.

The cases here point to the need for curricular and research reforms that recognize PCA as a clinical competence and a domain of scholarly work. This means teaching students how to read and build medically literate records of harm, how to evaluate the probative value of imaging, telemetry, and clinical logs in areas of armed conflict, and how to integrate survivor testimony ethically into clinical advocacy. It also means supporting research programs that analyze health system collapse through combined epidemiologic and sociolegal lenses, recognizing that the excess mortality induced by the destruction of hospitals, blockade of supplies, and disruption of referral chains is not collateral but predictable. Assembling these frames while building methodological guidance on attacks on health care, including verification standards and analytic approaches, is essential in further expanding PCA practices. Embedding those methods in clinical training can help ensure that future documentation is not an improvisation but a practiced skill.

When the formal system withholds remedy, social movements have turned to public hearings (such as those often seen in the student encampments), juries convened by civil society, and people's tribunals to gather testimony, apply international standards, and issue findings that create a durable public record. These do not replace courts, and they should be designed to avoid replicating judicial exclusions. Their value lies in legitimating survivor knowledge, truth-telling, setting out standards of conduct for professions and institutions, and generating moral and political pressure that accumulates over time. For health sector harms, people's tribunals can be organized around human rights, including duties to respect medical neutrality, to allow humanitarian access, and to protect infrastructure essential to life. They can hear testimony from clinicians, patients, logisticians, and engineers; they can commission independent technical assessments; and they can specify remedial actions, including the restitution of equipment, reparations for destroyed services, and sanctions for officials and companies implicated in the destruction of care.[45] They can determine whether acts and omissions are grave breaches of human rights and humanitarian law. The jurisprudence on such tribunals shows that while they lack coercive power, they have shaped public understandings of atrocity and informed subsequent legal processes.[46]

Licensure boards, medical colleges, and hospital accrediting bodies have authorities that can be activated when clinicians or institutions abrogate the duties of medical ethics in contexts of atrocity. This delicate terrain demands robust consideration of a range of human rights, including due process and the prohibition against torture and cruel, inhuman, or degrading treatment, as well as the denial of health care. There is precedent for professional sanctions against clinicians complicit in abuse.[47] In Gaza, where testimonies describe medical neglect and complicity in ill treatment within detention settings, professional bodies can initiate inquiries into collaborations with complicit Israeli institutions and health care workers, suspend institutional partnerships where due diligence fails, and articulate conditions for an anti-apartheid, anti-genocide framework. These measures are neither collective punishment nor the politicization of scholarship. They are applications of long-standing commitments to do no harm and to refuse participation in cruelty. They reconfirm health professions as accountable actors.

PCA must confront directly the political economy that sustains impunity. Appeals to conscience have limited traction when the same states that arm perpetrators control the venues where verdicts are rendered. Arms-transfer suspensions, targeted sanctions on entities that dismantle health systems, and guaranteed safe humanitarian corridors are not extraneous to health; they are preconditions for the availability, accessibility, acceptability, and quality that define the right to health. The flotillas' experience shows both the possibility and the hazard of civil society routes. The task ahead is to combine that courage with policy design. Maritime and land corridors can be protected by third parties and monitored by independent medical observers. Also, emergency energy systems for hospitals can be leased and deployed by consortia of cities and health systems, not by states and states alone. None of this will substitute for political settlement, but all of it can reduce preventable mortality in the meantime. If the global health community takes seriously its commitments to equity and to the right to health, it must learn from PCA in Gaza and invest in structures that convert documentation into material protection, review into enforceable norms, and remedy into living capacity.

Conclusion

Despite profound challenges, PCA and human rights accountability from below show significant promise. Doctors Against Genocide, Healthcare Workers Watch, and the Freedom Flotilla Coalition demonstrate resilient, adaptable practices that fill gaps left by faltering SLA. The optimal model is synergy: SLA and PCA working together.

PCA, as articulated by Palestinian clinicians and allies, aligns with decolonizing critiques in global health. The aim is not to replace one authority with another but to reorder who can speak about, verify, and decide what counts as harm and repair. Social movements are part of the care ecology, with their own epistemologies, ethics, and practices of remembrance. For clinicians, allyship demands refusing to normalize the dismantling of care, the routinization of death in custody and disappearance, and the separation of duty from advocacy when separation costs lives. Debates on decolonization often call for shifts in authorship, agenda setting, and resource control. Gaza calls for restoring material conditions for health and centering Palestinian clinical authority as prerequisites for the right to health.

These ideals are not rhetorical. They are clinical, juridical, human rights, and ethical propositions tested in one of today's hardest cases. Gaza is both a site of suffering and one of methodological advance. Clinicians and communities have shown that credible, clinically grounded evidence can be produced under siege; coalitions can bridge professions and identities; and remedies can matter at the bedside. Still unfinished is building effective institutional protective arrangements, sustaining inside-outside accountabilities that resist co-optation, and reorienting professional authority toward prevention rather than post hoc lament. If state-centered systems remain unable or unwilling to deliver, accountability from below will proceed—counting the dead with accuracy, confirming human rights violations and violators, preserving the names and methods of those who cared, and insisting that the right to health is a claim on power exercisable by the people themselves.

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Neglected Harms: Health Workers Organizing for Accountability in Tigray

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Abstract

Among the many crimes committed during the Tigray war from 2020 to 2022, the systematic destruction of health care has been extensively documented and contributed to the suffering and death of hundreds of thousands of civilians. Despite the direct harm that Tigray's health care workers experienced and their role in sustaining care under siege, these professionals have been excluded from a transitional justice process that remains performative rather than substantive. We argue that this exclusion represents a violation of international legal obligations and a failure of both the Ethiopian government and the multilateral organizations involved through financing and diplomacy. Despite their marginalization, Tigrayan health workers have continued to exercise agency through sustained grassroots advocacy, documentation, and collective action. In this case study, we amplify the voices of these professionals as they assert their rights, record unacknowledged harms, and demand meaningful participation in the very mechanisms intended to deliver justice. Their experience demonstrates that truly centering victims requires centering health workers as well—addressing their material, legal, and psychological needs as part of any effort to uphold health as a human right.

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Competing interests: None declared.

Introduction

Beginning in late 2020, the war in Tigray quickly devolved into a campaign of mass violence against civilians. United Nations (UN) investigators and human rights groups have concluded that Ethiopian, Eritrean, and Amhara forces committed war crimes, crimes against humanity, and acts of genocide—through starvation, sexual violence, and the destruction of civilian infrastructure.[1] Hundreds of thousands of civilians died, many from preventable causes such as hunger and untreated illness. By mid-2021, more than 90% of the population required humanitarian aid.[2]

The region's health system was systematically dismantled. The Ethiopian National Defense Forces, Eritrean troops, and Amhara regional forces bombed and looted hospitals and clinics.[3] Health professionals labored unpaid, often without electricity, anesthesia, or sterile equipment. Some were displaced; others struggled to deliver care as the health system around them collapsed.

Yet as Ethiopia's transitional justice process unfolds, the voices of the health workers who continued working amid such devastating conditions remain sidelined and ignored. They have received no back pay and no mental health support. Some continue to work in damaged or unreconstructed facilities, while others now face eviction or legal action for unpaid debts. Still others have been arrested for protesting or have been forced to flee. The consequences ripple outward across communities: a fractured health system, worsening care, and deepening public harm.

This paper advances two arguments. First, the destruction of Tigray's health system and the exclusion of its workers from transitional justice constitute a violation of international legal obligations, including the right to health under the International Covenant on Economic, Social and Cultural Rights (ICESCR).[4] Second, despite their exclusion, Tigrayan health workers have maintained agency and efficacy through sustained, grassroots advocacy and action. We highlight Tigrayan health professionals who, in response to this institutional failure, seek to assert their rights, document unacknowledged harms, and demand inclusion in the very processes that claim to deliver justice. This case study emphasizes that centering victims means also centering health workers and addressing their material, legal, and psychological needs as part of a broader mandate to uphold health as a human right.

Destruction of Tigray's health system

The war in Tigray dismantled one of Ethiopia's strongest regional health systems, leaving it in ruins. Before the conflict, Tigray maintained an extensive network of hospitals, clinics, and village-level health posts, all connected by a functioning ambulance referral system.[5] Ethiopian government forces, Eritrean troops, and Amhara militias targeted and destroyed infrastructure during the war.

Humanitarian assessments documented widespread attacks, looting, and the obstruction of care. At Semema, a rural health post was looted twice before being burned by soldiers; at Sebeya, a rocket destroyed the maternity ward.[6] Ayder Hospital in Mekelle, the region's flagship facility, operated under siege conditions, while many smaller clinics were overrun or deserted.[7] Only 3%–3.6% of health facilities in Tigray remained fully operational during the war.[8] More than 77% of health centers and 60% of hospitals were partially damaged or destroyed.[9] In Eastern Tigray, 83% of infrastructure was affected, and just 11.5% of ambulances remained functional.[10] Rural health posts were virtually non-operational.

Independent investigations have concluded that this destruction was intentional. Médecins Sans Frontières (MSF) reported that many health facilities appeared "deliberately vandalised to make them non-functional."[11] In town after town, medical equipment was smashed, pharmacies ransacked, and clinics set on fire after being stripped of supplies.

Under international humanitarian law, medical units are specially protected objects. Attacks on them violate the Geneva Conventions and their Additional Protocols.[12] Yet Ethiopian federal forces and allied troops repeatedly breached these protections. Ambulances were commandeered—about 20 were seized in one area alone and later observed transporting military goods.[13] MSF reported that one in five facilities they visited had been occupied by armed forces, some for extended periods, in clear violation of medical neutrality.[14]

These acts cannot be justified by military necessity. They reflect a calculated effort to dismantle health infrastructure, disrupt emergency care systems, and erode the region's social foundation. The systematic looting, vandalism, and militarization of medical spaces suggest an intent not only to disable care but to destroy the region's social foundation and ability to sustain life—an intentional constellation of actions that, when directed at a specific ethnic group like the Tigrayans, can constitute an act of genocide under article II(c) of the Convention on the Prevention and Punishment of the Crime of Genocide ("inflicting on the group conditions of life calculated to bring about its physical destruction"). As seen in other contexts of genocide and mass atrocity—such as Gaza, Yemen, and Darfur—attacks on hospitals, the denial of medical supplies, and the obstruction of humanitarian relief have transformed health systems into instruments of collective destruction.[15]

Health effects

The war in Tigray triggered a region-wide collapse of health service delivery, cascading into overlapping humanitarian crises. By mid-2021, maternal and child health services were nearly nonexistent, with only a fraction of facilities offering limited care. Maternal mortality surged from 186 to 840 deaths per 100,000 live births—a more than fourfold increase—reflecting a near-total breakdown in obstetric care and a severe reversal of Sustainable Development Goal 3.[16]

Routine immunization programs halted, and 91% of the population became food insecure, with more than a quarter of children screened found malnourished.[17] Tens of thousands of patients with chronic illnesses—including HIV and diabetes—lost access to life-sustaining treatment.[18] HIV prevalence more than doubled, from 1.4% to 3.0%, rising to 5.5% among internally displaced persons and 8.5% among sex workers, largely due to conflict-related sexual violence and loss of preventive services.[19]

Mental health burdens rose sharply: more than 50% of internally displaced persons met the criteria for posttraumatic stress disorder or depression.[20] Sexual and gender-based violence was widespread yet critically under-addressed. Nearly half of surveyed women experienced violence, but most received no medical or psychological care.[21]

The conflict displaced more than 2 million people and killed an estimated 600,000 civilians, many due to starvation and treatable illness.[22] The health workforce was devastated—only 1,300 of 20,000 pre-war professionals remained by 2022. Facilities resorted to expired supplies and ad hoc materials to maintain minimal services.[23]

Together, these indicators suggest the deliberate dismantling of Tigray's health infrastructure, with lasting consequences for population health and any future recovery.

Health effects on health care providers

Tigrayan health professionals endured profound physical and psychological hardship throughout the conflict.[24] Many lost colleagues and family members, suffered displacement, or were directly targeted. On June 24, 2021, three MSF staff members were executed by Ethiopian National Defense Forces near Abi Adi while clearly marked in MSF gear.[25] This targeted attack highlights the extreme dangers medical workers face and reflects a disturbing collapse of medical neutrality in the region.

Providers treated overwhelming numbers of critically injured civilians under siege conditions—without pay, without supplies, and often under threat. Some fled the region entirely, while others continued to work in extraordinary deprivation.[26]

Exposure to mass casualties, sexual violence, and other forms of violence without adequate psychosocial support generated widespread vicarious trauma, moral injury, emotional exhaustion, and symptoms consistent with posttraumatic stress disorder. Many reported persistent anxiety, intrusive memories, and moral distress from impossible triage decisions.[27] Many health workers were unpaid for extended periods, exacerbating financial strain and eroding their ability to cope.[28]

The following testimonies—collected in March 2024 through in-person conversations and written accounts compiled by the Tigray Medical Association for advocacy and documentation purposes—illustrate the lived realities of health professionals working under siege. These accounts were later incorporated into advocacy letters submitted to the World Bank, the United States Agency for International Development (USAID), and other international organizations, and participants provided their experiences with the understanding that their words would be used publicly to raise awareness of the conditions faced by health workers under siege. We include them here to illustrate the physical, emotional, and psychological toll on providers working under blockades, with all identifying details removed to protect confidentiality and safety.

At Ayder Hospital, which remained partially functional despite the blockade, health workers faced immense obstacles. A nurse explained:

> *I walked 10 kilometers to and from the hospital each day, on an empty stomach, while drones circled overhead. I kept going because I felt obligated to care for patients who had traveled from rural areas hoping to be saved.*

A nephrologist reflected on the devastating consequences of medical supply blockades:

> *I lost two-thirds of my dialysis patients due to infection. We were using the same dialyzer more than 20 times, even though it was supposed to be a one-time use. There was no alternative.*

Another surgeon spoke of desperate improvisations to continue providing surgical care:

> *We had to use expired anesthesia. We even went to churches to ask people to donate their cotton clothes—traditional garments worn during religious services. We cut them, sterilized them, and used them as gauze for wound care and surgery.*

A nurse coordinator of the emergency department at Ayder recalled a moment of personal crisis:

> *When I heard my brother's house was destroyed by a drone attack, I still went to work, knowing the victims of the drone attack will be coming to the emergency room and the patients and staff depended on me. The need was overwhelming.*

These testimonies reveal the immense burdens carried by health workers at Ayder Hospital—members of the Tigray Medical Association who continued their lifesaving efforts despite near-impossible conditions.

Yet the experiences of Tigrayan health professionals also demonstrate how these burdens were refracted through dimensions of gender, profession, and geography. Female clinicians frequently faced gendered violence and emotional strain linked to caregiving roles; one medical intern described hearing that two students had been raped by soldiers in the same classroom where she trained.[29] Male ambulance drivers, by contrast, faced lethal security risks—as seen, for instance, in the June 2021 killing of MSF driver Tedros Gebremariam Gebremichael during a marked humanitarian mission.[30] Displaced providers such as Dr. Tewodros Tefera, who continued treating civilians in Sudanese refugee camps after mass expulsions in western Tigray, spoke of "the slow death of Ethiopia."[31] In Irob, near the Eritrean border, a health professional reported that colleagues were killed or detained by occupying forces, forcing most remaining staff to flee. Together, these accounts trace a spectrum of vulnerability shaped by profession, gender, and geography within the broader devastation of Tigray's health system.

Violations of the right to health under international law

The deliberate dismantling of Tigray's health system constitutes a grave breach of the right to health as articulated in international human rights law. The violations documented are classifiable as war crimes under international and humanitarian law and the Ethiopian Penal Code.[32] Additionally, article 12 of the ICESCR, as elaborated in General Comment 14, establishes four interdependent criteria for the right to health: availability, accessibility, acceptability, and quality.[33] Each was systematically violated in Tigray by Ethiopian National Defense Forces, Eritrean troops, and Amhara regional forces:

- *Availability* was decimated: <10 % of facilities remained functional after looting and strikes.[34]
- *Accessibility* was blocked by road closures, bank shutdowns, and a blanket aid embargo.
- *Acceptability* eroded as clinicians were forced to reuse gloves, operate without anesthesia, and attempt equipment sterilization using makeshift materials.
- *Quality* collapsed as medications—antibiotics, insulin, and vaccines—ran out, maternal mortality quadrupled, and some hospitals discharged inpatients due to a lack of food, while others turned away new patients unless they brought their own supplies.

These outcomes cannot be justified as resource limitations, either hypothetically or given the specific details of direct targeting noted in this case. Under General Comment 14, states may not invoke scarcity to excuse the non-fulfillment of core obligations, including access to essential primary and emergency care.[35] The destruction of Tigray's health infrastructure and workforce reflects not mere neglect but active dismantling—violations that fall within the scope of non-derogable obligations under international law.

If left unaddressed, these violations not only re-traumatize survivors but legitimize retrogressive measures.[36] Any credible transitional justice process must recognize the right to health as both a site of harm and a domain of reparation.

The transitional justice process

The 2022 Pretoria Agreement marked an end to formal hostilities in Tigray and included the Ethiopian government's commitment to establish a transitional justice process.[37] In early 2023, a draft transitional justice policy was released for public consultation, with support from the African Union and the Office of the United Nations High Commissioner for Human Rights.[38] The policy invokes international frameworks, including the African Union Transitional Justice Policy and the UN Secretary-General's 2010 guidance note on transitional justice, which emphasize victim-centeredness, comprehensive redress, and participatory design.[39]

On paper, the policy reflects these standards. It acknowledges "gross violations," promises institutional reform, and adopts the four pillars of transitional justice: truth, accountability, reparations, and guarantees of non-repetition. In reality, however, these commitments are largely performative. No truth-seeking commissions have taken place, no perpetrators have been held accountable, and victims have received neither reparations nor recognition. The process suffers from three interlocking deficits:

- First, *it lacks impartial oversight.* No national or international bodies were invited to participate in the policy's design or implementation, despite credible allegations that state actors themselves committed crimes against humanity. This structural conflict of interest renders the process legally and morally suspect.
- Second, *it excludes key victim groups*, including frontline health professionals and civil society actors in Tigray. Despite their central role in sustaining care under siege, these individuals and health care unions were not consulted, not invited to testify, and not included in reparative planning. Their exclusion contradicts both the letter and spirit of the UN guidance note, which holds that victims must be agents in defining justice.[40]
- Third, *it fails to confront the role of Eritrean forces*, whose documented atrocities—massacres,

> sexual slavery, and destruction of health infrastructure—are omitted entirely from the draft policy's mandate.

In sum, Ethiopia's transitional justice process, while procedurally constructed, substantively fails. By omitting social and economic rights, silencing health workers, and shielding perpetrators, it transforms what should be a reckoning into a narrative of forgetting. A justice framework that fails to account for the destruction of health care—both as a system and a site of human dignity—risks entrenching the very impunity it was designed to overcome.

Health professionals' mobilization: Accountability from below[41]

Against this backdrop, health professionals in Tigray are constructing an alternative, victim-led architecture of accountability. At the forefront of this effort is the Tigray Medical Association (TMA), a professional body that, during the siege of Mekelle, transformed into a rights-based coalition.[42] Its evolution reflects the demands of a health system in collapse and a transitional justice process that has largely ignored the economic, psychosocial, and professional harms endured by providers.

Throughout 2023 and 2024, TMA documented the conditions faced by health workers: more than 17 months of unpaid wages, forced labor under siege, and psychological trauma resulting from extreme shortages. Many clinicians were evicted from their homes, summoned to court for unpaid rent, or forced to pull their children from school. Despite these harms, the federal government's transitional justice blueprint—released in early 2023—excluded any reference to the health system's collapse or to the rights of public sector workers. In response, TMA began organizing formal petitions demanding salary restitution, psychosocial support, and participation in transitional justice policymaking. Letters were submitted to the Ministries of Health and Higher Education and to the Prime Minister's Office.[43]

When domestic appeals failed, TMA pursued a multi-track strategy. It appealed to donors such as the World Bank and the USAID, requesting that future health sector funding be conditioned on remedial action. These actions gave rise to a broader campaign framing the denial of pay and protection as violations of international and domestic law.

This advocacy work culminated in the creation of a transitional justice working group in 2024—a coalition of TMA, civil society organizations, women's associations, and legal advocates. Through workshops and structured dialogue, the working group began developing a victim-centered position statement grounded in international norms: the Committee on Economic, Social and Cultural Rights' General Comment 14 (on the right to health), article 16 of the African Charter on Human and Peoples' Rights, and International Labour Organization Convention 95 (on wage protection), alongside Ethiopia's own Labour Proclamation.[44]

The initiative has received coordination support from Irob Anina Civil Society, a Canada-based civil society organization, as well as financial and technical assistance from Irish Rule of Law International and pro bono guidance from independent international human rights lawyers. Additional engagement has come from the European Union, the African Union, and the US State Department's Bureau of Democracy, Human Rights, and Labor—though this remains limited relative to the scale of need. These modest partnerships highlight both the emergence of a fragile transnational solidarity and the enduring absence of sustained, rights-based support for survivor-led accountability within Ethiopia's transitional justice process.

One promising avenue for redress has emerged in domestic litigation. In 2025, TMA began exploring the possibility of suing the federal government in Tigrayan courts for unpaid wages, following a precedent set by the Tigray Teachers' Association, whose successful legal challenge resulted in the freezing of the Interim Administration's Commercial Bank of Ethiopia account.[45] TMA has consulted with the teachers' legal team to assess the viability of a similar strategy for health workers.

Collectively, these actions instantiate the tripartite conceptualization of accountability—monitoring, review, and remedy—as recognized in human rights scholarship.[46] They assert that the exclusion of health workers from redress mechanisms constitutes a retrogressive measure under the ICESCR. Their campaign demands that transitional justice expand beyond the narrow focus on civil-political violations to encompass socioeconomic rights, positioning clinicians as primary claimants to restitution and setting a precedent for embedding health system reconstruction within post-conflict legal remedies.

Transitional justice literature emphasizes that victims often occupy complex roles and are simultaneously harmed and mobilized to alleviate harm. As Erin Baines argues, such "complex victimhood" challenges the passive portrayals and assumptions of survivors.[47] Health professionals in Tigray show this dual role: enduring trauma while coordinating efforts for redress. This demonstrates how survivor-led initiatives, such as TMA and the transitional justice working group, constitute emergent forms of accountability from below, transforming lived harm into a collective fight for justice.

Accountability lies at the heart of transitional justice, serving as the mechanism through which truth, reconciliation, and justice can be meaningfully achieved. Without it, transitional justice risks becoming symbolic or ineffective, as ongoing impunity erodes public trust, reconciliation, and respect for the rule of law. Conversely, robust accountability processes strengthen transitional justice by establishing clear legal norms and consequences for violations, thereby advancing human rights protection and the foundations for lasting peace.

Roadblocks: Structural barriers to health-worker-led accountability

The efforts of Tigrayan health professionals to construct a bottom-up framework for justice have encountered a set of formidable barriers—legal, institutional, and geopolitical. While the coalition's actions embody the participatory and remedial spirit of international human rights law, the architecture of transitional justice in Ethiopia has largely foreclosed their inclusion. The result is a justice process procedurally closed to those it purports to serve, structurally resistant to social rights claims, and increasingly complicit in the ongoing marginalization of those who sustained life during the war.

Despite multiple formal communications, the coalition has received no official response from the Ministry of Health, the Ministry of Higher Education, or the Office of the Prime Minister. This non-engagement constitutes a denial of procedural justice. Under ICESCR, the right to health includes not only access to care but meaningful participation in governance—especially by those most affected.[48] Excluding health workers from Ethiopia's transitional justice process violates this principle. The refusal to recognize them as a distinct victim group further undermines the process's legitimacy.

Federal-regional dysfunction compounds the problem. The Tigray Regional Health Bureau acknowledges the legitimacy of providers' demands but claims that jurisdiction lies with the federal government, which has disavowed responsibility and created no path for redress.

International donors—particularly the World Bank and USAID, two of Ethiopia's largest health sector financiers—have likewise failed to respond substantively to the coalition's appeals. While the considerable power over state affairs that their financing role affords them represents an unjust form of neocolonialism, their failure to exercise it in this case also stands in tension with their stated institutional commitments.[49] For example, USAID's Automated Directives System 201 series and human rights due diligence protocols mandate that US assistance not reinforce discriminatory or rights-violating practices.[50] Yet both donors have remained "neutral," effectively endorsing a state-centered approach that prizes institutional continuity over remedial justice. This abdication of responsibility contravenes General Comment 14, which affirms the obligation of international cooperation in realizing the right to health, especially in post-conflict settings.[51]

Attempts by health workers to publicly demand redress have also met with repression. In 2025, multiple physician associations in Ethiopia—including those in Oromia and Tigray—were threatened with deregistration following coordinated labor actions over unfair and unpaid salaries.[52] Several health workers who participated in peaceful demonstrations were arrested.[53] This criminalization of protest violates rights to free expression and assembly and chills future mobilization. Without legal protections or institutional recognition, Tigrayan health professionals are simultaneously excluded from formal processes yet vulnerable to sanction when they assert their rights.

These obstacles expose the limits of a transitional justice process that favors procedural form over substantive inclusion. The government's rhetorical commitment to "best practices" contrasts with its refusal to engage frontline actors. Neglecting the harms suffered by health workers threatens not only justice but the survival of Tigray's public health system. Without redress, both individual clinicians and institutions are deteriorating—consequences already visible across Tigray.

Consequences of inaction: Individual and structural harm

The most immediate effects of exclusion have fallen on health workers themselves. Deprived of income, mental health support, and a voice in the justice process, many now face profound instability. With no pay, no restitution, and no pathway for reintegration, providers are being driven out of public service and out of the area altogether. The result is a slow, corrosive exodus that threatens the viability of Tigray's entire health system.

Systemically, the consequences are profound. After the war, the Health Resources and Services Availability Monitoring System baseline survey found that only 6.3% of 853 health facilities were fully functional, while 60% of health centers and 39% of hospitals sustained physical damage. Access to essential services remained critically impaired: only 2% of facilities provided full emergency care, and 5% surgical services.[54] The continued exclusion and attrition of trained personnel only deepens this crisis. Young doctors and nurses—many of whom remained during the war at enormous personal cost—are now being forced to leave in search of economic survival or safer working conditions. The result is a growing vacuum of clinical expertise at precisely the moment when rebuilding is most urgent.

This vacuum reflects a direct violation of international law. General Comment 14 makes clear that states must not adopt—or allow—policies that lead to a *retrogressive deterioration* in the availability and quality of health services. Paragraph 43 of the general comment affirms that the collapse of trained personnel and health infrastructure undermines the right to health for all.[55] The ongoing erosion of Tigray's medical workforce, combined with infrastructural paralysis, places the region's population at immediate risk of preventable death, disease, and protracted suffering.

Moreover, these conditions threaten the broader prospects for recovery and development. Without functioning health services, communities cannot return to work, children cannot safely attend school, and displaced populations cannot resettle. Public health emergencies—whether cholera, malaria, or malnutrition—are already emerging and will likely worsen in the absence of skilled providers.[56] Development, in any meaningful sense, is impossible when a population remains sick, untreated, and structurally neglected.

In this context, failing to support Tigrayan health professionals will have long-term, system-wide consequences. The right to health cannot be realized unless concrete action is taken to recognize, compensate, and reintegrate these professionals. These steps must include the reconstruction of health infrastructure in Tigray as a national priority, ensuring safe and functional facilities and a supportive working environment for those operating under extreme pressure. Psychosocial support programs should be integrated into health institutions, in partnership with professional associations, to address widespread trauma and burnout among health care workers.

Salary backlogs must be immediately resolved through transparent administrative action, backed by legal safeguards against retaliation. Where restitution is denied, domestic litigation—such as that being pursued by TMA—offers a legitimate path toward reparation. TMA should be formally represented in transitional justice consultations, as the current policy framework lacks the participation and structural guarantees necessary to address health workers' rights claims.

The Ethiopian government bears the primary responsibility to uphold these obligations and to comply with fundamental labor rights under article 7 of the ICESCR. International donors to Ethiopia's health sector, including USAID and the World Bank, must also use their financial and diplomatic leverage to ensure compliance. Their conditional support should be explicitly tied to restitution, workplace safety, and psychosocial rehabilitation for health workers. Only through these coordinated actions—grounded in legal accountability and survivor participation—can the rebuilding of Tigray's health system be both just and sustainable.

Conclusion

A transitional justice process that overlooks the destruction of health systems—and the professionals who struggled to sustain them—is neither credible nor complete. Tigrayan health workers endured systematic violence, unpaid labor, and psychological trauma. Justice must begin by acknowledging these harms and offering redress grounded in international law. Under the UN Basic Principles on the Right to Remedy, reparations must extend beyond symbolic recognition to include the following:

- restitution: payment of salary arrears and reinstatement of employment;
- compensation: for financial losses and deprivation;
- rehabilitation: including mental health support and professional reintegration; and
- guarantees of non-repetition: through facility reconstruction and employment protections.[57]

Yet where formal mechanisms have failed to deliver these obligations, Tigrayan health professionals are working to advance accountability from below through grassroots, survivor-led efforts that seek justice through collective organization, legal innovation, and moral authority.

First, TMA is currently building collective awareness and delivering capacity-building trainings for its members on transitional justice principles, documentation techniques, and the rights of survivors. Additionally, it is sensitizing members to alternative accountability options. The goal of this effort is to reach a collective and informed decision, following which TMA aims to develop a consensus on whether, and to what extent, it should engage with the Ethiopian transitional justice process.

Second, TMA's strategy will prioritize domestic legal avenues to recover unpaid salaries and enforce labor rights. This approach will follow the precedent set by the Tigray Teachers Association's lawsuit, which achieved a landmark ruling that froze government bank accounts and protected funds for Tigrayan teachers. This shows how grassroots litigation can create legal and moral pressure from below.

Third, through the transitional justice working group, TMA and other members are in the process of organizing a synergistic movement for collective justice efforts. Together, they aim to document violations, organize truth-seeking through trusted local institutions, and engage international nongovernmental organizations and donors to press for payment of 17 months of unpaid salaries. Their advocacy reframes what might appear as administrative neglect into systematic violence and collective punishment—another expression of accountability from below that reclaims justice as a civic right rather than a political concession.

Fourth, acknowledging the institutional limitations of local justice, as in the case of the Tigray Teachers Association, TMA is preparing to pursue regional and international mechanisms. It is planning, for example, to submit the case to the African Commission on Human and Peoples' Rights and engage UN treaty bodies and Special Rapporteurs on the right to health and transitional justice. These steps position Tigray health professionals to demand justice before regional and international mechanisms, asserting that this matter is the responsibility of the state and international actors.

Further, a truly victim-centered process must be health-centered. This means including health workers in the design and oversight of justice mechanisms, recognizing them as victims, and repairing the systems that they held together under siege. What Tigrayan health workers have done—organizing in the aftermath of war, documenting harm, and articulating a vision for repair—must be met with action if transitional justice is to move beyond performance and toward genuine accountability. Their ongoing mobilization represents a living model of accountability from below, demonstrating that when institutions above fail, survivors themselves can drive justice upward.

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Accountability for Sexual and Reproductive Health and Rights in Humanitarian and Disaster Situations: Case Studies from Uganda, Bangladesh, and Nepal

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Abstract

Sexual and reproductive health and rights (SRHR) during conflicts and disasters are protected under multiple legal and policy frameworks; however, weak accountability mechanisms often prevent these rights from being realized. Drawing on case studies from Uganda, Bangladesh, and Nepal, this paper examines rights-based approaches for strengthening accountability for access to health services at the local level. The case studies adopt a "circle of accountability" as both a conceptual framework and implementation strategy to monitor, review, and prompt remedial action when reproductive rights are not respected. We argue that four interrelated strategies offer a promising approach to advance accountability for SRHR in displacement contexts marked by weakened governance, overlapping duty bearers, and power imbalances within humanitarian systems: (1) strategic legal and policy advocacy to promote alignment with human rights standards; (2) multi-sectoral partnerships and human rights champions to facilitate commitments among humanitarian actors; (3) equitable participation in humanitarian platforms to shape decision-making and remedial action; and (4) reimagined rights-based evaluation methods to promote people-centered accountability. Ultimately, we offer a road map for practitioners working in other humanitarian and disaster contexts to shift accountability for reproductive rights beyond performative checklists toward addressing both the immediate needs of displaced communities and systemic remedial action.

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Competing interests: None declared.

Introduction

In an era of unprecedented humanitarian need, the complexity and scale of interconnected global crises demand more innovative and accountable approaches to humanitarian and disaster response.[1] This is particularly relevant in the domain of sexual and reproductive health and rights (SRHR), where there is continued need for maternal health care, contraception, comprehensive abortion care, holistic support for survivors of sexual and gender-based violence, and the protection of the rights to life, bodily autonomy, and nondiscrimination. Yet the availability of and access to health services are often fragmented and disrupted.[2] Access to sexual and reproductive health services and information is further limited in crisis by the influence of non-enabling legal and policy environments, harmful gender norms, misinformation during emergencies, and insecurity.[3] Global evidence consistently affirms SRHR as a lifesaving priority, with positive outcomes from the early implementation of key sexual and reproductive health activities at the onset of an emergency.[4] However, SRHR remains neglected across humanitarian response and preparedness cycles due to underfunding, limited health system capacity, and poor integration across humanitarian frameworks.[5]

To situate our discussion, we adopt the World Health Organization's definition of SRHR as encompassing both a broad range of health services (such as contraception, maternal health services, the prevention and treatment of sexually transmitted infections, and protection from gender-based violence) and the recognition that access to these services is a human right.[6] This framing distinguishes SRHR from narrower conceptions of sexual and reproductive health that focus mainly on service delivery and instead emphasizes rights-based entitlements, individual agency, and the structural conditions necessary for people to make decisions about their bodies and lives, linking health outcomes to autonomy, equality, and accountability.[7]

Established legal frameworks and practice standards protect access to sexual and reproductive health services in humanitarian situations, with both formal and informal accountability mechanisms ensuring that commitments made by states and professionalized civil society organizations are met.[8] These mechanisms—from global-level treaty monitoring bodies and Special Procedures, to core health indicators and monitoring frameworks for sexual and reproductive health, to local-level feedback and response systems—enable the identification of gaps, pathways for redress when violations occur, and ways to ensure that duty bearers uphold their obligations.[9]

Humanitarian standards and associated accountability mechanisms are well-established in theory, yet the reality of implementation is complex. Political will, systems' capacity to be timely and responsive to feedback from persons who are displaced, and power dynamics within the humanitarian system significantly influence and often constrain accountability for access to sexual and reproductive health services. These structural barriers create substantial gaps between legal and policy commitments and actual service delivery. This is further compounded by how SRHR programs in humanitarian and emergency situations are arranged to involve a complex network of actors with varying degrees of power and influence.[10] For example, while multilateral agencies provide normative guidance for international and national nongovernmental organizations (NGOs) that often serve as implementing partners, local actors with crucial contextual knowledge often occupy limiting roles in decision-making hierarchies. These power dynamics are also shaped by funding structures, with international donors exercising influence over program design and implementation through priority setting and reporting requirements, thus perpetuating vertical accountability structures.

The United Nations' *Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Morbidity and Mortalit*y envisions a restructuring of power relations and mechanisms for improved rights-based accountability.[11] The guidance situates accountability as one of four interdependent principles of a human rights-based approach—participation, nondiscrimination, empowerment, and accountability itself—and as a cross-cutting principle that underpins policy design, implementation, monitoring, review, and remedy. Within the guidance, the "circle of accountability" (CoA) builds on these foundations by embedding accountability throughout all stages of policy and program cycles, from national planning and budgeting through implementation and monitoring to mechanisms for assessment and redress, rather than treating it as an isolated response to rights violations or abuses.

Within the CoA framework, accountability reflects the legal obligation of duty bearers to be answerable for their actions and the entitlement of rights holders to demand redress, transforming displaced persons from passive beneficiaries into rights holders who can claim entitlements. It also contributes to transforming health systems and sustaining change by recognizing contextual and political factors, ensuring meaningful engagement in the realization of rights and access to justice, and envisioning the enforceability of decisions and actions from the outset of the policymaking cycle.[12]

Although the CoA does not prescribe specific rights-based benchmarks against which health interventions should be reviewed (thereby risking procedural rather than substantive accountability), adopting it alongside complementary accountability mechanisms that define measurable rights-based standards ensures review against health rights obligations. In humanitarian contexts, accountability must grapple with displacement-specific challenges, including the absence of traditional state-citizen relationships, the multiplicity of duty bearers with overlapping mandates, and power asymmetries embedded within humanitarian architectures. Implemented holistically, a rights-based CoA should identify and eliminate barriers that prevent or delay the inclusion and leadership of displaced persons in accountability processes and support transformative remedies that promote the realization of reproductive rights.[13]

While there is rhetorical traction for rights-based approaches and accountability in widely accepted humanitarian sector standards, such as the Core Humanitarian Standard on Quality and Accountability and the Sphere Standards, concrete policy and programmatic examples that apply and enforce health rights standards are limited.[14] This gap reflects persistent ambivalence and resistance to rights-based approaches and accountability frameworks within the humanitarian sector, rooted in concerns about their compatibility with traditional humanitarian principles of neutrality, operational efficiency, and depoliticized aid principles that, despite their ostensibly apolitical framing, are themselves argued to constitute political positions.[15]

Since 2019, the Center for Reproductive Rights has worked in partnership with humanitarian and human rights organizations to design and implement contextualized CoA models that respond to this gap: first, with CARE Uganda and South Sudanese refugees in settlements in Adjumani, Uganda; second, within the Rohingya refugee crisis in Bangladesh in partnership with Bangladesh Legal Aid and Services Trust, CARE Bangladesh, and Naripokkho; and third, in disaster-affected municipalities in Kailali District, Nepal, with CARE Nepal, the Forum for Women, Law and Development, and NEEDS Nepal. The relationship between humanitarian agencies and state health institutions providing sexual and reproductive health services varies across these contexts, reflecting differences in crisis status, state priorities, refugee policies, and health and legal systems. However, human rights principles remain universally applicable, providing a common thread to guide both the design and delivery of the case studies.[16] We designed all the initiatives with a rights-based accountability focus and used the CoA as a conceptual framework, yet varied their design processes, implementation strategies, and methodologies to ensure contextualization and fitness for purpose.

The methodologies and results from the case studies are presented elsewhere, including case study reports, advocacy materials, and toolkits to support other humanitarian practitioners in clarifying SRHR obligations and replicating methodologies in their respective contexts.[17] In this paper, we focus on promising cross-cutting strategies emerging from the case studies. In our view, these strategies will support future health rights efforts to hold the broad range of humanitarian actors, including states, multilateral agencies, and professionalized civil society organizations, accountable for providing more people-centered sexual and reproductive health services, platforms, and processes. Drawing on comparative insights from these three country case studies, we present four common and transferable strategies for accountability. Specifically, we explore how health rights initiatives can navigate legal and policy alignment and advancement; benefit from multi-sectoral partnerships to build human rights champions; center community participation and decision-making in humanitarian platforms; and transform evidence requirements from standard evaluation into a process for improved accountability and remedial action.

Our analysis is underpinned by practitioner reflections that were shared during a February 2025 partners' dialogue. The cross-regional dialogue brought together organizations and allies engaged in the three initiatives for shared learning and knowledge exchange. Through structured discussions and deliberative processes, practitioners shared their perspectives and evidence, contested the different project models and strategies, and formed consensus-based recommendations to advance accountability for SRHR in humanitarian and disaster situations. Drawing on the meeting output documents and recommendations, we argue that for rights-based programming and accountability to be transformative rather than tokenistic, it must operate not only at the level of health service delivery but also as an institutionalized norm for redistributing power, guaranteeing meaningful participation and inclusion, and expanding legal, political, and social protections for SRHR.

Summary of the three case studies

This section summarizes the three case studies that we explore throughout this paper. The initiatives adopted a broadly coherent three-stage approach.

First, they were co-designed with refugee and host-community stakeholders through participatory workshops, focus group discussions, and key informant interviews to map SRHR accountability gaps and devise new strategies and systems, drawing on the CoA as a blueprint for the promotion and protection of SRHR.

Second, the initiatives trained and legitimized local community leaders and human rights defenders through structured capacity-strengthening, complemented by follow-up support and peer-learning sessions, to document SRHR claims, monitor service delivery against SRHR standards, and advocate for change through various platforms when reproductive rights were not respected. Among other topics, the capacity-strengthening addressed progressive legal and policy frameworks on SRHR at the regional, national, and global levels, survivor-centered documentation and referral procedures, and evidence-based advocacy strategies.

Finally, the initiatives monitored remedial action taken by duty bearers. Monitoring combined quantitative tracking of case outcomes (e.g., rates of resolution of cases and responsiveness time frames) with qualitative assessment of remedial outcomes, acceptability of remedies among refugee communities, and emerging institutional learning and adjustments, laying a foundation for sustained policy and practice change.

Adjumani District, Northern Uganda

In 2019, the Center for Reproductive Rights and CARE Uganda piloted a community-centered model for SRHR accountability in refugee settings. The co-designed model aimed to address the failure of existing humanitarian feedback mechanisms in the Pagirinya refugee settlement (e.g., feedback boxes, public dialogues, and hotlines) and enable more responsive remedial action when reproductive rights were not respected. As described by one South Sudanese woman living in the settlement, "When we use the current feedback boxes, we see no change and no response."

The Pagirinya model established three interconnected pillars: (1) a council for SRHR made up of refugee and host-community members who were trained to document SRHR issues; (2) an ombudsperson who served as an independent reviewer of SRHR-related complaints, with district government backing; and (3) community-based monitors who tracked SRHR programs and services to assess whether commitments and state-mandated changes in response to complaints were implemented. Over a three-year period, the model led to concrete remedial actions to improve service delivery, including a newly authorized human rights and respectful maternal health care training for health service providers, adolescent-friendly appointment times at primary health centers, and permanent budget lines for maternal health departments to buy assistive devices for persons with disabilities.

Cox's Bazar District, Bangladesh

Building on the learning from Uganda, a partner consortium established a human rights-based accountability initiative in Rohingya refugee camps in Cox's Bazar between 2022 and 2025. The program integrated legal, social, and participatory accountability mechanisms, with leadership from Rohingya women and community leaders at its core. An adaptive program design framework characterized by flexibility and continuous evolution was used based on real-time data, national and local political constraints, and community recommendations.

Accountability for access to sexual and reproductive health services was operationalized through the establishment of four interconnected components: (1) a rights-based coordination platform for data-driven dialogue between humanitarian health stakeholders at the camp level; (2) community solidarity networks that provided peer support and feedback relating to SRHR, gender, and human rights realities; (3) an independent monitoring system within primary health facilities led by national and local women's rights defenders; and (4) holistic support centers where human rights lawyers and health advocates provided integrated health and legal assistance. Key remedial actions over the four-year project period include immediate measures to provide 24/7 outdoor lighting at health facilities to reduce the risk of sexual and gender-based violence at night; securing access for human rights defenders to accompany Rohingya women and girls to sexual and reproductive health services to reduce fears of discrimination and abuse; and guarantees from humanitarian organizations providing health services to train and support their staff in the delivery of respectful maternal health care, in response to reports of mistreatment.

Kailali District, Nepal

The 2023 collaboration in Nepal aimed to better understand the adaptability and transferability of the CoA strategies and arrangements tested in Uganda and Bangladesh, within the context of disaster. Similarly to the Uganda initiative, this model connected service users with municipal health authorities and providers using (1) a council for SRHR; (2) community monitors who were trained by national reproductive rights advocates and lawyers in human rights monitoring approaches and tools; and (3) improved feedback channels to document, monitor, and resolve SRHR complaints within existing municipal-level health monitoring and reporting systems.

The initiative also led legal and policy advocacy at the district and municipal levels, resulting in the government institutionalizing amendments to the Godawari municipal disaster preparedness and response plan guaranteeing the continuity of sexual and reproductive health services during emergencies. Strategic advocacy subsequently achieved the formal passage of the municipality's Safe Motherhood and Reproductive Health Rights Act of 2025, marking the first enactment of the national reproductive health law at the local level in Nepal.

Accountability for SRHR: Four pathways for change

These initiatives in Uganda, Bangladesh, and Nepal provide examples of innovative approaches to hold states, professionalized NGOs, and multilateral humanitarian agencies accountable for their SRHR commitments. In this section, we outline common pathways for change that the initiatives have found effective in holding powerful actors accountable and achieving real-time remedial action to improve SRHR. These approaches are promising to improve right to health realities and recenter the agency and rights of affected populations in humanitarian and disaster response governance.

Pathway 1: Strategic legal and policy advocacy to meet and advance human rights standards

The complex humanitarian landscape demands both the provision of essential sexual and reproductive health services and the strategic navigation of legal, political, and community contexts. While service delivery metrics remain important, true accountability requires dismantling structural barriers to sexual and reproductive health service access through integrated legal and policy advocacy. The three case studies actively engaged at various levels with legal and policy frameworks as leverage to advance rights protections.

In a notable example from Uganda, following increasing reports of sexual and gender-based violence during the COVID-19 pandemic, the ombudsperson identified a policy opportunity to strengthen local-level protections. With support from lawyers from the Center for Reproductive Rights, the ombudsperson worked with the local government to review national health rights standards and revise subnational bylaws to ensure better alignment with constitutional protections and the National Policy on Elimination of Gender Based Violence in Uganda.[18] The advocacy process highlighted how even with national legal frameworks in place, implementation often falls short due to local officials' discretionary power, revealing a significant gap during instability and crisis.

At the regional level, partners from the Uganda initiative drew on project evidence to advocate for the adoption of the African Commission on Human and Peoples' Rights Resolution 492, and the General Comment on Article 22 of the African Charter on the Rights and Welfare of the Child.[19] These landmark documents strengthen protections for women and children in armed conflicts by mandating prevention measures and comprehensive survivor support, including accessible sexual and reproductive health services. Partners are now using Resolution 492 and General Comment on Article 22 as key accountability resources to hold other conflict-affected African nations accountable and to inform recommendations to member states.

Similar efforts in Nepal focused on incorporating reproductive rights protections enshrined in the country's Safe Motherhood and Reproductive Health Rights Act of 2018 into Godawari municipal laws to ensure the continuity of sexual and reproductive health services during natural disasters.[20] Strategies that contributed to the policy adoption included rigorous mapping and review of existing laws and disaster frameworks to identify SRHR gaps; continuous multi-stakeholder consultations and policy dialogues involving municipal and provincial leaders, health officials, legal experts, and community representatives; and civil society support with drafting and validating language.

Policy advocacy also resulted in the revision of Godawari's disaster preparedness and response plan to secure SRHR priorities across all phases of disaster management, including provisions for the minimum initial service package, gender-based violence prevention, menstrual health, and a designated disaster response focal person trained in human rights and SRHR. Community-led advocacy through the CoA model, with trained community monitors collecting and escalating complaints, also directly informed legal and policy reform. These combined efforts not only codified SRHR protections at the local level but also institutionalized key components of the CoA conceptual framework. The Nepal case study showcases how local government engagement can accelerate, rather than impede, the implementation of reproductive health and accountability frameworks, which differs from our strategies used in other contexts.

Contrasting Uganda's and Nepal's experiences, where local and regional law and policy advancements were achievable, the initiative in Bangladesh was uniquely complex due to the limited protection framework for Rohingya refugees and the national political context.[21] Without strong entry points for advocacy, the project adopted a two-pronged approach: advocating for stronger rights-based standards in multilateral and international NGO (iNGO) humanitarian platforms and providing evidence to support existing legal sector efforts to expand refugees' access to family courts for restitution following SRHR violations.

Opportunities also arose to engage with the interim government's newly appointed Commission on Women's Affairs to discuss potential SRHR law and policy reforms that would improve the lived realities of all women and girls experiencing displacement in Bangladesh. This strategic combination of prioritizing remedial action within nonstate humanitarian platforms, while aligning with long-term and ongoing strategic entry points for national law reform, demonstrates how to achieve incremental progress toward accountability even in restrictive law and policy environments.

This pathway operationalized the CoA's commitment to structural and legal accountability by transforming evidence from community-level rights claims into enforceable policy and standards across local and regional systems. By codifying SRHR protections in municipal disaster plans (Nepal), subnational bylaws (Uganda), and regional human rights instruments (Africa), the initiatives embedded accountability within the policy design and budgeting stages of the cycle, establishing legal obligations that redefined the relationship between duty bearers and rights holders, whose entitlements became increasingly justiciable (i.e., amenable to third-party adjudication by suitable judicial or non-judicial bodies.)

Pathway 2: Building multi-sectoral partnerships and local human rights champions

SRHR-related humanitarian policy and programs straddle sectors and disciplines, including health, protection, water and sanitation, and shelter, yet implementation often occurs through siloed institutions and strategies.[22] For example, protection actors may focus narrowly on responding to gender-based violence, health actors on service delivery for survivors, and human rights actors on broader power relations and gender inequality factors that are often deemed peripheral but are, in fact, central to addressing gender-based violence and achieving equitable SRHR outcomes. Since humanitarian hierarchies and coordination structures are closely tied to funding and access, power dynamics and ways of working that privilege certain actors and sectors become further entrenched, while longer-term rights and gender priorities remain marginalized. The case studies addressed these dynamics directly through intentional cross-sectoral partnerships that unite health actors, lawyers, and community advocates in shared accountability problem-solving spaces.

In Bangladesh, humanitarian organizations, human rights advocates, and legal aid providers collaborated on a shared implementation strategy, overcoming initial disagreements about the meaning and focus of accountability. For example, during the design phase, legal practitioners questioned the enforceability and obligations underpinning social strategies and models, whereas social practitioners challenged the underlying power dynamics of legal frameworks and whether they meaningfully deliver access to justice and accountability in practice. While these orientations and organizational mandates related to accountability remained, deep collaboration during the design phase and routine partner meetings throughout implementation ultimately eliminated operational blind spots that might have otherwise limited addressing SRHR accountability as an issue of health service delivery or sexual and gender-based violence alone.

Direct partnership with refugee-led groups was modeled in the Uganda case study through co-led project design, implementation, assessments, and the resulting three community structures. At project closure, leaders of these structures led a self-directed process to register as the Women Empowerment Initiative Center (WEIC), a Ugandan community-based organization dedicated to sustaining community accountability for SRHR and health services.

Since 2021, WEIC has achieved notable remedial actions when health rights standards have gone unmet, including successfully advocating for a permanent maternity ward to replace a temporary structure that existed during the project period and which had registered poor maternal health services and outcomes. WEIC also conducts community monitoring of sexual and reproductive health outcomes through health facility and household visits, hosts weekly radio awareness programs, and conducts community dialogues on comprehensive and adolescent-focused SRHR. Additionally, the organization is entrusted by health authorities to support counseling and referrals from the community level to settlement health facilities, which the refugee-led team funds directly through monthly member contributions of UGX$50,000 (approximately US$14).

At present, this member-supported model remains the primary funding source; however, WEIC is actively pursuing funding streams to diversify resources and strengthen long-term sustainability. While this self-financing mechanism reflects a high degree of community ownership, it also raises important considerations regarding reliance on member contributions, which may constrain participation and introduce inequities into otherwise inclusive governance structures. WEIC aims to mitigate risks of exclusion through hybrid financing arrangements, such as pooled donor funds and partnering with national NGOs, with a focus on promoting inclusivity and maintaining local autonomy. The evolution of this partnership demonstrates the value of institutionalizing community-led systems beyond conventional project time frames, whereby groups are formally recognized within the broader accountability ecosystem that outlasts the project and funding cycle. This strategy mitigates the limitations of projectized models, which often prioritize short-term outputs over integrating initiatives into broader systemic strategies and outcomes. Relatedly, Nepal uses a unique model requiring iNGOs to partner with national and local organizations for project delivery, creating a deliberate and long-term framework for collaboration rather than informal or emergent partnership strategies seen in other contexts.

A common theme across the case studies was the need for enhanced capacity-building for both the partnership and allied implementing organizations, especially concerning human rights standards and their practical application among humanitarian health workers. Early assessments in all three contexts confirmed that training and organizational onboarding for humanitarian and disaster response workers lacked this content. The absence of rights-based knowledge within humanitarian skill-building is not merely a training gap but a reflection of the broader ambivalence and resistance to rights-based approaches within the humanitarian sector, an orientation that obscures the intrinsically political dimensions of such work. Consequently, humanitarian workers have limited exposure to rights-based approaches and little awareness of how such strategies have transformative potential to support their mission and mandate. A significant gap also exists in basic advocacy training for humanitarian workers, which is necessary for those who serve as organizational representatives on key platforms and processes that make decisions on SRHR and human rights. These practitioners need dedicated skill-building to strategically advocate for important issues, especially stigmatized issues such as reproductive rights.

Interactive training programs on SRHR and human rights designed for humanitarian and health actors addressed these gaps. In Bangladesh, targeted health care and legal sector worker training programs served multiple capacity-strengthening purposes: improving SRHR awareness, clarifying service delivery standards, building trust with initially skeptical humanitarian and legal providers, and cultivating champions to advocate for rights-based sexual and reproductive health services and accountability on key humanitarian platforms. Training feedback surveys revealed broadly positive responses to this approach, with participants reporting high satisfaction with human rights education. One training participant acknowledged prior training gaps, commenting in their survey that “the second R (rights) of SRHR is rarely covered in humanitarian trainings and skill-building programs.”

Ultimately, this pathway gave practical effect to the CoA’s principles of participation and empowerment by redistributing power and knowledge through cross-sectoral partnerships that institutionalize community-led accountability beyond project cycles. It brought together health actors, legal advocates, and community monitors in shared problem-solving spaces to dismantle institutional silos that had fragmented SRHR into discrete technical domains. The collaboration also secured sustainable structures to maintain accountability beyond external funding and remain controlled by rights holders rather than implementing partners.

Pathway 3: Equitable participation in humanitarian platforms and processes to shape remedial action

Participation is a cornerstone of the human rights framework and mutually reinforcing of accountability; yet in humanitarian contexts, participation is often reduced to consultation without power.[23] The case studies applied community-centered participatory design and monitoring to legitimize initial situational assessments and inform the design. While approaches varied significantly based on context and challenges, solidarity groups were fundamental across implementation strategies.[24] Uganda's and Nepal's models worked directly with refugee and local community members to lead health system monitoring and oversight and to hold duty bearers accountable. In Uganda, the evolution from informal refugee-led groups to a self-sustaining community-based organization demonstrates the organic growth of community ownership and accountability through these strategies.

Comparatively, the Bangladesh effort focused on securing openings for refugee voices in program design and broader humanitarian systems. Bangladesh's more restricted context for refugee inclusion necessitated creative approaches to overcome state limitations on Rohingya participation and leadership.[25] The program worked through existing "women and girls safe spaces" and established the Naripokkho women's center, which was complemented by door-to-door outreach led by human rights defenders, referred to in the camp context as community support monitors. Human rights defenders were experienced members of national feminist movements and previously supported programs that monitored quality of care in state hospitals. They understood their role as a balance between building trust to provide accurate SRHR information to the Rohingya community and challenging prevailing power dynamics that affect SRHR outcomes.

Following an accompaniment model, human rights defenders reported improved relations with midwives after recognition of their monitoring mandate in health facilities. Human rights defenders' logbooks confirmed that over a two-year period, Rohingya women's self-reported uptake of and referral to sexual and reproductive health services increased in the camp blocks where human rights defenders were working. According to local health actors and the camp administrative government, the broader camp dynamic during this time was conversely trending downward for health service uptake.

In Nepal, the strategy of mobilizing community monitors, who held a similar role and mandate to those in Uganda, resulted in positive potential for institutionalizing community monitoring as a recognized accountability mechanism. This was achieved through reforms to the municipal disaster preparedness and response plan, which was revised as a result of the project evidence and advocacy. While this role for local monitors has not yet been tested in a state of emergency, longer-term oversight will determine whether volunteers from Kailali continue to be systematically integrated into planning and response processes following the project closure.

The case studies surfaced consistent limitations on participation in traditional humanitarian accountability mechanisms (e.g., feedback boxes, complaints and feedback response mechanisms, and in-facility reporting systems).[26] These conventional arrangements often fail to address power imbalances, cultural and language barriers, and fear of reprisal among displaced populations who rely on humanitarian assistance.[27] Mapping accountability ecosystems as part of each initiative's design highlighted how these widely accepted and adopted arrangements frequently fall short in delivering meaningful accountability and ensuring responsiveness for SRHR abuses and violations.

Yet even systems designed to be innovative and responsive and to shift decision-making authority require participatory review and adaptation. Limited claims associated with certain stigmatized SRHR issues were common and indicate how contextually designed initiatives can still fall short of full rights alignment. For example, the Uganda initiative needed regular reassessment of its outreach and advocacy strategies to ensure inclusive participation and to address underreported issues of adolescent SRHR, including unsafe abortion. Project staff made additional efforts to gather testimony concerning SRHR and increased the number of adolescent peer-to-peer solidarity groups to provide safer, smaller spaces for adolescents to meet. In the Rohingya refugee camps, human rights defenders conducted extensive follow-up with health providers to verify that counseling and menstrual regulation referrals were being provided. Experiences from both settings show that while improvements to traditional accountability systems are necessary, significant time and advocacy capacity are often required to do so.

At the global level, ensuring meaningful opportunities for local actor participation in humanitarian and human rights decision-making forums cannot be overlooked. The three case studies prioritized resources, capacity-building, and support to ensure participation at the global level. Forum events included human rights defenders from Uganda and Bangladesh directly engaging in briefing Human Rights Council member states during critical discussions on accountability for women and girls in humanitarian settings. Leveraging project evidence in shadow reports submitted to Special Procedures and multilateral organizations also helped ground international guidance in lived realities rather than theoretical frameworks alone.[28] Finally, South Sudanese refugee leaders effectively utilized high-level forums, addressing member states at the United Nations Economic and Social Council Humanitarian Affairs Segment to call on states to fulfill their SRHR obligations and commitments as part of the global protection agenda.[29]

These platforms, coupled with strategic advocacy, amplify local voices and create direct channels for influencing global policy and practice, potentially transforming the traditional top-down humanitarian system into a more inclusive and responsive framework. However, global-level opportunities for direct engagement are rarely prioritized in humanitarian project planning and budgeting. This indicates a need for donors, organizations, and project designers to proactively incorporate and fund local actor participation across these crucial platforms from the outset.

In sum, this pathway applied the CoA's participatory and iterative principles by embedding displaced persons' leadership within community consultation, monitoring, legal accompaniment, and advocacy processes that directly informed remedial actions and institutional decisions. Through these mechanisms, rights holders identified violations, set priorities, and accessed safe accountability pathways created by human rights defenders and legal advocates, ensuring the inclusion of marginalized groups such as adolescents and persons with disabilities. Capacity-strengthening and engagement in global platforms further advanced empowerment by positioning refugee and disaster-affected communities as experts capable of challenging duty bearers at the highest levels. In this way, accountability evolved from passive feedback collection to a dynamic cycle of documentation, response, and review that redistributed power over how SRHR is defined and delivered.

Pathway 4: Reimagining evidence and evaluation as a process for improved accountability and remedial action

A common reflection across the case studies was that the most meaningful changes—power shifts, more accessible and enabling environments, and expanded participatory space—were the least evident through partners' standard monitoring, evaluation, research, and learning (MERL) tools. The Uganda initiative adopted mixed-methods research, including formal baseline and endline assessments, as well as routine monitoring of health service responsiveness and remedial follow-up rates.[30] Yet the most significant change according to participants and refugee leaders was a change in how community members perceived themselves and asserted their SRHR claims as rights holders. COVID-19 pandemic restrictions in Uganda also catalyzed a shift toward more rights-based data ownership during the project period. When humanitarian partners could not travel to the settlements, community monitors took increased leadership and control of data collection and analysis, using real-time information for local advocacy. This change in situation accelerated the move away from an extractive MERL process, where iNGOs and implementing partners often control the data chain, and instead empowered refugee leaders to conduct evidence-based advocacy in their communities and with key duty bearers.

Similarly, Bangladesh project partners frequently reported the most significant change as subtle shifts in humanitarian actors' accountability norms. This is despite the minimal formal uptake of rights-based indicators beyond sexual and reproductive health-specific working groups and platforms operating in Cox's Bazar. Human rights defenders in Bangladesh also pioneered innovative documentation approaches through community monitoring, overcoming significant limitations on the Rohingya's access and freedom of movement. By building trusted networks and working through community intermediaries, they enabled Rohingya women and adolescents to safely share their experiences and define accountability and acceptable remedial action in their own terms. Both Rohingya and host communities in Bangladesh received training that enabled them to recognize SRHR issues, including reproductive decision-making, disrespect and abuse during maternity services, and discriminatory denial of essential medicines based on factors such as age or HIV status. This bottom-up approach to data collection proved successful in Nepal as well, helping center communities' understanding of SRHR and related services.

Nepal's approach stands out for also successfully developing and validating a set of human rights-based indicators and a checklist tool for the national human rights institutions to monitor SRHR services in disaster-affected areas, including the National Human Rights Commission and the National Women Commission. The checklist supports the tracking of SRHR outcomes both during and after disasters and includes indicators that measure not only service delivery (such as access to contraception, maternal health, and sexual and gender-based violence services) but also nondiscrimination, respect, and equity in care. This comprehensive framework will better ensure that SRHR monitoring captures the full spectrum of rights-based service provision in emergencies. The indicator development process involved consultations with the National Human Rights Commission, the National Women Commission, partners, and other Kailali District community stakeholders. An inclusive process helped ensure that the indicators were not only aligned with international human rights standards but also grounded in local definitions of rights, accountability, and community priorities. Both the National Human Rights Commission and the National Women Commission agreed to incorporate the indicators into their institutional monitoring systems—commitments that were recorded in formal meeting minutes, marking a major step toward institutionalizing SRHR accountability in Nepal's disaster governance.

Rights-based MERL methods are well-placed to redefine what counts and to develop metrics that are grounded in legitimacy, responsiveness, and structural change—not only health service uptake and coverage.[31] Reporting burdens, overstretched humanitarian workers, and the need for streamlined core indicators that expand beyond service-level metrics must be acknowledged.[32] Yet MERL experiences demonstrate how generating evidence and leveraging it with meaningful opportunities for participation and decision-making can lead to more promising long-term outcomes at local, regional, and global levels.

While reproductive decision-making and enabling legal environment indicators found in Sustainable Development Goal 5.6.1 and 5.6.2 provide a recognized foundation for the sector, it is equally important to incorporate measures that evaluate dignity and service quality from the perspective of rights holders themselves.[33] Expanding and adapting participatory methodologies are feasible and promising approaches to better capture power shifts and decision-making dynamics in complex settings.[34]

This pathway operationalized the CoA's monitoring and review dimensions by reframing evidence generation as a participatory and rights-affirming process that transfers data ownership and evaluative power to affected communities. By centering rights holders' perspectives on what constitutes evidence, the case studies redefined monitoring and assessment from extractive exercises led by implementing partners into instruments for accountability. These processes enabled communities to evaluate duty bearers' performance, expose structural barriers such as discrimination and lack of dignity in care, and use evidence to drive both remedial action and systemic policy reform, thereby completing the accountability cycle from remedy back to policy design and resource allocation.

Conclusion

By institutionalizing multilevel and participatory accountability arrangements, health systems facing significant pressure from conflict and disaster can be supported to respond to immediate needs while also promoting long-term human rights objectives. This paper has sought to demonstrate how innovative accountability mechanisms to ensure access to sexual and reproductive health services and that address root causes of reproductive rights violations can be achieved through legal, policy, and social change strategies that build duty bearers' capacity and holds them to account. The case studies' experiences reveal concrete distinctions between the superficial integration of rights-based approaches and opportunities for transformative system change within the context of humanitarian and disaster response.

We propose that effective rights-based approaches require a comprehensive accountability framework—one that is embedded throughout the policy and program cycle and moves beyond reactive measures to generate a systemic and transformative realization of rights. The CoA offers a strong starting point for applying such a framework for humanitarian and disaster contexts. However, while it establishes pathways for monitoring, review, and remedy, the CoA provides limited guidance on compelling duty-bearer compliance beyond voluntary commitments. This limitation underscores the need to accompany it with complementary mechanisms that translate accountability principles into enforceable and practice-oriented obligations within complex humanitarian systems. Promising ways to implement this approach include adaptive legal and policy strategies; institutionally supported cross-sectoral partnerships and a commitment to building human rights champions at the local level; the genuine redistribution of power through more participatory platforms and processes; and MERL methods that prioritize rights realization alongside efficiency. The case studies also offer practical examples of how social and legal accountability practitioners, humanitarians, and advocates seeking to operationalize rights-based approaches can conceptualize program design, policy advocacy, and partnership development through a CoA framework that moves beyond aspiration and creates sustainable models for respecting, protecting, and fulfilling reproductive rights.

Acknowledgments

We extend our appreciation to the program implementers and community leaders in Uganda, Nepal, and Bangladesh, whose dedication, insights, and partnership were instrumental to this work. We specifically acknowledge colleagues from Bangladesh Legal Aid and Services Trust; CARE International (Bangladesh, Nepal, and Uganda); Forum for Women, Law and Development; Naripokkho; and NEEDS Nepal. We also thank members of the South Sudanese refugee community in Adjumani, members of the Rohingya refugee community in Cox's Bazar, and residents of Godawari municipality, who engaged with and supported the initiatives, offering their time, trust, and feedback, which enriched the findings and recommendations.

Funding

This work was funded by the Margaret A. Cargill Philanthropies (Bangladesh) and the David and Lucile Packard Foundation (Nepal). The funders had no role in program design, data collection, analysis, decision to publish, or preparation of this manuscript. The views expressed in this article are solely those of the authors and do not necessarily reflect the views or positions of the funders.

Ethics approval

Research conducted in Uganda involving human subjects received ethics approval from the Mildmay Uganda Research Ethics Committee (#REC REF 0505-2021). Program monitoring and evaluation activities—including data collection and analysis protocols, instruments, and informed consent materials—for the initiatives in Bangladesh and Nepal received ethics approval from two independent research experts and qualified legal counsel. Ethics approval was issued in accordance with the Declaration of Helsinki, Bangladesh Medical Research Council regulations, and the International Ethical Guidelines for Health-Related Research Involving Humans issued by the Council for International Organizations of Medical Sciences.

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Human Rights Accountability in Global Health Multi-Stakeholder Partnerships: The Case of the Access to COVID-19 Tools Accelerator

GAMZE ERDEM TÜRKELLİ AND ROSSELLA DE FALCO

Abstract

The 2030 Agenda for Sustainable Development promotes multi-stakeholder partnerships (MSPs) to achieve sustainable development, including global health-related goals. MSPs typically involve three or more types of actors, including states, corporations, philanthropic organizations, civil society, and multilateral institutions. While MSPs often operate in sectors that are crucial for the realization of health-related rights, they are seldom analyzed through a human rights lens. This paper will advance knowledge in this field through an exploration of the Access to COVID-19 Tools Accelerator (ACT-A), launched in 2020. In doing so, the paper sheds light on the direct accountability of MSPs to rights holders, as well as the state obligations to *respect* and *protect* human rights in the context of MSPs. The paper outlines a human rights accountability framework to investigate the ACT-A's accountability structure. The analysis confirms three systemic accountability problems: diffused *responsibility* in terms of the applicable normative and legal frameworks; limited *answerability* to rights holders; and weak *enforceability* in terms of remedies. This, in turn, limits the possibility of health rights accountability, including *review*, *monitoring*, and *remedial* action. The conclusions highlight three solutions: that MSPs themselves should at least have the duty *to respect* human rights, as do other corporate entities; that an independent, people-centered mechanism to hold MSPs accountable should be established; and that multilateral governance solutions, including seats at the table for less powerful actors, should be prioritized over multi-stakeholder approaches.

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Competing interests: None declared.

Introduction

The 2030 Agenda for Sustainable Development promotes multi-stakeholder partnerships (MSPs) as a tool to finance and deliver sustainable development. The Sustainable Development Goals feature goal 17 on strengthening global partnership for development, with targets 17.16 and 17.17 focused on MSPs. Today, the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) and Gavi, the Vaccine Alliance are among the largest global health MSPs.

Scholars refer to such agreements using different terms, including "international health initiatives" or "global health partnerships."[1] In this paper, we rely on Barbara Gray and Jill Purdy's definition of MSPs as cooperative partnerships involving three or more types of actors, such as states, corporations, nonprofit organizations, academic actors, civil society, philanthropic actors, or multilateral institutions (such as the World Health Organization or the World Bank).[2]

Because MSPs include a broader range of actors and operate under flexible, often context-specific agreements, they are fundamentally different from public-private partnerships, which normally entail a long-term contract between a state and a private health care actor.[3]

Concerningly, MSPs have been gaining center stage in global development policymaking without due regard to human rights accountability.[4] For instance, while the actors that participate in MSPs manage substantial financial resources that could impact the lives of many, their obligations under international human rights law, as well as their development cooperation commitments, are still unclear.

This paper seeks to address this gap through the case study of the Access to COVID-19 Tools Accelerator (ACT-A), a global collaboration launched in April 2020 and aimed at accelerating the development, production, and equitable distribution of COVID-19 tests, treatments, and vaccines at the height of the COVID-19 pandemic.

The paper first introduces a normative and operational framework to analyze human rights accountability in global health MSPs. The second section details states' obligations to respect, protect, and fulfill health-related rights within and beyond their jurisdictions, as well as the direct human rights responsibilities of companies and international organizations. In the third section, the paper applies the human rights accountability framework introduced in the first section to the case study of the ACT-A, using its governance structure as a springboard for discussion.

Given that MSPs have emerged from the 1990s onwards as global governance tools in response to global discussions around the financing and achievement of sustainable development, we build on earlier and broader work by Erdem Türkelli on the accountability of MSPs as development financing actors, which inspects the problems of diffused responsibility, limited answerability, and weak enforceability in transnational MSPs. We use a hybrid lens by then connecting these known limitations to health rights accountability, including review, monitoring, and remedial action.[5] The paper thus seeks to analyze whether and to what extent human rights accountability existed in the context of the ACT-A's multi-stakeholder partnership model while it was operational.

Methodologically, this reflection uses case study analysis to draw conclusions that may be helpful for understanding the larger accountability challenges posed by MSPs in global health. It relies on desk research and document analysis of publicly available academic and gray literature related to the ACT-A over 2020–2025.

The conclusions critically examine the implications for the people-centered sphere of health rights accountability, suggesting potential solutions and highlighting future research agendas.

Navigating accountability in health MSPs: Developing a framework

Human rights accountability is a process by which states are required to show, clarify, and justify how they discharged their obligations under international human rights law.[6] Accountability may be judicial, quasi-judicial, political, administrative, or social.[7]

Beyond state-centric forms of accountability, social movements, civil society, and human rights defenders have developed their own strategies to hold governments accountable, including in global health. For instance, in describing a process of "global health governance from below," Lisa Forman highlights the pivotal role played by AIDS activists in reframing access to essential medicines as a human right through campaigning, advocacy, mobilization, and strategic litigation, leading to major wins.[8]

Matthew Canfield and Sara Davis, instead, reflect on people-led forms of accountability in institutionalized spaces, such as MSPs.[9] While conceding that there are several human rights concerns associated with MSPs, the authors argue that human rights activists may be developing new ways to exercise "moral power" in these new global health partnerships, including through formal representation, oral statements, and internal lobbying.[10]

From a sustainable development and human rights perspective, we rely on three components of accountability: responsibility, answerability, and enforceability.[11] Responsibility denotes the existence of "clearly defined duties and performance standards" for those involved in decision-making roles; answerability requires to "provide reasoned justifications" to affected individuals and communities; and enforceability includes prevention and correction when necessary.[12] This framework can be easily adapted to the field of cooperation and development aid, and it is well-suited for normative analysis at a systems level across different human rights.[13]

This theoretical framework is further complemented by a tripartite conceptualization of health rights accountability: monitoring, review, and remedial action.[14] *Monitoring* means providing critical and reliable information on results and resources, including through the collection of quality and disaggregated data. *Review* means assessing "whether pledges, promises and commitments have been kept by countries, donors and non-state actors"—for example, has the health of populations progressively improved? Finally, *remedial action* involves remedies, reparations, and redress.[15] For the purpose of this paper, we conceptualize accountability for the right to health as combining the metrics of responsibility, answerability, enforceability, monitoring, review, and remedy at an operational level.[16]

The growing role of MSPs in global health

The health sector features some of the earliest examples of transnational partnerships. In 1974, the World Health Organization (WHO) launched the Onchocerciasis Control Programme in partnership with the World Bank and the United Nations Development Programme to control onchocerciasis in Western Africa. Later examples include the Medicines for Malaria Venture, launched in 1999, set up as a collaboration between a range of institutional, public, and private stakeholders, including WHO, the World Bank, the Rockefeller Foundation, and the US government.[17]

Transnational MSPs experienced a surge in all global governance domains starting with environmental governance after their incorporation into the global sustainable development agenda through the idea of a global partnership for sustainable development (Agenda 21 of the 1992 Rio de Janeiro Conference and later Millennium Development Goal 8). The 2002 Johannesburg Summit embraced so-called Type II outcomes (voluntary actions running alongside negotiated intergovernmental outcomes), further enabling multi-stakeholder approaches to various sustainable development domains. In the 2030 Agenda for Sustainable Development, goal 3 focuses on health, while goal 17 seeks to "strengthen the means of implementation and revitalize the global partnership for sustainable development."

Beyond environmental governance, multi-stakeholderism started permeating global health widely through partnerships such as the Global Fund and Gavi. Alongside these, new private-led development financing tools also rapidly expanded, such as the International Finance Facility for Immunisation, advance market commitments for vaccines, the Affordable Medicines Facility-malaria, and the Global Fund's Debt2Health swaps.[18]

Some philanthropic actors that were key in establishing global health partnerships, like the Gates Foundation, have also become influential, thanks to their diplomatic network, in global norm-making responses to infectious diseases, including in epidemic and pandemic settings.[19]

The expansion of multi-stakeholder solutions to global health problems is based largely on promises of flexibility and agility. For instance, proponents of MSPs argue that they provide a rapid response to health challenges by bringing together interested partners that are willing to collectively act, including through mobilizing both public and private funds. Based on this promise, the multi-stakeholder partnership model has become the "go-to" template when faced with new health challenges.

Despite their promises, when MSPs are employed as the first line of intervention in tackling global challenges, public accountability may be compromised.[20] For instance, in vaccine development, a recent scoping review finds weak legitimacy, transparency, and accountability mechanisms across multiple MSPs.[21] A range of studies find that MSPs may also dilute accountability, promote the interests of private actors, create power imbalances, and overfocus on disease-specific interventions rather than health systems strengthening.[22] Furthermore, they also often facilitate the involvement of private actors in domestic health care systems, which some observers find problematic.[23]

Given that there is currently no clear human rights law framework governing MSPs as human rights duty bearers, in the following section we outline the human rights framework that applies to the constitutive parts of global health MSPs, especially during public health emergencies: states, international organizations, and nonstate actors, particularly business enterprises and philanthropic actors.

The applicable legal framework

Tripartite obligations for right to health and public health emergencies

States' human rights obligations are tripartite: respect, protect, and fulfill. For instance, the Committee on Economic, Social and Cultural Rights specifies that states must *respect* the right to health by refraining from limiting access to health care services or imposing discriminatory practices.[24] Furthermore, states must *protect* the right to health by ensuring, inter alia, equal access to health care provided by third parties or by controlling the marketing of medical goods by third parties.[25] The obligation to *fulfill* refers to a wide range of measures, such as the adoption of a national health plan.[26]

In the context of public health emergencies, states must ensure that human rights are protected both by respecting them and by taking positive steps.[27] In particular, the International Covenant on Economic, Social and Cultural Rights (ICESCR) obligates states to progressively realize the right to health, including by taking steps necessary for "the prevention, treatment, and control of epidemic, endemic, occupational and other diseases."[28] Health rights accountability includes effective judicial and other remedies at both national and international levels for those who have suffered violations.[29]

The ICESCR also protects the right to benefit from scientific progress and its applications (the right to science).[30] While access to vaccines and other medical goods is deeply compromised by global inequalities, the Committee on Economic, Social and Cultural Rights has reaffirmed that the intellectual property regime should be interpreted and implemented as reinforcing states' duty "to protect public health and, in particular, to promote access to medicines for all."[31]

Human rights beyond borders: Extraterritorial obligations

So-called extraterritorial human rights obligations bind states to abide by their human rights obligations beyond their borders.[32] In the context of health, extraterritorial human rights obligations are grounded in article 2(1) of the ICESCR, which imposes a legal duty on states to realize economic, social, and cultural rights through, inter alia, international assistance and cooperation.

States also retain their full range of human rights obligations as members of international organizations, as reiterated by both the Committee on Economic, Social and Cultural Rights and the Committee on the Rights of the Child in their various general comments, including those on the right to health.[33]

The United Nations Guiding Principles on Business and Human Rights additionally note that member states of international organizations should "ensure that those institutions neither restrain the ability of their member States to meet their duty to protect nor hinder business enterprises from respecting human rights" and "encourage [international organizations] … to promote business respect for human rights and, where requested, to help States meet their duty to protect against human rights abuse by business enterprises, including through technical assistance, capacity-building and awareness-raising."[34]

Human rights beyond the state

International organizations. Beyond the human rights duties of the member states of international organizations, many scholars have argued that international organizations themselves are or ought to be direct human rights duty bearers.[35] This position is also espoused in the Maastricht Principles.[36] Duties of international organizations under international human rights law are linked to their mandates as conferred to them by state parties and enumerated in their foundational documents, as well as human rights treaties. For instance, article 22 of the ICESCR points to harnessing the expertise of United Nations organs, subsidiary organs, and specialized agencies to "contribute to the progressive implementation" of the covenant. Article 24 of the ICESCR notes the "respective responsibilities" of various United Nations organs and specialized agencies with respect to economic, social, and cultural rights. The Committee on Economic, Social and Cultural Rights highlights that international organizations should "cooperate effectively with states parties, building on their respective expertise, in relation to the implementation of the right to health at the national level, with due respect for their individual mandates," calling on the World Bank and International Monetary Fund to pay special attention to the right to health in their activities.[37]

Central for this discussion is the role of WHO, which is the sole United Nations health agency. The WHO Constitution lists one objective for the entire organization—"attainment by all peoples of the highest possible level of health" (art. 1)—and mentions the right to health in its preamble. WHO's functions include, inter alia, directing and coordinating international health work, assisting states, and coordinating lawmaking and standards in the context of global health. The Committee on Economic, Social and Cultural Rights further notes that WHO plays a critical role in the realization of the right to health, particularly given its technical know-how and capabilities.[38] While the WHO Constitution describes the institution's role in addressing infectious disease as "to stimulate and advance work to eradicate epidemic, endemic and other diseases" (art. 2(g)), the preamble refers to the potential adverse impacts of "unequal development" on the "promotion of health and control of disease, especially communicable disease."

Private actors: Businesses and charitable foundations. The human rights responsibilities of businesses and philanthropic actors, often legally assuming the form of charitable foundations, are domains in which human rights law has been in constant evolution over the last decades. With the Human Rights Council's endorsement of the Guiding Principles on Business and Human Rights, as well as the ongoing drafting of a legally binding instrument on business and human rights, there is growing consensus that corporations hold certain human rights duties, albeit with a more limited scope than states.[39]

The Guiding Principles on Business and Human Rights introduce a three-pillar framework (protect, respect, and remedy): states have the primary obligation to *protect* human rights from interference by third parties (including business enterprises); businesses have a responsibility to *respect* human rights by, inter alia, not causing harm or contributing to adverse human rights impact; and *remedy* ought to be provided in case of adverse human rights impacts caused by or contributed to by businesses. The baseline duty of businesses to respect is to be carried out through human rights *due diligence* as a mechanism to identify, prevent, mitigate and account for possible human rights violations.[40]

The human rights community has also paid attention to the human rights responsibilities of private actors when they provide essential services, such as in the context of health care. As noted by Paul Hunt, former Special Rapporteur on the right to health, pharmaceutical companies should ensure transparency, price and licensing flexibility, and access to information, and they should be accountable to the public.[41] The Committee on Economic, Social and Cultural Rights has also emphasized that "business entities, including pharmaceutical companies, have the obligation, as a minimum, to respect Covenant rights" and that states should "refrain from invoking intellectual property rights in a manner that is inconsistent with the right of every person to access a safe and effective vaccine for COVID-19."[42] Further, the committee has rightly noted that "private providers [of public services] should … be subject to strict regulations that impose on them so-called 'public service obligations.'"[43]

Nonetheless, the question of accountability around the actions of charitable foundations, particularly very strong and influential ones, such as the Gates Foundation or the Wellcome Trust, has not been subject to much contemplation in legal scholarship. At the same time, while philanthropic organizations lack accountability to the public, they wield arbitrary power, often shape decision-making and discourse, and wield their influence and power consciously through network diplomacy.[44] Thus, human rights responsibilities of charitable foundations or other philanthropic actors should at least mirror those of business enterprises and cover the baseline duty to *respect* human rights in all circumstances as well as be analogous to those of private providers in cases where these actors provide public services.

A case study: Access to COVID-19 Tools Accelerator

Launched in April 2020, the ACT-A was framed as a global "collaboration to accelerate development, production, and equitable access to COVID-19 tests, treatments, and vaccines."[45] The ACT-A rapidly brought together private foundations, international organizations, and other multi-stakeholder initiatives, including Gavi and the Global Fund.[46] The ACT-A comprised three pillars, respectively dedicated to vaccines, therapeutics and diagnostics, and one transversal Health Systems and Response Connector. Governments and the Gates Foundation were part of the ACT-A Facilitation Council, formally launched during a virtual meeting of its members on September 10, 2020.[47]

Katerini Storeng and others describe the resulting institutional arrangement as an experimental "super-[public-private partnership], which resembles a series of Russian Matryoshka dolls of decreasing size nested into each other."[48] The authors further argue that this institutional complexity has led to unclear accountability mechanisms and blurs the boundaries between public and private spheres.[49]

Suerie Moon and others also note that "the mix of public and private authority within a multistakeholder initiative raises challenges for ensuring accountability in the public interest."[50] The authors do not find an ACT-A-wide accountability mechanism; rather, each participating organization was accountable to its own governing body.[51] The authors further noted that it remained unclear whether and how governments could exercise authority within the ACT-A, also given the role of WHO as host and technical advisor.[52]

Jelena von Achenbach contends that the vaccine pillar of the ACT-A, COVID-19 Vaccines Global Access (COVAX), fell short of accountability mechanisms.[53] Achenbach contends that there was no way of holding Gavi, the legal administrator of COVAX, accountable on specified targets, and that this is consistent with COVAX being based on "freedom of contract under private law and the voluntary nature of state action."[54]

During its early phase, the ACT-A action was reviewed and evaluated largely internally, including the interim ACT-Accelerator Strategic Review conducted in October 2021.[55] The review noted problems related to a lack of accountability but considered it as a trade-off for rapid responsiveness. Subsequently, an external evaluation of the ACT-A was commissioned in 2022, through the initiative of the Facilitation Council (by then-co-chairs South Africa and Norway), to identify lessons learned for future pandemics.[56] The review found that most delivery targets were not met, except for the vaccine pillar, which, although falling short of its objectives, still managed to deliver nearly two billion doses of COVID-19 vaccines globally.[57] Despite its relevance in the rapid response to the COVID-19 pandemic when it was most needed, the partnership's informal coordination model was deemed insufficient, the coordination across the different pillars of diagnostics, therapeutics, and vaccines too weak, and the financing gap between needs and resource mobilization too large.[58]

Overall, the ACT-A's COVAX had ambitious aims but was unable to deliver its objective to shape markets and make vaccines available at better rates for developing countries. Developing countries (those classified as either low income or lower-middle income) were not included in the governance and did not feel ownership. According to the evaluation, the ACT-A was seen as "sacrific[ing] inclusion for an assumed decisive and rapid response."[59]

The partnership remained global but did not effectively engage with regional platforms, undercutting its eventual results and its potential to assist in developing local capabilities.[60] The operating model of the partnership was reckoned as having "limited cross-pillar and within-pillar coordination, insufficient accountability," a lack of integration with beneficiary country health systems, and "an insufficient focus on delivery."[61]

With respect to accountability, the key concerns identified by surveyed stakeholders were threefold: the accountability system was decentralized and delegated to individual agencies and pillars; decision-making, resource allocation, and reporting were not fully transparent; and the structure was top-down and informal but also complex.[62] Even if some constitutive institutions of the ACT-A had inclusive and strong management systems, they could not exercise effective oversight over this ad hoc partnership. Some respondents even lamented the lack of a "structure to enable collective accountability" at the MSP level, while insufficient accountability and transparency allowed corporate partners and donors to have an outsized influence.[63]

Even in the pillars of the ACT-A that were considered a success by the evaluation, particularly the vaccine arm and COVAX Advance Market Commitments, performance was not fully satisfactory. The pillar on therapeutics did not achieve its delivery targets for treatment drugs, but oxygen delivery was considered improved. The diagnostic pillar was seen to make "substantial upstream contributions" but was "hampered by an insufficient focus on delivery and by late WHO guidance for self-tests."[64]

Consistent with literature on the topic, we underline that the ACT-A relied on an amalgamating action through previously established health initiatives, ranging from research to the development of new vaccines (see Figure 1).

Figure 1 illustrates several different types of co-conveners of the four pillars, in addition to states that were involved as donors or recipients of international cooperation:

- International organizations: WHO and the World Bank
- Existing global health MSPs: the Global Fund (focusing on HIV/AIDS, malaria, and tuberculosis), Gavi (focusing on vaccines), and Coalition for Epidemic Preparedness Innovations (focusing on creating new vaccines for emerging infectious diseases)
- Charitable foundations: Wellcome Trust, Unitaid, and FIND.

Finally, as seen in the ACT-A setup, international organizations often act as liaisons between the multilateral system and MSPs. WHO can both coordinate with the United Nations, special agencies, governments, scientific and professional organizations, and "such other organizations as may be deemed appropriate" (as per its Constitution, art. 2(b)), and consult and cooperate with international nongovernmental organizations (art. 70). Additionally, the World Bank can act as a link from an MSP to health systems and health policy at the national level or provide trusteeship for the funds pooled within an MSP. The World Bank can be a trustee of such funds under the rubric of either trust funds or financial intermediary funds.[65]

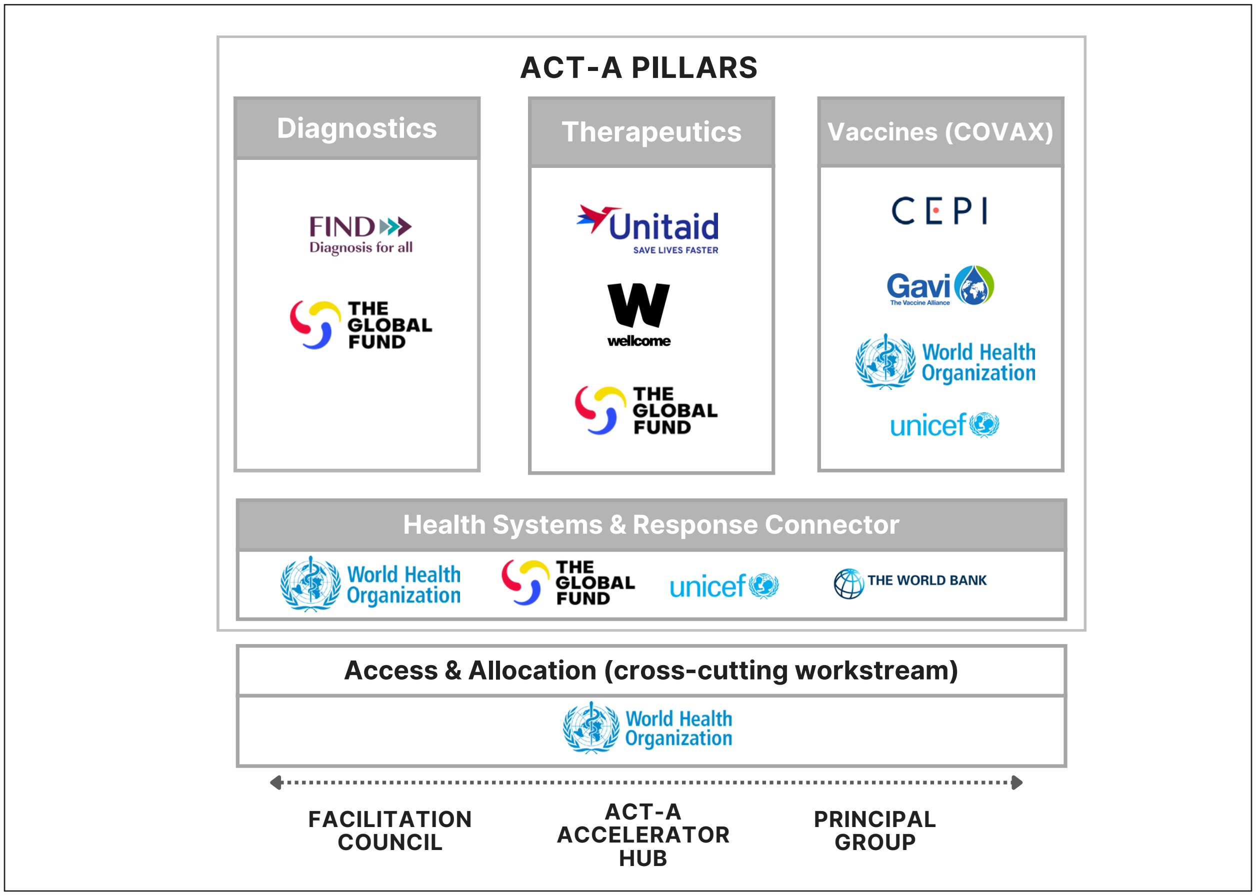
Human rights accountability in the ACT-A: Analysis and findings

In this section, we apply the working framework of accountability outlined earlier to the case study of the ACT-A.

Multi-stakeholder approaches to responding to health emergencies often aim at providing rapid responses and effective collaboration between a range of public and private actors. This is the broader structural and systemic context in which MSPs are created to tackle health emergencies caused by infectious diseases. Within this context, health MSPs may be centralized or decentralized, and they may or may not include mechanisms for transparency and accountability. For this reason, we analyze health and human rights accountability in multi-stakeholder responses to pandemics at two levels: (1) the structural and systemic level and (2) the intervention and partnership (ACT-A) level.

Responsibility (clearly defined duties and performance standards) as a component of accountability

Figure 1. ACT-A's governance structure (simplified; pillars co-convenors as of 2022)



Source: Authors' own elaboration based on information available at https://www.who.int/initiatives/act-accelerator/about and https://www.who.int/publications/m/item/act-accelerator-transition-plan-(1-oct-2022-to-31-mar-2023).

The ACT-A exposed a lack of clearly defined duties and performance standards for public and private actors involved in pandemic preparedness and response.

From the viewpoint of international human rights law, donor states—both individually and as members of WHO and the World Bank—were bound by their right to health and international cooperation obligations. Yet beyond a broad international cooperation obligation under human rights law, the differentiated situation of developing versus wealthy countries did not guide the actions of wealthy countries in allocating resources in ways that prioritized the most vulnerable. As Antoine de Bengy Puyvallée and Katerini Storeng point out in relation to COVAX, "boards of the respective participating institutions formally [bore] the ultimate responsibility for the organizations' actions, but ha[d] no mandate for the overall COVAX initiative and these boards [we]re dominated by donor governments and the pharmaceutical industry."[66] The multitude of actors—both public and private—also obfuscated who owed international cooperation duties, as well as duties in relation to sharing the benefits of scientific progress. Furthermore, beyond the human rights duties of the ACT-A's constituent institutions, the human rights duties that applied to the partnership remained unclear given its hybrid setup bringing together a diverse set of public and private actors, as well as its ad hoc and time-bound nature.

Answerability as a component of accountability

There has been a complete lack of rights-holder centricity in multi-stakeholder action in global health, particularly around pandemics. All institutions—including states, which have clear obligations under international law with respect to respecting, protecting, and fulfilling the right to health and international cooperation—have participated in the pandemic response based on charity. The action of nonstate entities has also been guided by the same logic but without the imperatives of human rights law. Notwithstanding the fact that companies participating in the ACT-A, such as the pharmaceutical companies, were operating within their core business and not purely charitably, the ad hoc and voluntaristic nature of the partnership also obscured the baseline duty of these business enterprises to respect human rights, including, in this case, the right to health. As noted by global civil society organizations, such top-down and charity-oriented programming is not in line with a rights-based or people-centered approach.[67] This has led to the ACT-A not being answerable to rights holders who ought to have been the ultimate beneficiaries.

The opportunity cost of investing in time-bound, multi-stakeholder, market-based, or charity-based solutions is also difficult to quantify. Nonetheless, multi-stakeholder solutions may have contributed to deprioritizing structural solutions, such as the proposed waiver to certain provisions of the Agreement on Trade-Related Aspects of Intellectual Property Rights in the context of the COVID-19 emergency.[68] Given that patent waivers were the main demand of the People's Medicine Alliance, a global movement of more than 100 nongovernmental organizations across 33 countries, we note that multi-stakeholder approaches risk further sidelining civil society's voices.[69]

Enforceability as a component of accountability

There is a lack of enforceability of human rights and other standards, such as in relation to whether MSPs meet the health rights criteria of availability, accessibility, acceptability, and quality, which also rings true for the ACT-A. Even as this ad hoc partnership constituted the main coordinated response to the pandemic at the global level, right to health norms were not enforceable in the context of that response. First, the multi-stakeholder approach espoused could not be scrutinized on whether it fostered or hampered availability, accessibility, acceptability, and quality. Second, human rights norms and criteria were not enforced against decisions and actions in the context of the ACT-A once it was set up and operational.

Monitoring, review, and remedial action as components of accountability

The monitoring, review, and remedy framework, when applied to the ACT-A, sheds light on various shortcomings linked to this ad hoc partnership.

With respect to *monitoring*, some data tracking facilities were created, including the COVID-19 Access Tracker, the ACT-Accelerator Commitment Tracker, and the UNICEF COVID-19 Market Dashboard, but there was criticism about the top-down, uncoordinated, and ad hoc establishment of such data trackers.[70]

With respect to *review*, there were shortcomings from the beginning, owing to the lack of inclusivity and transparency in decision-making and accountability. Reviewing and assessing the practice of the ACT-A against promises and assurances, as well as against human rights and other standards, seldom took place. While some of the constituent entities such as the Global Fund may have their own mechanisms for auditing and investigating allegations of fraud and abuse, the ACT-A did not have a mechanism of its own. Civil society and community representatives to the ACT-A sent a letter early in February 2021 to leaders of institutions participating in the ACT-A to, inter alia, raise concerns about the lack of transparency in decision-making and the lack of input from civil society representing the interests of rights holders. The letter also noted poignantly that beneficiary countries were not consulted, and some were "learning about their COVAX allocations from press announcements rather than through formal communications from the COVAX Facility itself."[71]

With respect to *remedy*, the ACT-A, as an entity, did not establish any redress or remediation mechanisms. It is unclear whether existing accountability mechanisms under the auspices of the ACT-A partners could be deployed for redress and remedy of claims related to the ACT-A.

Conclusion

Our empirical human rights analysis of the ACT-A confirms its accountability challenges, including *diffused responsibility* due to a lack of clarity about the rules and norms that apply to various types of public and private partners and the division of duties between these partners. In addition, *answerability* to beneficiaries is often limited, while the interests and priorities of powerful partners, who often promote private interests and corporate models, prevail. Finally, when rights holders seek to enforce the commitments that have been made voluntarily by MSPs, they encounter weak or nonexistent *enforceability* mechanisms. This in turn also influences the ACT-A showing weak *monitoring*, inconsistent *review*, and largely absent *remedial* mechanisms. While additional comparative research is needed to generalize our findings related to the ACT-A to other health MSPs, this paper reinforces the evidence provided by previous scholarship on the topic.[72]

These shortcomings are problematic in the context of future pandemic governance, which is likely to continue building on disease-specific, multi-stakeholder approaches. For instance, in September 2022, the Financial Intermediary Fund for Pandemic Prevention, Preparedness and Response (Pandemic Fund), hosted by the World Bank, was established, and concerns about it are already being raised.[73] By the same token, the WHO Pandemic Agreement introduced the Global Supply Chain and Logistics Network, which would be "developed, coordinated and convened" by WHO in partnership with "relevant stakeholders" to enhance and facilitate "access to pandemic-related health products for countries in need."[74]

However, like the ACT-A experience, future multi-stakeholder approaches may prioritize private interests while sidelining rights holders as well as developing countries' priorities, especially in a broader context in which global health law developments are not being fully foregrounded in human rights law.[75] To tackle future health emergencies, strengthening existing multilateral global health systems allows the global community to provide a structural response. By contrast, ad hoc, amalgamated multi-stakeholder initiatives, which appear only to disappear or become obsolete, risk further fragmenting global health policy and diverting resources away from the public sector.

Based on our findings, and the future prominence of multi-stakeholder responses to global health emergencies, we need to rethink how to tackle accountability deficits of multi-stakeholder approaches to global health problems. Multi-stakeholder solutions often overlook less powerful actors, such as states (especially developing countries) and human rights holders. This is because philanthropic foundations and existing powerful MSPs tend to divert public financing to charity and market-based approaches with the promise of rapid response and agility, which often do not materialize, to the detriment of rights holders. In other words, we need to rethink how global health policymaking can effectively be devised without the intermediation of powerful private actors.

We propose three potential solutions. First, from a legal standpoint, we argue that—at a minimum— the baseline duty contained in the business and human rights frameworks of respecting human rights in all activities, decisions, and relationships should apply to philanthropic actors and charitable foundations as well as MSPs. When any of these actors engage in the provision of public services, they should also similarly be subject to "public service obligations" as outlined by the Committee on Economic, Social and Cultural Rights in General Comment 24.[76]

The committee also highlights that "priority in the provision of international medical aid, distribution and management of resources, such as safe and potable water, food and medical supplies, and financial aid should be given to the most vulnerable or marginalized groups of the population."[77] Going forward, discussions around public accountability for pandemic prevention, preparedness, and response, whether based on multi-stakeholder approaches or purely public approaches, should ensure that the rights of the most vulnerable and marginalized parts of the global population are respected and their health care needs met.

Second, within existing MSPs, a solution might be to devise an external, independent body that effectively holds them and their constitutive members accountable. This mechanism would include procedural requirements to ensure the effective and meaningful participation of those affected by the development projects that MSPs handle. Such independent review and monitoring bodies may be built into existing multilateral institutions with global membership, such as WHO, UNESCO, the Food and Agriculture Organization, and others, depending on the issue area.

Finally, looking for solutions at the interface of human rights law and governance, multilateral, structural solutions embedded in international cooperation duties and guided by human rights norms should be prioritized over multi-stakeholder approaches. Pivotally, these long-term solutions should envision seats at the table for developing-country representatives as well as public interest civil society groups.

Funding

The research on which this paper is based is funded by the European Union (ERC Starting Grant, GENESIS, 101117107). The views and opinions expressed, however, are those of the authors only and do not necessarily reflect those of the European Union or the European Research Council Executive Agency. Neither the European Union nor the granting authority can be held responsible for them.

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Deepening Accountability: The Fair Pharma Scorecard and Access to Medicines in a Fragmented Global Health Law Landscape

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Abstract

The international legal landscape governing global health is characterized by regime complexity and legal fragmentation, with overlapping and sometimes conflicting legal norms. This fragmentation can blur lines of accountability, particularly in the context of access to medicines, where responsibility is dispersed across multiple stakeholders. Traditional frameworks of accountability in human rights law emphasize a vertical relationship between states as duty bearers and individuals as rights holders—failing to capture the multifaceted reality of global pharmaceutical governance, where access to medicines is shaped not only by the relevant state but also by a range of nonstate actors. Among these, pharmaceutical corporations play a pivotal role in shaping a state's capabilities to ensure access to medicines for its population. In this context, we argue that the development and deployment of a pharmaceutical accountability scorecard offers an innovative tool to address some of the existing accountability gaps. This paper presents the Fair Pharma Scorecard – Cancer Edition, developed by the Dutch nonprofit Pharmaceutical Accountability Foundation, as an innovative tool to address some of the existing gaps. Grounded in a normative framework that draws on various international legal and health-related instruments, this scorecard evaluates the extent to which multinational pharmaceutical companies fulfill or neglect their responsibilities to ensure equitable access to medicines.

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Competing interests: None declared.

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Introduction

Half of the world's population lacks access to basic health services, including essential medicines.[1] At the forefront of this crisis are the estimated 80% of people living in low- and middle-income countries (LMICs), who disproportionately bear the burden of limited access to health care.[2] In this context, cancer presents a particularly urgent challenge. It is now a leading cause of death worldwide, particularly in LMICs where under-resourced health systems are unable to absorb the high costs of (patented) cancer medicines.[3] A growing body of research on prevailing inequities in cancer health care shows that survival rates are significantly lower in LMICs, driven by late-stage diagnosis and limited access to treatments.[4]

Ensuring equitable access to (cancer) medicines is both a health care concern and a legal obligation grounded in international human rights law. The right to health, enshrined in instruments such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), includes access to essential medicines as a core component.[5] However, the implementation and enforcement of this right is complicated by the state-centric design of international human rights law, which places the onus of accountability on governments.

Moreover, the international legal landscape governing global health is characterized by regime complexity and legal fragmentation, with overlapping and sometimes conflicting legal norms. This fragmentation can blur lines of accountability, particularly in the context of access to medicines, where responsibility is distributed across multiple and diverse stakeholders. From a human rights law perspective, traditional frameworks of accountability emphasize a vertical relationship between the state as duty bearer and the individual as rights holder. However, this model fails to capture the multifaceted reality of global pharmaceutical governance, where access to medicines is shaped not only by the relevant state but also by a range of nonstate actors. Among these, pharmaceutical corporations play a pivotal role in shaping a state's capabilities to ensure access to medicines for its population.

In this paper, we adopt Margaret Young's vision of "productive regime interaction" as a response to the fragmented nature of accountability in global health.[6] We build on this idea by advancing a framework of multifaceted accountability, which recognizes that obligations related to access to medicines cannot be adequately understood or enforced through a single legal or institutional lens, or by a single actor. Multifaceted accountability, in this sense, involves a range of actors beyond the traditional nation-state, including pharmaceutical companies, civil society and community actors, and other nonstate entities. It also implies that accountability mechanisms can take diverse forms, from hard-law obligations and soft-law instruments to public scrutiny and civil society-led initiatives. To exemplify this, we argue that the development and deployment of a pharmaceutical accountability scorecard offers an innovative tool to address some of the existing accountability gaps.

This paper presents the Fair Pharma Scorecard – Cancer Edition, developed by the Pharmaceutical Accountability Foundation (PAF), as a way to address these gaps. Grounded in a normative framework that draws on a range of international legal and health-related instruments, including international human rights law, authoritative soft-law instruments, and ethical principles underlying medical research, this scorecard evaluates the extent to which multinational pharmaceutical companies fulfill their human rights responsibilities to ensure equitable access to medicines.[7] We apply the scorecard to cancer medicines, where issues of access, affordability, and accountability are especially acute. We first map the legal and human rights landscape, and then highlight the limits of this state-centric model, before presenting the Fair Pharma Scorecard as an accountability mechanism that reflects the distributed nature of responsibility in global health governance and can support bottom-up norm crystallization by civil society.

The legal landscape

The human right to health and access to essential medicines

At the core of global health and access to medicines is the recognition of health as a fundamental human right.[8] Most notably, this includes the ICESCR, whose article 12 imposes a tripartite obligation on 171 state parties (excluding the United States and Cuba, among others) to respect, protect, and fulfill the right of every individual to the highest attainable standard of physical and mental health.[9] Article 12 on the right to health thus reflects broad global consensus on the legal imperative to advance health equity.

A key component of this right is access to essential medicines. The Committee on Economic, Social and Cultural Rights, in its General Comment 14, identifies such access as a core obligation under article 12.[10] Core obligations represent a non-derogable minimum standard that states must fulfill regardless of available resources. According to the committee, the right to health should be understood not as a guarantee of being healthy but rather as the assurance of certain fundamental conditions that support a life of dignity, including access to essential medicines and health services.[11] General Comment 14 also introduces the AAAQ framework (availability, accessibility, acceptability, and quality) as a standard for evaluating the adequacy of health services and goods. While general comments are not legally binding, they are widely regarded as authoritative interpretations of treaty obligations. Since this right has been widely studied, we keep this overview brief.[12]

Because only states are party to the ICESCR, the legal obligations arising out of the covenant are binding only on them. Private actors, such as pharmaceutical companies, are not directly bound by international human rights law. Their conduct is governed primarily through the lens of the appropriate state—under the ICESCR, the duty to protect obliges states to ensure that businesses under their control do not, as a minimum, undermine the right to health.[13]

However, it is now widely recognized that nonstate actors, including corporations, have *responsibilities* to respect human rights, though these are nonbinding. The United Nations Guiding Principles on Business and Human Rights, adopted in 2010, clearly articulate that businesses should respect human rights and that governments must ensure compliance, including by regulating corporate conduct.[14] This position has since been echoed and expanded on by United Nations (UN) treaty bodies, including through general comments that increasingly acknowledge the growing influence of corporate actors in either facilitating or undermining the enjoyment of rights.[15] For instance, in General Comment 14, the Committee on Economic, Social and Cultural Rights recognizes businesses' responsibilities in relation to health, stressing that "while only States are parties to the Covenant and thus ultimately accountable for compliance with it, all members of society … [including] the private business sector—have responsibilities regarding the realization of the right to health."[16] In General Comment 24, the committee further recognizes that companies may be directly linked to adverse human rights impacts through their business operations and that they bear responsibility to avoid such harms.[17] General Comment 24 elaborates on the obligations of states to protect against human rights abuses by business enterprises, calling on states to impose "strict regulations" on private providers of public services, including private health care providers, which "should be prohibited from denying access to affordable and adequate services, treatments or information."[18]

In the context of access to medicines, Paul Hunt, during his tenure as UN Special Rapporteur on the right to health (2002–2008), was instrumental in outlining the specific responsibilities of pharmaceutical companies, which he set out in the 2008 Human Rights Guidelines for Pharmaceutical Companies in Relation to Access to Medicines (often referred to as the Hunt Guidelines).[19] The role of the UN Guiding Principles and Paul Hunt in shaping corporate accountability for health-related human rights interferences will be examined in more detail later. Before that, we shift focus to the broader legal landscape in which the right to health operates—one that is increasingly fragmented and shaped by intersecting legal regimes.

The right to health in a fragmented legal landscape

Broadly defined, global health law includes "all international legal regimes relevant to public health—international environmental law, international humanitarian and human rights law, international trade and labor law, international laws relating to arms control, and so on."[20] Narrower interpretations of global health law restrict it to legal instruments explicitly designed to manage health threats, including the International Health Regulations, the Framework Convention on Tobacco Control, and the Pandemic Agreement adopted in response to the COVID-19 pandemic, while broader interpretations include a variety of international legal instruments that indirectly impact health (for instance, the World Trade Organization Agreements).[21]

Global health law can thus encompass both hard and soft law, together forming a regulatory architecture aimed at realizing the highest attainable standard of health for all.[22] It also does not exist as a unified legal regime. Rather, it operates within a fragmented and multilayered legal environment shaped by diverse actors—including states, international organizations, corporations, and civil society—and an evolving body of legal and nonlegal instruments. This landscape is marked by competing priorities. For instance, the fulfillment of the right to access medicines may be constrained by exclusive patent rights under intellectual property law, or by trade rules that limit a country's capacity to regulate medicine prices.[23] These tensions are rarely resolved through a single legal framework and are often negotiated in political and institutional forums that differ significantly in power and influence.

This institutional and normative complexity has deep historical roots. From the latter half of the nineteenth century, a variety of intergovernmental organizations were created to govern activities with international impact—for instance, the International Telegraph Union, established in 1865; the Universal Postal Union, set up in 1874; and relevantly, the Office International d'Hygiène Publique, established in 1907, which subsequently became an early forerunner of the World Health Organization (WHO).[24] In recent decades, however, global health governance has undergone a fundamental transformation: a shift from a centrally governed international order based on political representation toward a more decentralized, pluralistic field. Public-private partnerships, philanthropic foundations, and corporate actors—particularly from the pharmaceutical industry—have taken on increasingly prominent roles. The result is a governance ecosystem characterized by a diversity of actors: research institutes, multilateral organizations, nongovernmental organizations, philanthropic institutions, Western pharmaceutical companies, generic manufacturers from the Global South, and more.[25]

This shift has profoundly changed the structure and functioning of the global public health sector. Authority and decision-making are now dispersed across a network of interdependent actors, many of whom are not formally accountable under international law. While human rights law continues to impose obligations on states, it seldom provides direct enforcement mechanisms for either public or private actors whose decisions affect access to medicines.[26] Global health governance is therefore not only legally complex but also characterized by fragmented accountability structures and fragmented or absent enforcement mechanisms. This regime complexity contributes to normative uncertainty and can undermine efforts to ensure equitable access to medicines, particularly in the face of corporate influence and market-driven imperatives.[27] The current director-general of WHO has even framed fragmentation as a barrier to the Sustainable Development Goals and achieving progress in global health.[28] The following section explores how this fragmentation in global health law contributes to the diffusion, and often dilution, of accountability for access to medicines.

Fragmentation in global health law: Legal and accountability challenges

The development of international law as a system of horizontal norms through multiple, often overlapping legal regimes has led to a phenomenon called fragmentation.[29] Fragmentation, while not inherently problematic, can become so when norms from different regimes come into conflict with one another, as there is no clear hierarchy between regimes.[30] Thus, when governments have ratified multiple international treaties and agreements, they may face difficulties implementing their obligations under one regime when these conflict with other international rules.

For example, industry actors frequently challenge the adoption of health regulations when doing so impacts trade and investment, thus limiting states' ability to regulate health matters.[31] This is exacerbated by the fact that the enforceability of global health standards is limited, particularly when contrasted with the robust mechanisms available for enforcing international economic law.[32] International trade law under the auspices of the World Trade Organization (WTO) has, for instance, traditionally been characterized by a compulsory dispute settlement mechanism and retaliation measures in case a WTO member does not comply with a ruling—although the system has come under threat in recent years due to a crisis at the WTO Appellate Body.[33] Regardless, a regulatory imbalance between global health governance and international economic law continues to persist, weakening the protection of human rights, especially the right to health, which is threatened by corporate activities prioritizing economic gains over health and well-being.[34] Consequently, accountability in global health becomes fragmented, with responsibility dispersed among multiple actors.

Of relevance for this paper, responsibility for access to medicines is similarly distributed across a complex array of actors, including states, international organizations, and nonstate actors such as pharmaceutical corporations. While corporations increasingly play a decisive role in shaping access to medicines, human rights accountability mechanisms have not evolved to reflect this complexity. Traditional accountability mechanisms under human rights law, through UN treaty bodies, the Universal Periodic Review process, and Special Procedures such as the Special Rapporteur on the right to health, are state-centric. The role of private actors is seen largely through the lens of the concerned state, which is obliged to ensure that the private actors under its control do not violate human rights.[35] This model is premised on a vertical relationship between states and individuals and assumes state control and capacity to deliver on its obligations.

Consequently, even though pharmaceutical companies exercise considerable control over the availability, pricing, and distribution of medicines, they still remain largely outside the scope of binding international and human rights obligations. Attempts to address this accountability gap, such as the UN Guiding Principles on Business and Human Rights and the Hunt Guidelines for pharmaceutical companies, have contributed useful soft-law frameworks.[36] Still, these remain voluntary and unenforceable, offering no real recourse when corporate actions interfere with the right to health. In the context of access to medicines, this interplay between multiple legal regimes, institutional actors, and competing norms blurs lines of accountability.

In 2006, the International Law Commission examined the issue of fragmentation within international law.[37] One of its conclusions was that fragmentation could be addressed, in part, by "interpreting treaties in accordance with other relevant rules and principles that apply between the parties" (including human rights), an approach known as systemic integration or interpretation. Building on this, Young has proposed the idea of a "legal framework for regime interaction" to manage fragmentation.[38] She argues that the interaction between different legal regimes can generate "productive friction," potentially resulting in a more adaptive and effective international legal system than what each regime could achieve on its own. Given its inherently cross-cutting nature, global health law is uniquely positioned to serve as a bridge between normative divides and to address fragmentation. In sum, the fragmentation of international law and the inadequacy of existing accountability structures are mutually reinforcing. Together, they enable powerful actors to evade responsibility, hinder the realization of the right to health, and weaken efforts to ensure equitable access to medicines. Addressing these dual challenges will require not only legal reform but also the development of new accountability mechanisms that can hold both states and private actors accountable within a more integrated global health governance framework.

Since Young's foundational work, scholarship has further explored how weak accountability and fragmented governance shape global health outcomes. Neil Spicer et al. demonstrate that "unbalanced accountability" (strong upward reporting to high-income donors versus weak downward accountability to recipient countries) exacerbates fragmentation and limits coordination between global health actors.[39] Gisela Hirschmann introduces the concept of "pluralist accountability," emphasizing how third-party actors, including nongovernmental organizations, courts, and networks, can hold both public and private actors accountable outside of formal delegation structures, often by leveraging reputational pressure and benchmarking.[40] Akiko Kato and Yoshiko Naiki also highlight the role of nongovernmental organizations in improving access to medicines by fostering "polycentric governance," where multiple state and nonstate actors interact and where indicators and rankings (such as the Access to Medicine Index) can act as practical regulatory tools that influence behavior and encourage corporate responsibility.[41] Similarly, Judith Kelley and Beth Simmons show how indicators can influence policy through the pressure of comparison.[42]

Together, these insights show how fragmentation, accountability gaps, and intersecting governance structures create both challenges and opportunities.

Scorecards and benchmarking: Practical tools for accountability

Since traditional, state-centric human rights accountability mechanisms fall short in addressing the dispersed and fragmented responsibilities of private actors in ensuring equitable access to medicines, alternative forms of accountability are needed to create a more integrated and responsive governance framework.[43] We argue that scorecards and benchmarking offer practical tools for social accountability where formal legal mechanisms are inadequate for holding nonstate actors accountable.[44]

This approach aligns with the International Law Commission's view of "special regimes," where regimes are defined not only by state actors but by their functional specialization.[45] This implies that the goals, norms, and activities of nonstate actors are integral to regime formation and evolution. Thus, the influence of technical experts, nongovernmental organizations, regional and international courts (such as the European Court of Human Rights, the WTO panels, etc.), and other nonstate participants must be considered when analyzing regime interaction. These actors shape the dynamics of governance and accountability and are therefore essential to building more inclusive and adaptive frameworks for global health governance.

Moreover, civil society organizations are not constrained by the same boundaries between regimes or hierarchies of norms that often limit state-based actors. Tools such as scorecards operate not in opposition to legal mechanisms but in the gaps between fragmented regimes, providing a practical means of promoting accountability and norm convergence. In this way, they illustrate how the complexity of global health governance can be harnessed to develop more effective accountability structures. This also reflects Young's concept of productive friction between legal and normative systems, where competing systems can generate innovative governance responses by exposing tensions and gaps between them.

Therefore, scorecards, especially those developed by civil society organizations, can serve as critical tools for addressing the accountability gap by creating structured, evidence-based, and citizen-informed assessments of corporate behavior.[46] We present the Fair Pharma Scorecard as an example of how civil society can evaluate pharmaceutical companies on their alignment with human rights norms relating to access to medicines. In doing so, we show how scorecards offer new, practical means for shifting the locus of accountability beyond traditional state institutions, enabling broader stakeholder engagement and public oversight.[47]

We first draw on the conceptualization of social accountability embraced in the public services and development literature. Social accountability has been defined as "an approach towards building accountability that relies on civic engagement, i.e., in which it is ordinary citizens and/or [civil society organizations] who participate directly or indirectly in exacting accountability."[48] Originating in the early 2000s to refer to community-led initiatives to hold governments accountable outside of only election-based systems, the term has since evolved to encompass a diverse range of citizen-led initiatives, such as community scorecards, citizen report cards, participatory budgeting, and social audits.[49] A common element across these mechanisms is the emphasis on citizen agency and oversight. While social accountability has traditionally been oriented toward control over, and accountability of, public sector institutions, we argue for an expansion of these mechanisms to include the private sector, particularly pharmaceutical companies whose actions bear significant implications for public health and human rights.

There is a long history of indicators, benchmarks, and scorecards in business and human rights. In the late 1990s and early 2000s, scholars and policy makers explored standardized approaches to holding corporations accountable.[50] As a result, scorecards and ratings, including those created by civil society organizations, have emerged as promising innovations in the business and human rights landscape.[51] In the sphere of medicines access, the Access to Medicine Index is a notable example.[52] Early initiatives addressing corporate responsibility in a broader context include the 1999 UN Global Compact, which encouraged companies to evaluate their conduct in light of human rights principles, including the ICESCR.[53] The Global Compact ushered in a new standard of corporate conduct being benchmarked against international law.[54] The UN Working Group on the Issue of Human Rights and Transnational Corporations and Other Business Enterprises has also highlighted the key role of indicators in holding corporations accountable for their impact on human rights, noting the desirability of "establishing measurable and transparent indicators to assess [the] effective implementation" of the UN Guiding Principles.[55]

Importantly, scorecards and other indicators for monitoring corporate human rights impacts are not merely technical tools; they also contribute to the creation and evolution of new norms through processes of interaction, interpretation, and practice among diverse normative communities.[56] Over time, repeated use and convergence around certain indicators may contribute to norm crystallization—that is, the transformation of soft or emerging standards into more widely accepted and authoritative norms, especially when these benchmarks begin to guide state behavior, corporate conduct, and stakeholder expectations in consistent and predictable ways. The Access to Medicine Index published by the Access to Medicine Foundation is a good example of this: "board-level responsibility for access to medicines"—one of the indicators assessed in the index—was initially rare in 2008–2010 but became standard practice by the 2020s. The index continues to include the indicator, but it functions more as a baseline expectation or "accepted practice."[57]

Finally, numerical-based indicators such as scorecards, benchmarks, and ratings offer several advantages. Companies are often driven by reputational concerns to join and comply with these indicators, since their profits and share values are acutely responsive to public perception.[58] Scorecards, often grounded in naming-and-shaming strategies, can therefore be powerful drivers of corporate compliance, sometimes more effective than state regulation. They also provide clear, accessible information that allows easy comparison and ranking of companies.[59]

The Fair Pharma Scorecard – Cancer Edition

Building on the precedent set by the Fair Pharma Scorecard for COVID-19 products, PAF is currently developing a methodology to evaluate how multinational pharmaceutical companies fulfill their responsibilities to ensure equitable access to cancer medicines.[60] Funded by the Dutch Cancer Society (KWF Kankerbestrijding), this new initiative focuses on a subset of essential cancer therapies selected from the WHO Model List of Essential Medicines, ensuring alignment with global priority-setting processes.

Cancer is a leading and increasing global cause of death, with new cases and deaths projected to rise by 60%–70% by 2040 compared to 2018.[61] Despite this growing need for treatment, access to cancer medicines remains deeply unequal. In LMICs, many patients lack access to even the most basic cancer medicines, while in high-income countries, new drugs are often launched at unsustainably high prices, straining even robust and (comparatively) well-resourced health systems.[62] This inequality in access to treatment severely affects survival rates: WHO estimates that over 80% of children with cancer in high-income countries will be cured, compared to 10% in LMICs, which bear nearly 80% of the global cancer burden but receive less than 5% of resources for combating the disease.[63] Given the scale, urgency, and inequity of the cancer burden, ensuring affordable and equitable access to treatment is a global health and human rights imperative—and the driving reason behind this scorecard.

The Fair Pharma Scorecard on access to cancer medicines serves three core purposes: first, to empower procurers of cancer medicines (governments, international agencies, or other buyers) with transparent, product-specific insights that support stronger price negotiations and better affordability; second, to act as a tool encouraging pharmaceutical companies to adopt more equitable and consistent access practices across their cancer treatment portfolios by setting standards and exposing (un)fair behaviors; and third, to inform and guide the development of stronger, evidence-based legal and policy frameworks at national, regional, and international levels, promoting system-level improvements in equitable access to essential cancer therapies.

Here, we present the methodology for the cancer scorecard, explaining the normative basis behind the criteria and the basis for scoring. The scorecard evaluates the behavior of 15 companies across 18 cancer medicines within 12 countries. Countries were chosen to ensure representation across WHO geographic regions and income groups, while also considering the availability of data in each of these countries. While final product selection is to be confirmed, it will include all cancer medicines listed on the 2025 WHO Model List of Essential Medicines that remain under primary or secondary patent protection. The final set of companies to be evaluated will be determined based on this product selection.

While a detailed discussion about product, company, and country selection falls beyond the scope of this paper, it is relevant to note that companies are scored per product, not overall, in an effort to acknowledge that corporate behavior can vary by product. This approach enables us to identify whether there are inconsistencies in corporate behavior and if so, how to interpret these differing practices.

The methodology was developed by a team of human rights lawyers in consultation with a multidisciplinary scientific advisory committee and a feedback group comprising academics, legal experts, access-to-medicines advocates, representatives from the Dutch Cancer Society, and experts in pharmaceutical policy. This consultative process was central to the methodology's normative legitimacy and the scorecard's interdisciplinary nature, integrating perspectives from public health, law, and policy. All dimensions of the methodology were developed independently of pharmaceutical companies and governments. The final methodology consists of a structured framework that scores pharmaceutical companies across 18 criteria, grouped into six thematic categories: (1) commitments and accountability, (2) transparency, (3) regulatory systems, (4) licensing and technology transfer, (5) pricing, and (6) access initiatives. Each category operationalizes key dimensions of the corporate responsibility to respect.

Table 1 outlines the 18 criteria across the six thematic categories, along with the scoring metric for each criteria, while Table 2 displays the country selection.

Company behavior will be assessed on a four-point scale, following a modified traffic light system: red for *non-compliant behavior* or inadequate disclosure; yellow for *partially compliant* behavior; green for *compliant behavior*; and double green for excellent behavior that forms *good practice*. Numerical values are assigned to each score (double green = 3, green = 2, yellow = 1, red = 0), and a company's total score is calculated by dividing the cumulative points by the number of criteria. Each criterion is weighted equally.

Data will be drawn from a combination of company responses and publicly available sources. A questionnaire will be sent to companies, allowing them to provide relevant information. This will be complemented with publicly available data from company websites, filings, annual reports, and public databases, including information on country registrations, licensing agreements, and clinical trials. Given the significance of transparency as a foundational element influencing the effectiveness of the other criteria, the public availability of relevant data is crucial and will inform how companies score on these criteria.

The normative foundation underpinning this framework draws from a composite of binding and nonbinding sources: international human rights law, authoritative soft-law instruments, national and regional legal frameworks, internationally accepted ethical principles, and established best practices from pharmaceutical companies themselves, all grounded within a broader framework of public health and health care considerations. The legal sources referred to in the design of the methodology include the ICESCR, General Comment 14 and General Comment 24 of the Committee on Economic, Social and Cultural Rights, the UN Guiding Principles, the 2008 Hunt Guidelines, World Health Assembly resolutions relevant to access to medicines, various UN declarations and political commitments, and ethical standards such as the Helsinki Declaration.[64]

The process of developing the indicators was therefore inherently normative and designed to contribute to norm crystallization. By explicitly linking each category and criterion to these legal and normative sources, this scorecard is intended not only as a benchmarking tool but also as a vehicle for articulating and advancing an emerging consensus on the responsibilities of pharmaceutical companies in global health.[65] Its aim is to embed these expectations within a transparent, independent and methodologically robust framework capable of informing both corporate practice and public advocacy efforts.

Building on this normative foundation, the scorecard proposes a new form of accountability that extends beyond traditional legal enforcement mechanisms. This approach acknowledges the gaps in existing international human rights frameworks in regulating corporate behavior and offers a complementary tool that leverages evidence-based evaluations to drive corporate responsibility by empowering civil society and other stakeholders to assess and publicly report on pharmaceutical companies' performance. In doing so, it fosters a broader accountability ecosystem that engages a diverse range of stakeholders, from patients and advocates to policy makers and the general public. The scorecard thus forms one of several mechanisms—from legal obligations to civil society initiatives—that must collectively be deployed in a coordinated manner to effectively hold pharmaceutical companies accountable within the current fragmented global health landscape.

Limitations

While scorecards hold potential as tools for accountability, important caveats remain. Scorecards draw their legitimacy from the authority of their creator, as well as their substantive content. Further, due to the often limited availability of data, these scorecards may rely on partial data that are standardized for the sake of comparison, risking distorted or incomplete results through reductive metrics.[66]

Another important consideration is whether individuals and communities that are most tangibly impacted by the relevant corporate conduct

TABLE 1. Criteria and scoring metric

Category	Criteria	Scoring metric
Commitments and accountability	1. The company publishes a global access plan (GAP) that takes into account the needs of disadvantaged and vulnerable populations.	🔴 No GAP has been published. 🟡 A GAP has been published. 🟢 The GAP mentions the needs of vulnerable groups (e.g., LMIC populations, marginalized communities, socially disadvantaged groups). 🟢🟢 The GAP outlines actions targeting vulnerable groups.
	2. The GAP integrates or operationalizes human rights, including the UN Guiding Principles on Business and Human Rights.	🔴 The GAP includes no reference to human rights. 🟡 The GAP includes passing reference to human rights. 🟢 The GAP includes specific reference to the UN Guiding Principles, acknowledging the human rights responsibilities of businesses. 🟢🟢 The GAP outlines specific actions in pursuit of businesses' human rights responsibilities.
	3. The company has a concrete access strategy for the product or for cancer.	🔴 The company has no access strategy specific to cancer or the product. 🟡 The company has an access strategy specific to cancer. 🟢 The company has an access strategy for different types of cancer. 🟢🟢 The company has an access strategy for the product in question.
Transparency	4. The company publishes its research and development (R&D) costs for the product.	🔴 No information on R&D costs is published. 🟡 The company publishes aggregate R&D costs at the company-wide level. 🟢 The company discloses aggregate R&D costs for cancer products as a therapeutic area. 🟢🟢 The company publishes R&D costs for the product in question.
	5. The company publishes its profit margin for the product.	🔴 No information on profit margins is published. 🟡 The company publishes aggregate profit margins at the company-wide level. 🟢 The company publishes aggregate R&D costs for cancer products as a therapeutic area. 🟢🟢 The company publishes the profit margin for the product in question.
	6. The company publishes its average/marginal costs of production.	🔴 No information on average or marginal costs of production is published. 🟢🟢 The company publishes the average and marginal costs of production for the product in question.
	7. The company facilitates publication of the prices of the product that have been negotiated in the selected countries.	🔴 The company does not disclose or facilitate the disclosure of negotiated or list prices in any country. 🟡 The company discloses or facilitates the disclosure of list prices only, without reflecting negotiated prices in practice. 🟢 The company discloses or facilitates the disclosure of negotiated prices in a limited set of countries (e.g., high-income only, or selectively). 🟢🟢 The company discloses or facilitates the disclosure of negotiated prices across all selected countries.
	8. The company publishes its production capacity and has a public reporting system for shortages due to manufacturing issues.	🔴 The company neither publishes its production capacity nor has a public reporting system for shortages due to manufacturing issues. 🟡 The company fulfills only one of the two requirements. 🟢 The company fulfills both requirements. 🟢🟢 The company goes beyond both requirements, such as by publishing detailed, facility-level production capacity with regular updates or by providing a real-time, publicly accessible reporting system on shortages, including causes and mitigation steps. Data are independently verified or audited.
	9. The company publishes the public subsidies received during product development or testing.	🔴 No information on public subsidies received is published. 🟡 The company publishes aggregate information on public subsidies received at the company-wide level. 🟢 The company publishes aggregate information on public subsidies received for cancer products as a therapeutic area. 🟢🟢 The company publishes information on public subsidies received for the specific product in question.
	10. The company registers its clinical trials for the product in question in public repositories.	🔴 The company does not register the clinical trials for the product. 🟢🟢 The company registers clinical trials for the product and publishes their results.
Regulatory systems	11. The company files for registration of its product in the selected countries.	🔴 The company files for registration of the product in fewer than 3 of the selected countries. 🟡 The company files for registration of the product in 3–6 of the selected countries. 🟢 The company files for registration of the product in 6–9 of the selected countries, *and* at least 3 of these are the selected low-income countries or lower-middle-income countries. 🟢🟢 The company files for registration of the product in 9–12 of the selected countries, *and* at least 5 of these are the selected low-income countries or lower-middle-income countries.

TABLE 1. *continued*

Category	Criteria	Scoring metric
Licensing and technology transfer	12. The company agrees to license its products to other companies or through the Medicines Patent Pool on equitable terms, with due consideration for geographic scope and in a timely manner.	🔴 The company does not license its product at all. 🟡 The company licenses its product to one company in one country. 🟢 The company licenses its product to multiple companies in multiple countries. 🟢🟢 The company licenses its product to multiple companies in multiple countries, including low-income countries and lower-middle-income countries.
	13. The company publishes the full text of the licensing agreement.	🔴 The company does not publish the licensing agreement. 🟡 The company publishes the text of the licensing agreement, with major redactions. 🟢 The company publishes the text of the licensing agreement, with some redactions. 🟢🟢 The company publishes the full text of the licensing agreement, either unredacted or with only minimal redactions that do not affect the substance, clarity, or quality of the licensing terms.
	14. The company engages in full technology transfer to other manufacturers, including know-how/trade secrets and support for end-to-end production (if 3+ years since first regulatory approval by the European Medicines Agency or US Food and Drug Administration).	🔴 The company does not engage in any form of technology transfer for the product to external manufacturers. 🟡 The company engages only in limited technology transfer, limited to downstream activities such as fill-and-finish or formulating and packaging. 🟢 The company engages in partial technology transfer that goes beyond fill-and-finish but does not enable full independent production (e.g., some selected process steps, quality assurance systems, transfer of know-how/trade secrets). 🟢🟢 The company engages in comprehensive technology transfer for the product to enable independent end-to-end production (e.g., technology transfer for active pharmaceutical ingredients, support for local capacity-building).
Pricing	15. The company has a policy on "fair" or affordable pricing.	🔴 The company has no policy on fair or affordable pricing. 🟡 The company has a policy on fair or affordable pricing but does not include a definition of what constitutes fair or affordable pricing, or has a definition that is vaguely worded. 🟢 The company has a policy on fair or affordable pricing that includes a general definition of what constitutes fair or affordable pricing but lacks contextual or implementation details. 🟢🟢 The company has a policy that provides a clear operational definition of fair or affordable pricing, with due regard for local economic context and resources.
	16. The company engages in tiered or differential pricing.	🔴 The company is not able to provide any evidence of tiered or differential pricing for the product. 🟡 The company is able to provide evidence of *limited* tiered or differential pricing for the product in only one WHO region or within one income classification. 🟢 The company is able to provide evidence of *moderate* tiered or differential pricing for the product across at least two WHO regions *and* across both low-income countries and lower-middle-income countries. 🟢🟢 The company is able to provide evidence of *robust* tiered or differential pricing for the product across more than two WHO regions and with due regard for vulnerable groups *within* low-income country and lower-middle-income country populations (e.g., marginalized communities, socially disadvantaged groups).
Access initiatives	17. The company participates in fairly priced pooled procurement programs.	🔴 The company does not participate in any fairly priced pooled procurement programs. 🟡 The company participates in fairly priced pooled procurement programs, but in only one WHO region or income group. 🟢 The company participates in fairly priced pooled procurement programs, with some diversity across WHO regions and income levels. 🟢🟢 The company participates in fairly priced pooled procurement programs across multiple WHO regions and income levels, including in low-income countries and lower-middle-income countries.
	18. The company engages in appropriate donation programs (drug or cash) that are compliant with WHO's Guidelines for Drug Donations.	🔴 The company does not make any donations (drug or cash) that are compliant with WHO's Guidelines for Drug Donations. 🟡 The company has occasionally (once or twice) engaged in donation programs of limited volumes that are compliant with WHO's Guidelines for Drug Donations. 🟢 The company regularly donates drugs or cash that are compliant with WHO's Guidelines for Drug Donations. 🟢🟢 The company engages in appropriate, long-term donation programs that are compliant with WHO's Guidelines for Drug Donations, donating a substantial volume of drugs or cash.

are actively engaged in the process of creating and applying these indicators—otherwise, the voices of rights holders, especially disadvantaged individuals and communities, may be marginalized.[67] Advocacy-oriented civil society organizations and technical experts play key roles in this process, but this should not come at the expense of affected individuals and communities, who, in the case of pharmaceuticals access, include patient groups, especially in Global South countries.[68] This aligns with the human rights principle of participation and is reinforced by initiatives such as the WHO Framework for Meaningful Engagement of People Living with Noncommunicable Diseases and Mental Health and Neurological Conditions.[69] As noted by Nora Götzmann, "it is a fundamental principle of democracy that people are entitled to participate in decisions that affect them."[70] However, she also finds that this consultation can be limited in human rights impact assessments, where it often occurs only after decisions have been made. To remedy this, she recommends that "rather than stakeholder consultation being just one of the impact assessment stages, [human rights impact assessments need] to make provisions for the inclusive participation of rights holders at critical points throughout the whole assessment process." This should also take into consideration "the power dynamics at play within communities, between rights holders, companies and state actors, as well as with regard to the persons comprising the assessment team."[71] Another caveat mentioned by Götzmann is that "the extent to which such assessments actually facilitate processes and outcomes that effectively address the adverse human rights impacts of business activities remains largely unknown."[72] Further research is therefore needed on both the quality of rights holder participation and the tangible impact of human rights impact assessments, including how they influence decision-making, strengthen accountability, and address power asymmetries in business and human rights practice.

Conclusion

Civil society-led scorecards such as the PAF Fair Pharma Scorecard can become a valuable and innovative tool to advance pharmaceutical accountability in global health. By integrating interdisciplinary perspectives and explicitly linking indicators to legal and normative frameworks, the scorecard may function both as a benchmarking mechanism and as a catalyst for norm crystallization around the responsibilities of pharmaceutical companies. This approach supports the need for a multifaceted accountability ecosystem that engages diverse stakeholders and mechanisms beyond the state to ensure equitable access to medicines. Cancer offers a salient case that exemplifies the necessity for such novel frameworks.

Table 2. Country selection

WHO region	World Bank income classification (2023)			
	High-income country (n=3)	Upper-middle-income country (n=4)	Lower-middle-income country (n=4)	Low-income country (n=1)
Africa (n=4)		South Africa	Kenya Senegal	Uganda
Americas (n=2)	Chile	Colombia		
Southeast Asia (n=1)			India	
Europe (n=2)	The Netherlands Romania			
Eastern Mediterranean (n=1)			Jordan	
Western Pacific (n=2)		Indonesia Mongolia		

Source: Yara de Koning and Anna Peiris, Pharmaceutical Accountability Foundation.

The scorecard is designed for three key functions: empowering medicine procurers with product-specific data; driving corporate behavior change through advocacy; and informing legal and policy development at multiple governance levels. The combined operation of all three is essential to catalyze meaningful, systemic change. By navigating the interstices of international human rights law, public health frameworks, and emerging soft-law norms, scorecards have the potential to harness the tensions between these regimes to forge new forms of accountability better suited to hold private actors responsible for their human rights obligations. In this manner, the scorecard presents an example of Young's concept of "productive friction," where regime complexity and interaction lead to the development of new governance mechanisms, reflecting a shift toward more effective and equitable accountability among global health actors. Furthermore, scorecards can contribute to bottom-up norm crystallization, as civil society reinforces emerging expectations of pharmaceutical companies through public pressure and advocacy, transforming evolving societal standards into concrete standards of companies' human rights responsibilities.

Ultimately, scorecards are an important and evolving part of the accountability ecosystem. Their value lies not only in benchmarking performance but in deepening a new paradigm of public accountability through which businesses are held to their human rights responsibilities. On their own, however, scorecards cannot deliver systemic transformation; sustainable change requires strengthening and expanding legal mechanisms to a wider range of actors, reflecting the growing role of corporations in shaping global health outcomes. Without structural change, the potential of scorecards remains inherently limited.[73] The real challenge, then, is to channel the momentum generated by scorecards toward lasting structural reform. Embedded within broader reforms, scorecards can act as powerful catalysts, transforming reputational pressure into systemic change and advancing meaningful corporate accountability for the right to health.

Acknowledgments

We would like to extend our thanks to Katrina Perehudoff, Hans Hogerzeil, and James Hazel for their valuable feedback on the scorecard methodology.

Funding

The research for this paper was funded by the Dutch Cancer Society (KWF Kankerbestrijding).

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No Place to Park the Clinic: Accountability, Expropriation, and the Social Function of Property in Pursuit of Health Equity in South Africa

LINDANI MHLANGA AND TAMANDA KAMWENDO

Abstract

As South Africa moves toward implementing the National Health Insurance scheme, the promise of universal health coverage remains constrained by material and legal obstacles to land access. Mobile clinics, vital for underserved communities, are undermined by tenure insecurity, fragmented land governance, and exclusionary property regimes. These obstacles expose an accountability gap: the state's failure to use available constitutional tools to dismantle entrenched spatial inequalities. This paper conceptualizes accountability through three interlinked features—monitoring, review against human rights standards, and remedial action—and uses this framework to examine the case of South Africa. We argue that equitable health care delivery requires transforming the property relations that structure spatial access. At the heart of this claim is the recognition that property is a social institution whose legitimacy depends on serving broad societal goals. Reframed in this way and coupled with expropriation as a constitutionally sanctioned remedial tool, land acquisition for health care infrastructure becomes a decisive test of accountability. Doing so repositions expropriation not as an exception but as a necessary instrument of social repair and redistributive justice, particularly where historical dispossession and spatial apartheid have left deep scars in access to health care.

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Competing interests: None declared.

Introduction

The South African Constitution guarantees everyone the right to access health care services.[1] Yet millions residing in rural areas, peri-urban townships, and informal settlements face a starkly different reality.[2] This absence of health care stems not merely from underfunding or weak political will but from apartheid's enduring spatial legacies and a fragmented land governance system.[3]

The National Health Insurance Act, aimed at achieving universal health coverage, seeks to redress these inequalities but faces a sore point in mainstream policy discourse: Where will the clinics be built? Much of the well-located land is privately held, underutilized, or locked in speculation, thus obstructing state delivery and frustrating constitutional promises. This paper approaches the problem through the lens of accountability, a cardinal principle of human rights. Accountability refers to the "processes, norms, and structures … that demand power holders account for their decisions and actions and remedy failures in delivering their duties."[4] From this definition, three interlocking features emerge: monitoring, review against human rights standards, and remedial action. Applied to South Africa's health care infrastructure, this underscores two priorities: reviewing the property regime against other human rights, given that it entrenches exclusion and disregards the social function of land, and taking remedial action through expropriation to unlock well-located land for clinics. Within this framework, the Expropriation Act 13 of 2024 provides a crucial feature of accountability (remedial action), thereby enabling the state to fulfill its constitutional obligations under section 27 to provide health care services to everyone.

Since 1994, South Africa's broader land reform debates touched on a wide range of ideas—from full state custodianship of land to defending secure private property rights to accelerating redistribution through existing mechanisms—united by a shared goal of dismantling entrenched exclusion.[5] This paper addresses the specific issue of expropriation for health care infrastructure as a constitutionally grounded feature of accountability. We focus on the narrower category of "public purpose" land acquisition aimed at serving immediate government needs rather than the wider redistributive debates on "public interest" expropriations aimed at historical justice.[6]

This paper comprises three parts: (1) a presentation of our conceptual framework, which draws on South Africa's constitutional commitment to ensure access to health care, the spatial legacies that obstruct its realization, and the principle of accountability in human rights law as applied to health care infrastructure delivery; (2) an analysis of how property regimes and entrenched private interests impede equitable health care planning in South Africa; and (3) an evaluation of the Expropriation Act 13 of 2024 as a tool to fulfill the government's constitutional obligations under section 27. We conclude by positing that expropriation for health care infrastructure constitutes a necessary remedial measure to advance both health equity and constitutional transformation.

From constitutional right to concrete access

The right of access to health care services arguably lies at the center of human rights, and such access cannot be realized in the abstract. As Benjamin Meier observes, "health is essential for human rights flourishing and the exercise of all other rights."[7] General Comment 14 gives concrete content to this principle by defining meaningful access in terms of availability, accessibility, acceptability, and affordability.[8] Read in this light, the constitutional commitment under section 27 places a duty on the state to take reasonable measures, within its available resources, to progressively realize this right. Rights must be given effect in ways that transform lived realities, not remain abstract promises.[9] Etienne Mureinik has described South Africa's transition as a move from a "culture of authority" to a "culture of justification," where every exercise of public power must be defended with reasons rooted in constitutional principle.[10] This culture of justification demands that health rights be delivered not only in form but in substance.

Meeting this constitutional duty requires mechanisms of accountability capable of addressing and remedying the persistent barriers to access. Accountability in this context is not reducible to administrative efficiency; it requires the state to fulfill both its constitutional and international obligations in ways that dismantle structural and systemic obstacles to equity. Solomon Benatar and others show that health inequities in South Africa are structurally determined and demand systemic interventions to dismantle their deep roots.[11] Historical patterns of exclusion shaped by race, gender, disability, and geography continue to determine who has access to health care facilities and where they are located.[12] The success of South Africa's National Health Insurance (NHI), a health-financing reform aimed at ensuring equitable access to health care services, will depend not only on its vision of universal health coverage but on the state's ability to deliver infrastructure where it is most needed. Although the NHI's policy framework positions health care as a public good and a social entitlement, persistent spatial inequality exposes the limits of policy commitments.[13] Policy documents underpinning the NHI recognize that unless systemic barriers are resolved, universal health care coverage will remain illusory.[14] Accordingly, Paul Hunt emphasizes that accountability is a cardinal principle of the right to health care, requiring not just monitoring but effective remedies when obligations are not met.[15] His insight resonates directly where government commitments to equity lack the institutional follow-through.

The normative dimension of accountability can be sharpened by key theoretical insights. Derrick Brinkerhoff distinguishes between answerability—the obligation of state actors to justify how they fulfill health-related duties—and enforceability—the mechanisms through which failures to meet those duties can be corrected or sanctioned.[16] Sandra Liebenberg similarly argues that enforcing socioeconomic rights requires the promotion of substantive equality and the indivisibility of rights by dismantling patterns of disadvantage that cut across health, equality, and property rights.[17] Karl Klare's conception of transformative constitutionalism strengthens this line of argument, insisting that South African law, including property law, must be continually reoriented toward egalitarian outcomes.[18] Together, these scholars underscore that accountability should drive structural change, and not merely oversee government efficiency.

Institutional and operational features further refine this picture. Claudia Baez-Camargo distinguishes between a "long route" of accountability centered on mandates, resource allocation, oversight, and sanctions at the institutional level and a "short route" that centers on citizen engagement and frontline responsiveness.[19] In the South African context, expropriation represents the long-route mechanism, equipping institutions with the authority to secure land to park clinics, while the short-route option remains essential for communities to monitor delivery and demand remedial action when implementation falters. Lara Stemple, however, cautions that accountability often collapses into fragility when legal obligations carry no meaningful consequences for noncompliance.[20] This fragility is evident in South Africa, where the government repeatedly restates commitments to equity but fails to activate the institutional tools available at its disposal. Weaknesses in the long route such as the non-use of constitutional mechanisms like expropriation undermine the state's capacity to act decisively. What emerges is a layered picture of accountability in health operating simultaneously through legal enforcement, political oversight, administrative monitoring, and remedial action. Danwood Chirwa offers a way forward by suggesting that the right of access to health care services can be enforced both in its own terms and through other related constitutional rights such as the right to property.[21] This dual pathway underscores that by neglecting expropriation, the state effectively abdicates its accountability duty, allowing inequities in access to health care to persist.

In this light, expropriation emerges as a decisive test of accountability. It reveals whether the state is willing to deploy its full constitutional authority to dismantle structural barriers to health care. In this regard, property law serves as a structural determinant of health care, influencing who receives care and where facilities are located. To treat property as an individualistic entitlement ignores its social function and capacity in advancing the public good. Expropriation, in this sense, is not a departure from constitutionalism but an affirmation of it, realigning property relations with the substantive obligations that flow from the right to health care. Within this context, expropriation without compensation is a constitutionally sanctioned remedial tool to promote fairer land distribution and health infrastructure, making the right to health care meaningful.

Property law as a barrier and as a solution

Theoretical foundations: Property as a social function

In applying a property theory lens, we must understand property as a social function as opposed to an absolute entitlement.[22] Property rights are legal constructs that must operate within a constitutional order committed to equality, human dignity, and social justice.[23] In South Africa, where historical land patterns continue to shape present inequalities, we argue that property must serve not only the private interests of its holder but also the legitimate needs of the broader public.[24] In this context, the expropriation of abandoned, neglected, or underutilized properties, or those held solely for long-term speculative gain, becomes legally justifiable and normatively imperative.[25] Universal health care cannot be spatially realized if valuable land remains locked in private hands while urgent public needs go unmet. Property law must recognize the social obligations attached to ownership and permit the state to intervene where private holding undermines urgent public objectives.[26]

The principle that ownership carries obligations to the broader community is long-standing, although its articulation and practical implications have varied across jurisdictions and historical moments.[27] We draw on the contributions of Timothy Mulvaney, Joseph Singer, and Amanda Byer, which sharpen the social function theory of property in ways directly relevant to South Africa.[28] Each underscores the public responsibilities of ownership amid inequality, transformation, and urgent social need.[29] Jane Baron reinforces this by showing that property rights are embedded in social and political commitments, underscoring their democratic and redistributive role.[30] Together, these perspectives provide a dynamic framework for understanding property's social function in South Africa's constitutional order.

Mulvaney views property as a relational and socially rooted institution, rejecting the classical liberal view of property as an unalienable domain of personal autonomy.[31] Accordingly, property rights depend on changing moral, environmental, and democratic imperatives rather than being fixed or absolute.[32] He argues that legitimate expectations in property must adapt to reflect the broader public interest, thus supporting state interventions where private property impedes access to essential services.[33] Singer frames property as a mechanism of governance, arguing that ownership must be evaluated through democratic principles such as equality, inclusion, and human dignity since it dictates access to essential resources such as housing and health care.[34] In doing so, Singer highlights the need for property law to set affirmative obligations in order to promote social justice rather than limit itself to safeguarding negative liberties.[35] In his co-authored work with Mulvaney, they argue that redistributive state interventions, including expropriation, are sometimes necessary to prevent property law from functioning as a barrier to social justice.[36]

Byer offers a cautionary perspective.[37] Drawing on legal geography, she reminds us that land was once viewed as relational space tied to kinship and ecology before being reduced to an abstract good.[38] The transition to abstract, market-oriented ownership has obscured these relational features and dislocated property from community and purpose.[39] Byer warns that vague doctrinal formulations risk becoming instruments of political discretion if not grounded in clear legal standards and procedural safeguards.[40]

Together, these theorists affirm that property carries social obligations, that state intervention may be necessary to realize rights, and that safeguards are critical to ensure legitimacy. In doing so, they establish a principled foundation for expropriation as a constitutional remedy to secure land for health infrastructure.

Convergences and tensions: Critical analysis

While each of these theorists approaches the social function of property differently, their insights converge around a common theme: ownership cannot be treated as absolute when it entrenches inequality or obstructs urgent public needs.[41] Mulvaney offers the most normatively expansive contribution by reimagining property as a responsive and evolving institution, grounded in shifting societal values rather than fixed entitlements.[42] He rejects the classical liberal framing of property as a zone of personal autonomy insulated from public claims and insists that property expectations must adapt to broader moral, democratic, and environmental imperatives.[43] This approach is compelling in contexts such as South Africa, where deeply entrenched ownership patterns obstruct equitable development.[44] Yet Mulvaney's reliance on judicial reasoning as the primary mechanism for effecting reform assumes a judiciary both willing and able to engage with evolving social norms, an expectation that may be unrealistic in legal cultures where the judiciary remains cautious, formalist, or institutionally constrained.[45] In South Africa, the legacy of apartheid-era formalism still exerts a powerful influence on legal reasoning and risks rendering Mulvaney's model normatively rich but practically inert.[46] Moreover, by offering little guidance on the role of legislatures or administrative bodies in reforming a property regime, his framework lacks a clear division of labor between institutions, an omission that weakens its applicability in transitional contexts requiring coordinated, multilevel interventions.[47]

Singer complements Mulvaney's approach by offering a more pragmatic and institutionally grounded vision of property reform.[48] Singer also rejects the idea of property as a purely private right and instead frames it as a form of governance with distributive consequences.[49] His work insists that legal entitlements be measured not merely by their formal validity but by their substantive effects on access to opportunity and the social conditions for flourishing.[50] Importantly, Singer shifts the emphasis from judicial interpretation to legislative responsibility.[51] He advocates for democratic processes that embed redistributive principles into the design of property systems.[52] In doing so, he charts a more politically legitimate path to reform, one that places obligations squarely on the shoulders of lawmakers rather than leaving reform to the incrementalism of courts.[53] While Singer advances a powerful normative vision of property rooted in justice and democracy, his work often stops short of proposing concrete institutional frameworks. This is particularly important in contexts such as South Africa, where fiscal constraints, administrative fragility, and political volatility complicate redistributive reform.[54]

Byer offers a critical intervention by shifting the conversation from abstract theory to grounded institutional realities.[55] She exposes how modern legal systems have displaced community-based, relational forms of land tenure with abstract, commodified ownership regimes.[56] This transformation, she argues, has eroded the social and ecological embeddedness of property, leaving it exposed to bureaucratic overreach and deepening public mistrust.[57] Byer warns that vague invocations of the social function of property without precise legal standards and procedural safeguards risk becoming instruments of political opportunism or legal incoherence.[58] In South Africa, where land reform efforts have often faltered due to administrative fragmentation, legal ambiguity, and elite capture, her caution is highly relevant.[59] Yet Byer's emphasis on institutional clarity and procedural safeguards, while crucial, risks underestimating the urgency of reform in societies where property continues to reproduce deep structural inequality.[60]

Together, the authors highlight the promise and the limits of the social function approach. Mulvaney underscores the need for property law to evolve with shifting moral and democratic imperatives, Singer grounds this duty in democratic governance and affirmative state obligations, while Byer cautions against vague formulations that risk abuse without procedural safeguards. In South Africa, their insights affirm that property law cannot afford to be merely a system of private entitlements. It must operate as a vehicle for redistribution, spatial justice, and social inclusion.[61]

Why expropriation without compensation is on the table

South Africa's democratic government committed to redressing the injustices of apartheid through a constitutionally grounded land reform program built on three pillars: restitution, redistribution, and tenure security.[62] The 2017 Land Audit highlights this imbalance, revealing that approximately 76% of land is privately owned, with over 30% concentrated in the hands of corporate entities and trusts, much of it underutilized or held for speculative purposes.[63] While debates on racial patterns in land ownership, financial mismanagement, and administrative dysfunction persist, our focus here is on the structural divide between state and private landholding and how it obstructs access to well-located sites for public infrastructure development.[64] The spatial reality is that much of South Africa's privately owned land lies in strategically important areas where infrastructure demand is highest and health care most limited.[65] To meet its constitutional obligations, the state must engage with or intervene in these holdings.[66] By contrast, most state-owned land lies in protected areas or former homelands, far from service demand. This misalignment creates a paradox: the land most accessible to the state is spatially irrelevant, while the land that is most needed remains locked in private hands.[67] This paradox is reinforced by inflated, market-driven compensation demands that entrench inequality by privileging profit over public welfare.[68]

As one of the most unequal societies in the world, South Africa's developmental trajectory is still shaped by the enduring legacies of apartheid and colonial exclusion.[69] Entire communities were forcibly removed from well-located urban areas to peripheral areas, depriving them of infrastructure and opportunity.[70] The black majority was systematically disempowered, denied quality education and health care, and subjected to a coercive migrant labor system that fractured families and entrenched economic vulnerability.[71] Housing and health policies actively reinforced this marginalization. The Public Health Act 36 of 1919 enabled the removal of black residents from urban centers under the guise of disease control, embedding segregation into the fabric of public health.[72] This logic was further entrenched through the Housing Act 35 of 1920, which facilitated racially segregated housing on urban peripheries.[73] Together, these measures produced a dual urban system whose legacy continues to shape exclusion today, underscoring that any strategy for health infrastructure must confront both material shortages and the institutional patterns inherited from this history.[74]

The principle that the state may expropriate land for public purpose within a clearly defined constitutional framework is neither novel nor exceptional. As early as the 17th century, jurists such as Hugo Grotius and Samuel von Pufendorf affirmed that private property rights are not absolute and can be constrained when necessary to advance public good.[75] Modern democracies have operationalized this idea; in the United States, for example, the doctrine of eminent domain is treated as essential to sovereignty and enables land acquisition for public use.[76]

In South Africa, however, the legitimacy of expropriation cannot be grounded solely in comparative traditions. Its normative foundation is also rooted in Indigenous jurisprudence, where precolonial land systems conceived of property not as individual entitlement but as communal stewardship.[77] Land was treated as a shared resource, governed by collective obligations to the community—a perspective reflected in Ubuntu, which emphasizes interdependence, human dignity, and equality.[78] From this perspective, repurposing land for the public good is not something novel; it is intrinsic to African legal and moral values.[79] Read alongside the global doctrine of eminent domain, these traditions provide a coherent basis for expropriation for public purpose in South Africa. For accountability to be meaningful in post-apartheid South Africa, it must fundamentally reconsider prevailing property norms.[80] This demands shifting from private individualistic ownership paradigms to a conception of property grounded in social function and public responsibility.[81] Properly exercised within constitutional safeguards, property's social function affirms rather than undermines democratic principle, recognizing that property rights, while protected, are not absolute and may yield to equity and the collective good.[82]

Expropriation Act 2024 versus 1975: Between symbolism and substance

The Expropriation Act 63 of 1975 (hereinafter referred to as the 1975 Act) reflected an apartheid-era order in which administrative discretion was both formally broad and substantively unchecked. The 1975 Act granted the state unrestrained authority to expropriate land for "public purpose," a term undefined and interpreted loosely, with judicial review limited to minimal rationality tests.[83] Compensation was tethered almost exclusively to market value, with limited scope to consider whether the amount was just or fair in light of broader equity considerations. Although property rights were formally preserved, in practice they were hollowed out by race-based statutory exclusions.[84]

By contrast, the Expropriation Act 13 of 2024 (hereinafter referred to as the 2024 Act) repeals the 1975 Act and repositions expropriation within the post-1996 constitutional framework.[85] It authorizes expropriation only for a public purpose or in the public interest and requires compensation to be just and equitable, balancing private interests with the broader public good.[86] These principles are operationalized through detailed procedures and a compensatory scheme that deliberately moves beyond the narrow market-value standard of its predecessor, enabling a more context-sensitive and constitutionally defensible approach.[87] Despite its normative fidelity to the constitutional text and values, the 2024 Act has generated considerable public anxiety and political resistance.[88] Much of this concern stems less from the 2024 Act's actual provisions (or any other redistribution effort in the past) than from the symbolic weight of land reform in South Africa's historical and political imagination.[89] Among historically advantaged groups, the 2024 Act is often perceived as a retributive economic instrument targeting otherwise blameless property holders in the name of historical redress.[90] While such perceptions are not without political significance, a closer reading shows that the 2024 Act strengthens, rather than weakens, property rights by introducing robust procedural safeguards and clear limits on expropriation, including a narrowly framed nil compensation clause.

The 2024 Act limits nil compensation to defined circumstances, such as abandoned land, property held purely for speculation, and land improved through state investment, targeting specific situations where paying market value would entrench inequality and frustrate public obligations.[91] Before assessing the 2024 Act's constitutional defensibility, it is necessary to analyze the act's substantive and procedural framework and compare it with its 1975 predecessor. Such an analysis clarifies what the current legal framework permits, dispels misconceptions, and identifies the legal safeguards governing its application to ensure compliance with the constitutional principles of property, administrative justice, and the rule of law.

Section 23 of the 2024 Act affirms that where the expropriating authority and the property holder do not agree on the amount of compensation to be paid, either may approach a court for a determination of what is just and equitable.[92] Courts are not limited to assessing the numerical value of the compensation; they must also weigh proportionality, fairness, and public interest as required by section 25(3) of the Constitution.[93] However, the 2024 Act stops short of requiring judicial review of the legality of the expropriation itself unless such a challenge is independently launched. Moreover, section 23(4) of the 2024 Act clarifies that the lodging of such an application does not suspend the expropriation or its effective date, meaning that the state acquisition of property may proceed before compensation disputes are resolved.[94] While this sequencing ensures administrative continuity, it raises constitutional concerns about whether dispossession without compensation can be reconciled with the imperative that expropriation be just and equitable at the time it occurs, as required by section 25(2)(b) of the Constitution.

The 2024 Act creates a dual-level system of constitutional review. First, the decision to expropriate must satisfy the administrative law standard of rationality, requiring only that it serve a lawful and non-arbitrary purpose.[95] Once that threshold is satisfied, the inquiry shifts to compensation, where section 25(3) of the Constitution demands that the compensation be just and equitable. This triggers a proportionality inquiry in which the court must assess whether the public interest invoked justifies the amount awarded and whether a fair balance has been struck between public purpose and private loss.[96] This proportionality-based test ensures that even when pursuing legitimate public goals, the state does not impose disproportionate burdens on individual rights.[97]

The effect is that while expropriation itself may satisfy the low threshold of rationality, the compensation awarded, particularly in cases of nil or below-market valuation, invites deeper judicial scrutiny of its substantive justifications. Proportionality enters the legal analysis indirectly, through the assessment of compensation rather than the legality of expropriation itself. At the same time, the 2024 Act collapses two distinct constitutional objectives—immediate infrastructure provision (public purpose) and longer-term land reform (public interest)—without drawing clear distinctions between them.[98] These two concepts, although both included in section 25 of the Constitution, differ significantly in their legal structure, policy rationale, and temporal implementation.[99] This conflation, while it satisfies constitutional requirements of procedural fairness and just and equitable compensation under section 25(2)–(3) of the Constitution, means that expropriation's capacity to deliver transformative outcomes is uncertain. Without clearer institutional architecture and policy guidance, expropriation risks being justified in overly broad terms, making it harder for courts and communities to hold the state accountable or to test whether actions genuinely advance urgent needs such as health care or the goals of redistribution.[100]

The 2024 Act also sees a fundamental departure from the institutional logic of its 1975 predecessor by centralizing all expropriation authority in the minister of public works and infrastructure.[101] By contrast, the 1975 Act permitted various public bodies, including universities and energy boards, to request that the minister of public works expropriate property on their behalf, provided that the request aligned with their statutory mandates.[102] This mechanism preserved the principle that expropriation decisions should be grounded in subject-matter expertise, allowing policy-competent departments to initiate action even if execution rested with a central authority. The 2024 Act contains no equivalent provision. It eliminates this conduit entirely, vesting expropriation power solely in the minister of public works. Land reform, for example, governed by section 25(5)–(8) of the Constitution, falls within the mandate of the minister of land reform and rural development.[103] Yet the 2024 Act empowers the minister of public works to expropriate land on grounds of "public interest," a formulation that includes land reform.[104] This creates a structural misalignment: authority is centralized in a minister lacking policy responsibility, while the department responsible for redistribution has no control over the expropriation itself.[105] The result is a breakdown in accountability, with no single actor responsible; this enables institutional evasion, weakens oversight, and frustrates both legal scrutiny and democratic accountability. Affected communities are left without a clear recourse.

Conclusion

Although land reform is a foundational element of South Africa's post-apartheid constitutional order, the country still lacks a comprehensive statute to give full effect to the right of equitable access to land. In this vacuum, the 2024 Act has inadvertently become the most visible instrument for both spatial development and redress. Yet the act blurs the distinction between expropriations for infrastructure (public purpose) and those aimed at redistribution (public interest), creating conceptual and institutional uncertainty.

In the context of the NHI, the need for spatially accessible health care infrastructure cannot be overstated. Urban and peri-urban lands held for speculation or private development are obstructing the state's ability to deliver equitable health care. South Africa's enduring accountability gap lies not in the absence of legal tools but in their underuse. When ownership obstructs health care equity and entrenches exclusion, the state must act not in defiance of rights, but in fulfillment of them.

Against this backdrop, this paper has argued that expropriation for NHI infrastructure is not merely an act of land redistribution—it is a crucial feature of accountability within the constitutional framework. Viewed through the accountability framework, the Expropriation Act embodies the remedial action feature by enabling the state to correct spatial inequities in access to health care. That is, it responds to the monitoring of spatial health care disparities, reviews property standards that privilege speculative land holding over need, and provides remedial action by securing land to park the clinics. Properly exercised, expropriation without compensation is not a circumvention of rights but a mechanism through which constitutional commitments to equality, human dignity, and health care are made tangible.

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Temporal Accountability and Taiwan's National Health Insurance System

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Abstract

Accountability is central to human rights, yet it has varied interpretations across contexts. Conventionally, accountability denotes blame and punishment or emphasizes hierarchical relationships between claim holders and duty bearers. However, accountability cannot be an episodic event. In health governance, continuous and iterative improvements are required to reflect changing social, economic, and political circumstances. Accordingly, we define "temporal accountability" as an institutional design that incorporates time-bound obligations for implementing corrective actions and remedial measures. Through a case study of Taiwan's Constitutional Court decision on expatriate residents' financial contributions, we analyze temporal accountability in action and draw broader lessons for human rights accountability, proposing measurable indicators and guiding principles of temporal accountability.

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Competing interests: None declared.

Introduction

Universal health coverage is a cornerstone of the right to health, positioning health systems as foundational social institutions that drive equality of opportunity.[1] Accountability—central to democracy and human rights—is often equated with political responsibility and, conventionally, with blame or punishment.[2] However, in practice, liberal democracies do not automatically guarantee this form of accountability, nor do missteps always yield political consequences. Understanding how accountability manifests within democratic contexts requires close examination of the dynamic interactions among institutional actors such as courts, parliaments, executives, civil society organizations, the public, the media, and human rights commissions. These interactions collectively shape access to health care and undergird the financial sustainability and fairness of health systems.

Through a case study on Taiwan, this paper contributes to the global dialogue on accountability, drawing generalizable lessons for creating sustainable and equitable health systems. Specifically, we examine how decisions about fair health financing evolve over time in response to changing societal needs and economic circumstances, capturing the operations of accountability mechanisms in practice as societies work to ensure that health financing arrangements remain both equitable and sustainable.

Accountability is a critical feature of health rights and yet it has various conceptualizations. Judicial accountability, for instance, focuses on legality and due process—emphasizing review mechanisms and remedies for individuals and communities who have been unlawfully harmed. As discussed in the next section, accountability relationships can be further classified as horizontal or vertical. Building on these frameworks, we identify temporal accountability as an important yet often overlooked dimension in health governance. This lens captures how institutional actors interact to address financial sustainability and fairness in health systems as social, economic, and political circumstances evolve over time.

Accordingly, we define "temporal accountability" as an institutional design that builds time-bound obligations for review, disclosure, and corrective action into the accountability cycle. Our approach builds on human rights accountability, which consists of three components: monitoring, reviewing, and remedial action.[3] We regard accountability as a continuous process that includes monitoring and iterative improvements through adapting policies to reflect evolving social, political, and economic realities. This understanding of accountability relies on institutional interactions—both formal and informal—and allows for assessing how states uphold health care-related human rights obligations. As we demonstrate, improvements occur iteratively, shaped by the perspectives and actions of diverse institutional actors.

We situate the discussion within liberal democracies, recognizing that health systems differ significantly across countries. Democratic deliberation is conventionally believed to serve as a vehicle for meeting health needs fairly in a democracy. In democracies, political disagreements can reveal different values, perspectives, and interests that are negotiated and interrogated to arrive at commonly acceptable—and therefore (arguably) equitable—outcomes.[4] However, majoritarian decision-making may not adequately consider minority groups' health needs or address the specific circumstances of vulnerable populations. Moreover, countries with well-functioning health systems increasingly face challenges of financial sustainability due to demographic shifts and changing economic circumstances. Balancing sustainable health financing fairly in the face of these evolving pressures is a considerable challenge that requires accountability mechanisms capable of adapting over time.

To explore how accountability mechanisms address this challenge in practice, we examine Taiwan's experience. We conduct a doctrinal analysis of the Constitutional Court decision *111-Hsien-Pan-19*, issued in 2022, and the National Health Insurance Act and its Enforcement Rules. We triangulate this with National Health Insurance Administration (NHIA) administrative notices, legislative records between 1996 and 2024, and major media coverage on policy changes. Tracing processes, we map the sequence of interactions among judicial, legislative, executive, and the public and link each to policy adjustments. We also descriptively summarize utilization and fiscal data from the media and NHIA, calculated at US$1 = NT$32 as of July 2025. Because available NHIA datasets are impartial, we relied on figures released by the NHIA and legislative comments. Since we did not conduct interviews because of resource constraints, our findings should be interpreted as a theory-building case analysis rather than causal inference.

This study relies on administrative and legal documents and publicly reported data to identify the interactions among various accountability mechanisms. The fiscal figures contained in this paper are descriptive rather explanatory accounts of decision-making processes.

The paper proceeds as follows: The first section outlines the accountability framework that guides our analysis of Taiwan's case. The second section provides background on the Constitutional Court's landmark ruling and examines its broader policy implications. The third section evaluates how our case study aligns with temporal accountability principles. The paper closes with a conclusion.

Accountability

Conceptualizing accountability in health systems

There are several conceptualizations of accountability. Accountability is commonly understood as a relational concept, characterized by either vertical or horizontal relationships.[5] Vertical accountability refers to the relationship between rights holders and those in formal positions of authority.[6] Horizontal accountability refers to relationships among state actors with formal responsibilities to provide explanations.[7]

Within health systems specifically, accountability takes on heightened importance as financial constraints intensify. Resilience-focused health systems emphasize responding efficiently to external shocks but do not necessarily prioritize fair outcomes.[8] Improving health systems focus on generating and applying evidence to improve health care delivery and reduce inequalities in health access yet often do so without stakeholder participation.[9]

From a human rights perspective, accountability represents "the formal and informal processes, norms, and structures, particularly in a democratic system that demands power holders or people in authority account for their decisions and actions and remedy and failures in delivering their duties."[10] While accountability is central to human rights, it can become invisible or marginal, deceptively familiar yet with various conceptualizations across different contexts.[11] Conventionally seen as blame and punishment, accountability can serve as a form of deterrence, paradoxically preventing governments from taking action in liberal democracies because of immediate political consequences or perceived administrative burdens.

However, Paul Hunt, former Special Rapporteur on the right to health, advocates for a broader view: accountability as a process in which successful practices are identified and ineffective ones are adjusted.[12] This constructive approach emphasizes ongoing monitoring, systematic evaluation, and continuous iterative improvement of health systems and policies.[13] This broader view of accountability moves beyond notions of fault-finding and focuses instead on transparent mechanisms that allow stakeholders to track progress, identify shortcomings, and make necessary adjustments to ensure that reasonable balances between competing interests are fairly achieved and maintained over time. Importantly, this conceptualization recognizes accountability as an ongoing institutional process essential to rights-based health care governance.

This conceptualization draws from Lynn Freedman's constructive and relational accountability. As Freedman puts it, constructive accountability "is about developing a dynamic of entitlement and obligation between people and their government and within the complex system of relationships that form the wider health system, public and private."[14] In a health system, relationships between stakeholders matter. They form the foundation of shared responsibility for ensuring health system functioning.

The Committee on Economic, Social and Cultural Rights' General Comment 14—which provides an authoritative and comprehensive interpretation on the right to health—establishes and articulates an AAAQ framework that encompasses availability, accessibility, acceptability, and quality, along with the cross-cutting principles of nondiscrimination, participation, transparency, and accountability.[15] These principles form the basis through which states are expected to respect, protect, and progressively fulfill their human rights obligations in the health domain.

Human rights accountability provides a valuable framework for advancing the various elements of health systems, including health equity, through a rights-based approach. This framework is particularly important because, as Lawrence Gostin observes, "The right to health would be all but meaningless without a powerful focus on equity. If governments had to ensure rights only for some but not for all, then the most marginalized and disadvantaged—the people who depend most on the right to health—would be left behind."[16] To that end, universal health coverage serves as an expression of the right to health with equity at the center. This equity-centered design is essential for ensuring that all members of society contribute according to their financial capacity while receiving care according to their needs.

While universal health coverage gives expression to the right to health, operationalizing it can be challenging. As Lisa Forman observes, "Rights are inherently indeterminate, and their application to various problems must be worked afresh in contexts that textual formulations are likely to address only abstractly."[17] This captures a key challenge in human rights: translating abstract principles into concrete action. In addition, health care governance must continuously adapt through regular review cycles—balancing competing values, responding to changing circumstances, incorporating stakeholder input, and establishing clear triggers for policy adjustments.

Temporal accountability

Temporal accountability addresses this challenge by contextualizing rights within specific circumstances and time frames, transforming abstract formulations into actionable steps that can be implemented, monitored, and adjusted. By embedding accountability mechanisms within defined time frames, it ensures that rights function as living principles—adapting to evolving contexts while maintaining normative force—rather than remaining aspirational statements. This approach recognizes that realizing rights requires ongoing cycles of evaluation, adjustment, and refinement, not episodic legislative or judicial acts.

Building on this foundation and recognizing that various meanings and concepts exist for accountability, we define "temporal accountability" as an institutional design that builds time-bound obligations for review, disclosure, and corrective action into the accountability cycle.[18] This process flows from courts to the legislature, the executive, civil society organizations, the public, and the media, and then back as feedback, transforming accountability from episodic "score-keeping" into an iterative process with mandated pacing. Unlike horizontal accountability that focuses on who holds whom to account, temporal accountability specifies when and how often actors must evaluate evidence, review, and adjust. We advance the temporal dimension of accountability to underscore how changes occur incrementally as societies attempt to solve complex social problems such as fair health financing in universal health coverage, rather than through sudden, dramatic shifts in response to evolving social and political climates.

Temporal accountability provides an analytic framework that expands on Freedman's understanding of accountability as going beyond the conventional focus on relationships between actors and builds on Hunt's broader perspective of accountability as more than blame and punishment. The temporal dimension matters because it reveals how accountability unfolds over time—or fails to—including when and how often actors must review, disclose, and correct their actions. This approach examines both scope (who is involved and what is covered) and timing (at what intervals or critical moments scrutiny occurs). It ensures that institutional mechanisms address ongoing challenges through sustained attention and iterative responses. In relation to contentious issues, such as health financing for universal health coverage, temporal accountability keeps relevant authorities answerable, continually adapting as circumstances evolve and new data emerge. This approach maintains transparency and responsiveness in managing complex health issues, reflecting the notion that fairness depends on socioeconomic context and the passage of time.

As we demonstrate in the third section, accountability emerges from overlapping institutional oversight, with continuous adjustments yielding responsive outcomes. However, its effectiveness depends on the quality and inclusivity of institutional interactions. We propose indicators to track progress, such as indicators for statutory deadlines, reporting frequency, disaggregated health care data, transparency, public participation, and legislative review.[19]

Case study

Ensuring a sustainable public health care system necessitates stable, reliable funding from all financially able participants. Yet in Taiwan, there is substantial debate among institutional actors concerning whether expatriates should be required to contribute to health premiums while living abroad. This debate does more than highlight differing perspectives—it is part of a complex web of accountability that fosters iterative improvement and aligns health policy with public expectations.

To understand how these accountability mechanisms work in practice, we examine a Taiwanese Constitutional Court case centering on a contentious health insurance policy known as the suspend-and-resume scheme. (See Table 1 for a chronological overview of the scheme.) This now-defunct scheme exempted long-term overseas residents from mandatory premium payments while abroad but reinstated these obligations upon their return—regardless of how long they stayed or whether they had alternative insurance coverage. This arrangement raised critical questions about fairness, equality, autonomy, and property rights. The exemption applied only to expatriates, creating unfairness for residents in Taiwan. Yet expatriates required to pay health premiums upon returning home also viewed the scheme as unfair. As we demonstrate below, fairness in health care emerges as both a relational and relative concept, highly dependent on one's position within the system—underscoring the importance of accountability.

Prior to discussing the Constitutional Court case, we provide some background on Taiwan's National Health Insurance (NHI) system, which

Table 1. Chronology of the suspend-and-resume scheme

Date	Actor(s)	Action(s)
August 9, 1994	Executive	National Health Insurance Act promulgated by the President's Order of Hua Chung (1) Yi Tze No. 4705
January 28, 1995	National Health Insurance Administration (Ministry of Health and Welfare)	Promulgation of the Enforcement Rules of the National Health Insurance Act, which included the suspend-and-resume scheme
November 18, 1999	National Health Insurance Administration (Ministry of Health and Welfare)	Revisions to the National Health Insurance Act; suspend-and-resume scheme remained intact
December 23, 2022	Constitutional Court	Judgment 111-Hsien-Pan-19 on the constitutionality of the suspend-and-resume scheme
December 23, 2022–December 23, 2024	Legislative Yuan	No proposed amendments to promulgate the suspend-and-resume scheme
December 23, 2022–December 23, 2024	Media	Reporting on expatriates' abuse of the suspend-and-resume scheme
December 21, 2024	National Health Insurance Administration (Ministry of Health and Welfare)	Termination of the suspend-and-resume scheme in accordance with Ministry of Health and Welfare Order Wei-Pu-Pao-Tzu No. 1131260719

illuminates how health policy reflects political choices.

Taiwan's National Health Insurance system

Taiwan introduced its NHI system in 1995, replacing fragmented programs that covered less than 60% of the population. Now mandatory for nearly all residents, NHI covers 99% of people and includes almost all hospitals, most clinics, and a majority of pharmacies. The NHIA oversees this single-payer, state-run program. NHI offers broad coverage, including preventive, curative, dental, maternity, and elderly care, as well as traditional Chinese medicine. The average monthly premium is US$42 (5.17% of monthly income), less than South Korea (7%) and Japan (10%), both of which have similar systems.[20] Low-income households are exempt, while others pay 30%–100% of premiums based on occupation and income.[21]

Despite the efficient and wide coverage of the NHI system, financial challenges and long-term sustainability concerns threaten its continued operational viability.[22] Any proposed increases to health insurance premiums must receive formal approval from the Legislative Yuan (Parliament), a process that encounters significant political resistance due to the widespread unpopularity of premium increases among voters. While raising health premiums is essential for ensuring the financial stability and continued functioning of the insurance system, such proposals inevitably remain politically contentious and emotionally charged issues.[23] These tensions reflect deeper questions about how Taiwan's democratic institutions balance the technical requirements of a sustainable health system with the political realities of democratic governance—questions that become clearer when examining the NHI system's historical role in Taiwan's political and economic development.

NHI system and democratization

In Taiwan, the national health system has played a crucial role in supporting the country's democratization process and economic development.[24] Because health is recognized for its instrumental value—good health is a precondition for economic prosperity—the relationship between health and economic prosperity is particularly evident in Taiwan.[25] The NHI system has supported the country's workforce through major economic transitions as Taiwan has evolved from an agricultural-based economy to a global hub of semiconductor manufacturing.[26] Similarly, the NHI system has facilitated the construction of a national identity and the cultivation of a sense of social solidarity during health crises, in particular during the COVID-19 pandemic.[27] The efficient health system has become a source of national pride, and its affordability and accessibility have enhanced the visibility of Taiwan's global health diplomacy efforts.[28]

Taiwan's national identity is shaped by its history and politics, with the NHI system central to building modern Taiwanese national consciousness. When Taiwan was under authoritarian rule, state health coverage mainly supported elites, leaving most citizens without adequate care. Former president Lee Teng-Hui, who oversaw the end of martial law, expanded health care access as part of the democratization process, leading to the 1995 National Health Insurance Act that guaranteed universal coverage. This strengthened both democracy and equality, ensuring universal access to affordable health care and enabling greater civic participation.

In addition, because health carries special moral significance due to its direct influence on individuals' life opportunities, decisions regarding health care resource allocation have become matters of substantial public interest and have invoked intense societal debate in the country.[29] Thus, when the suspend-and-resume scheme was in effect, allowing Taiwanese citizens residing in China to return specifically to access health care resources—particularly amid increasing geopolitical tensions between Taiwan and China—it triggered widespread public outrage, prompting serious questions about fairness, equity, and shared responsibility in maintaining and sustaining the national insurance system.[30]

Expatriates' health premiums exemption

While the National Health Insurance Act requires universal participation, the Enforcement Rules of the National Health Insurance Act (Enforcement Rules)—the accompanying administrative rules governing the implementation of the NHI—established a suspend-and-resume mechanism for Taiwanese citizens who lived overseas for more than six months.[31] This scheme allowed individuals to pause their health premium payments while abroad, benefiting approximately 210,000 Taiwanese living overseas.[32]

The suspend-and-resume mechanism originated under Taiwan's authoritarian regime to benefit specific groups, including retired civil servants who had moved to the United States, by exempting them from ongoing premium contributions.[33] After democratization, the Enforcement Rules allowed ordinary citizens residing overseas for more than six months to suspend coverage and resume immediately upon return by paying three months of premiums. Those abroad for more than two years faced automatic suspension, along with a six-month waiting period and payment requirement.[34] NHIA data showed steadily increasing use by overseas residents, particularly for elective surgeries.[35]

Landmark Constitutional Court decision

While scholars had long criticized the suspend-and-resume scheme for violating equal protection, the Constitutional Court did not address it until 2022. The plaintiff in the case, a long-term resident of Japan, challenged the US$70 health premium requirement during her annual visits home, arguing that it violated her property rights, self-determination, and equal protection under the Constitution.

The court ruled that mandatory participation in the NHI system falls within the government's social welfare responsibility.[36] However, it determined that such a policy must be enacted through Parliament, not solely by the NHIA, recognizing legislative scrutiny as essential for important health care decisions. In this regard, the ruling examined the constitutionality of articles 37(1) and 39 of the Enforcement Rules.

First, the Constitutional Court ruled that the suspend-and-resume scheme was unconstitutional because it had been adopted by way of an administrative ruling, basing its determination on the doctrine of *Gesetzesvorbehalt* (the principle that the authority to regulate must be grounded in statute for rights-relevant matters). This doctrine checks government power by requiring that significant decisions affecting citizens' rights pass through the legislature, thereby establishing *Gesetzesvorbehalt* as a baseline for accountability in health care matters.

Second, the Constitutional Court reviewed the suspension mechanism using three principles enshrined in the R. O. C. Constitution: equal protection (article 7), property rights (article 15), and the right to self-determination in health risk management (article 22). By introducing the concept of self-determination in health risks, the court highlighted the constitutional significance of health care and justified delegating related decisions to Parliament, enhancing accountability in Taiwan's health care governance.

The court's focus on the separation of powers highlighted the importance of accountability in health care governance by affirming that decisions affecting health care access are constitutional matters requiring democratic discussion. This intervention advanced Taiwan's constitutional law by mandating legislative debate and public scrutiny for health care rights, emphasizing that these rights involve both personal and collective responsibilities best addressed through public discourse. While the court ruled that the scheme was unconstitutional on procedural grounds because it was promulgated by an administrative agency lacking the necessary authority, the court found the substance of the scheme constitutional. It determined that requiring expatriates to contribute health premiums upon returning to Taiwan violated no protected fundamental rights.

Significantly, by requiring formal legislation on issues that affect citizens' health decisions, property rights, and health care resource distribution, the court elevated health matters into the realm of public consciousness and democratic discourse. The court also noted that compulsory health insurance promotes equality, where questions regarding fairness and nondiscrimination require parliamentary debate and oversight. Citing *Gesetzesvorbehalt,* the Constitutional Court set a two-year deadline for parliamentary debate to ensure democratic oversight of the scheme.

While the court did not specify which fundamental right underlies self-determination in managing health risks, this right connects to the broader right to health in international human rights law. Taiwan has voluntarily incorporated international human rights treaties into domestic law, providing an analytical framework to clarify this relationship: self-determination means personal autonomy over health care decisions, while the right to health covers wider legal claims, including social factors affecting health.

In our view, expanding the focus from self-determination to comprehensive health rights offers key normative advantages. First, it would clarify the contours of the right to health in Taiwan by recognizing that its realization depends on both government action and collective societal efforts. Second, since the right to health encompasses a legal entitlement to a functional health system—including sustainable health financing, equitable resource use, and a functional health care workforce—this broader interpretation would illuminate equality and nondiscrimination. It expands beyond self-determination and property rights to include the societal dimension of eliminating avoidable health inequalities.

This interpretation aligns with international standards, which understand the right to health as extending beyond medical care to include social factors such as better working conditions for health care professionals, strong government leadership, and oversight by human rights commissions. Although the Constitutional Court found that the suspend-and-resume scheme did not violate the right to self-determination under article 22 of the Constitution, the decision raises important questions about the broader right to participate in health policy development—a participatory right formally recognized in the Declaration of Alma Ata.[37]

Institutional interactions

Following the Constitutional Court ruling, the executive branch chose not to submit the suspend-and-resume scheme to Parliament.[38] The NHIA ended the scheme on December 23, 2024—the same day as the court's deadline—mainly due to financial sustainability, not human rights.

Although controversial, the scheme had persisted for nearly 30 years due to protective institutional barriers. When the court framed health care access as a constitutional issue, it permitted new legislative and executive actions. The NHIA's choice to terminate rather than amend the scheme addressed domestic and overseas residents' unequal treatment but bypassed the democratic process the court intended.

However, the legislature took no action after the court's ruling, despite having the authority to formally implement the scheme. Strong public opposition and fears of resource exploitation deterred parliamentarians. Even now, Parliament could promulgate the scheme, although involving legislators in health care decisions risks majoritarian outcomes that may overlook minority interests.

Temporal accountability and the suspend-and-resume scheme

This case study demonstrates how accountability emerges through interactions among the judiciary, legislature, and executive—each operating within distinct mandates yet forming an adaptive framework responsive to evolving societal expectations.

AAAQ analysis

Drawing from the international right to health as set out in General Comment 14, we examine some of the health rights features of the suspend-and-resume mechanism.[39]

Availability. Adequate health care availability depends on sufficient facilities, resources, and personnel. Taiwan's suspend-and-resume mechanism in the NHI system raised concerns about the ability to maintain service levels, though its financial impact was minimal (1.18% of annual revenue).[40]

Ending the scheme signaled a commitment to fairness and sustainable funding, but operational constraints—especially staff shortages and burnout—remain. Increased demand, such as returning overseas residents needing care, adds further strain. Ensuring both the financial and operational sustainability is vital for ongoing adequate health care access.

Accessibility. Accessibility consists of four dimensions: nondiscrimination, physical access, economic access, and information access. The suspend-and-resume mechanism led to discriminatory patterns, allowing overseas residents to pause payments but keep benefits, while domestic residents had to pay continuously. This created a two-tiered system privileging those abroad and undermining economic accessibility, as some could avoid supporting Taiwan's health care costs yet still use affordable services—resulting in moral hazard, especially for costly elective procedures. Although NHIA shared data on overseas usage to inform discussion, this information lacked details on the scheme's impact on marginalized groups, which is crucial for fair, evidence-based policy.

Acceptability. Acceptability in health services means respecting medical ethics, cultural appropriateness, gender, and confidentiality. Taiwan's suspend-and-resume mechanism challenged ethical principles by allowing some people to pause contributions, undermining solidarity and fairness in the system. Media coverage of misuse heightened public concerns about equity and burden-sharing. Acceptability also includes health care workers' rights; increased burdens from this mechanism raised further concerns, especially amid rising workplace violence and burnout.

Quality. Quality in health care requires scientifically appropriate services, skilled staff, approved medicines, proper equipment, safe water, and adequate sanitation. Although the suspend-and-resume mechanism did not directly impact clinical care, it indirectly affected system quality by influencing workforce sustainability. Consistent, high-quality care depends on sufficient, well-supported health workers. Operational challenges, such as fluctuating demand and workforce pressures, undermined quality standards and risked staff burnout. Quality also involves robust health financing, information systems, and governance. The suspend-and-resume scheme created financial uncertainties, threatening long-term investments in care quality. Sustainable and predictable funding is essential for ongoing service improvement.

In summary, although the suspend-and-resume scheme enabled some individuals to enjoy the right to health, it diminished the enjoyment of some features of the right to health for others.

Against this background, we now consider the efficacy of temporal accountability in relation to the case study explored above. The Constitutional Court's ruling demonstrates both strengths and weaknesses in temporal accountability—the requirement that government decisions be made within reasonable time frames and that accountability mechanisms operate with appropriate timing.

Strengths in temporal accountability

The court's decision enhanced temporal accountability in two ways. First, by establishing a clear deadline for legislative action (two years from the judgment date), the court created a specific time frame for democratic deliberation and decision-making. This temporal constraint prevented indefinite delay and forced institutional actors to confront the policy question within a defined period.

Second, by shifting health care financing decisions from administrative discretion to legislative authority, the court established a framework whereby significant policy changes must undergo timely democratic processes rather than emerging through gradual administrative drift.

Weaknesses in temporal accountability

However, the case also reveals temporal accountability shortfalls. Most significantly, the suspend-and-resume scheme operated for years without legislative authorization, demonstrating a prolonged period in which executive action proceeded without proper democratic oversight. The Constitutional Court addressed this issue only after substantial time had elapsed and the scheme had become entrenched in practice.

The two-year deadline set by the court, while creating temporal pressure, also introduced ambiguity. When neither the executive nor legislature acted within this time frame, the NHIA unilaterally terminated the scheme. This outcome raises the question whether temporal accountability was truly achieved, for the scheme ended not through democratic deliberation within the prescribed time frame but through administrative inaction and strategic timing.

Furthermore, the documented pattern of returning expatriates increasingly using the suspend-and-resume scheme for elective procedures suggests that temporal accountability failed to address emerging equity concerns promptly.[41] The system allowed exploitation to grow over time before institutional actors responded.

Assessment of temporal accountability

Overall, this case study demonstrates a mixed record for temporal accountability. While the Constitutional Court established that important health decisions must undergo legislative deliberation, the case itself emerged as a result of years of inadequate temporal accountability in the executive branch. The NHIA's ultimate decision to terminate the scheme at the deadline, rather than proposing legislation, suggests that temporal constraints can be strategically manipulated to achieve particular outcomes outside the democratic process envisioned by the court.

While terminating the scheme affirms the principle of solidarity through equitable contribution requirements, it is important to acknowledge that this change has created new financial burdens for certain groups. Students studying abroad, diplomatic personnel, and other citizens serving officially overseas now face additional costs that they did not bear under the previous system. When the scheme ended in December 2024, contributing to the NHI system became mandatory for all—no alternative exists.

The Constitutional Court correctly held that health policy decisions should be made through legislation given their public importance. However, it could have further promoted a rights-based approach by referencing international human rights frameworks, which emphasize the right to health, including social determinants and robust health systems. Effective health systems are central to realizing health equity and highlight the need for continual improvement of the NHI system.

The Constitutional Court's analysis of equal protection and nondiscrimination is key to understanding health equity in Taiwan's legal system. These obligations help define health equity in practice. Although scholars and the court have not deeply addressed health equity within the NHI system, this paper explores how equity principles support the right to health by promoting fair health care access and resource distribution for all citizens, regardless of socioeconomic status or location.

While various definitions of health equity exist in the literature, the concept can be generally understood as the fair distribution of health without creating unnecessary, avoidable, and unfair health inequities.[42] Since the NHI system aims to promote equality of opportunities, exempting overseas residents from health premium payments may introduce financial uncertainty to the system and result in a situation where overseas residents are treated preferentially over local residents without sufficient justification.

In this context, it is important to note that Taiwan's National Human Rights Commission, established in 2020, has the authority to investigate human rights violations, review government policies, and recommend reforms. Although not involved with the suspend-and-resume scheme, the commission could assess whether NHI coverage policies infringe on health rights—especially since citizens in Taiwan cannot legally challenge the scheme—and suggest policy changes. This would help address the accountability deficit.

Continuous adjustments prompted by changing social circumstances can yield more responsive outcomes. However, temporal accountability is not a panacea—its effectiveness depends on the quality and inclusivity of institutional interactions. We should not assume that temporal accountability necessarily achieves better outcomes than other approaches to accountability. In particular, risks of majoritarianism persist. When health care governance favors technocratic decision-making, procedural safeguards are necessary to uphold accountability and democratic legitimacy. These should include (1) a public comment period long enough for meaningful stakeholder input, especially from marginalized groups; (2) mandatory disclosure of impact assessments showing how policies affect various populations; and (3) legislative hearings to review outcomes, compare projections with actual results, and adjust policies accordingly. Such measures help balance expertise with democracy and safeguard public trust in health governance.

Scope and limitations of the framework

This case study demonstrates how temporal accountability functions in health systems under specific conditions: constitutional review with authority to set binding timelines, transparent administrative health data, universal coverage with residency-based eligibility rules, and democratic governance with constitutional courts that have limited enforcement power relative to other branches of the government. The insights from this case study may not transfer directly to common-law jurisdictions, where constitutional structures, judicial review, and the relationship between legislative and administrative authority operate under fundamentally different legal principles. To bridge these contexts, Figure 1 outlines five principles of temporal accountability for assessing institutional interactions in health care decisions.

Conclusion

Accountability is a crucial and complex feature of health rights. Our case study on Taiwan reveals how multi-layered accountability helps a national health insurance system adapt continuously to evolving societal needs through checks and balances among co-equal branches of government. We have demonstrated that temporal accountability, despite its shortcomings, offers a valuable lens for understanding rights-based approaches to health systems by emphasizing iterative improvements, time-bound commitments, and institutional oversight.

Temporal accountability in health care governance extends far beyond political responsibility. As the case study demonstrates, a comprehensive view encompasses temporal and human rights dimensions, fostering iterative improvements and transparency in decision-making that clarifies trade-offs between competing values and interests.

FIGURE 1. Five principles required by temporal accountability

1. **Court-specified compliance windows and required public reporting**: Establish clear deadlines for the implementation of judicial decisions, and mandate regular, publicly accessible progress reports.
2. **Pre-decision distributional impact statements**: Require an assessment of how policy changes will affect different population groups before decisions are made.
3. **Mandatory data publication**: Ensure the systematic publication of disaggregated data by age, sex, and residency status for transparency and monitoring.
4. **Time frames for public participation**: Create structured opportunities with defined time frames for public engagement in policy development.
5. **Legislative review with sunset or renewal triggers**: Implement automatic review that requires policies to be reevaluated and either renewed or allowed to expire after a specified period.

This expanded conceptualization of accountability enables better understanding of the institutional interactions involved in monitoring, evaluation, and continuous policy adjustments that respond to changing societal needs while maintaining the sustainability and equity of universal health coverage.

Acknowledgments

We thank Paul Hunt, Anuj Kapilashrami, and the two anonymous reviewers for their constructive feedback, and Carmel Williams and Morgan Stoffregen for their exceptional editorial support.

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Accountability Beyond Blame: Rethinking Maternal Death Surveillance and Response

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Abstract

Maternal death reviews or audits are among several interventions used to reduce maternal mortality. The maternal death surveillance and response (MDSR) system is one such mechanism, combining case identification with analysis of underlying causes to inform corrective action. Although introduced to generate information for accountability in maternal health, the meaning and implications of accountability in this context remain underexamined. A dominant framing of MDSR as an internal quality assurance tool—coupled with a narrow, punitive conception of accountability—appears to limit its potential to help address preventable maternal deaths. This paper draws on the stated objectives and structural design of MDSR to argue that reconceptualizing it as a mechanism of human rights accountability not only aligns with its normative aims but also provides a more robust framework for tackling maternal mortality. It responds to the challenge of achieving accountability without reducing it to blame, examining how MDSR can foster accountability consistent with international human rights standards and what this would entail in practice.

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Competing interests: None declared.

Introduction

Maternal mortality emerged as a global concern in the 1980s, propelled by small but significant data fragments from a few developing countries.[1] As attention to the issue grew—spurred broadly by research exposing the neglect of maternal health in global policy, increasing awareness of its preventability, and the convergence of the safe motherhood, reproductive rights, and human rights movements—the need to better understand its scale, causes, and distribution has grown in importance.[2] This depth of insight is essential not only for raising awareness and sustaining attention but also to support ongoing efforts to address it through learning.

These efforts gained momentum when it became clear that progress toward achieving the Millennium Development Goals on maternal and child health was falling behind. The United Nations Secretary-General's Global Strategy for Women's and Children's Health, issued in 2010, marked a pivotal moment in this regard. Recognizing and concerned by the slow progress in meeting maternal and child health goals, the strategy called on the World Health Organization (WHO) to chair "a process to determine the most effective international institutional arrangements for global reporting, oversight and accountability on women's and children's health."[3] This led to the establishment of the Commission on Information and Accountability for Women's and Children's Health.[4] The commission found that many countries with apparently high maternal death burdens lacked reliable systems to capture such deaths and that this absence of reliable data on key indicators, including maternal mortality, not only hampered efforts to monitor progress but also contributed to the persistent lack of meaningful improvement. Characterizing this as a "scandal of invisibility," the commission emphasized the importance of information for accountability.[5] Among other things, it recommended that states without functioning systems establish mechanisms to register vital events, including maternal deaths.[6]

This political momentum, combined with WHO's existing technical work on tracking maternal deaths and investigating their causes, contributed to the development of the maternal death surveillance and response (MDSR) system.[7] Primarily intended for countries without reliable systems to track maternal mortality, MDSR is a continuous process that identifies and reviews all maternal deaths to inform ongoing improvement.[8] Since the 2013 release of the MDSR Technical Guidance (hereafter WHO MDSR Guidance), many countries—particularly in Africa—have adopted the system under various names and with contextual adaptations. WHO continues to support its implementation through technical assistance, updated guidance, and progress reviews.[9]

Given its origin, MDSR—and maternal death audits more broadly—has been framed as an accountability mechanism for fulfilling maternal health commitments. As will be shown below, MDSR's operational instruments identify accountability as one of the system's objectives. The United Nations Special Rapporteur on the right to health expressed early concern that without a reliable civil registration system, many maternal deaths go uncounted and unreported.[10] He urged states to implement effective registration and a system of maternal death review.[11] More specifically, the Office of the United Nations High Commissioner for Human Rights lists maternal death reviews among human rights accountability tools.[12] Instructively, in an introduction to a foundational volume on human rights accountability for maternal mortality, Paul Hunt described maternal death audits as an example of novel human rights accountability approaches that complement efforts to strengthen existing mechanisms, stating:

> *The second approach is by identifying existing processes that were not conceived as accountability arrangements but—suitably refined—they might be able to serve this purpose, such as maternal death audits or reviews. Processes of this sort are often designed, and primarily used, by health professionals who have to be willing to listen to, and learn from, the human rights experts.*[13]

Nonetheless, positioning MDSR as a tool of accountability is not without challenges. References to accountability in this context are often inconsistent, even conflicting.[14] On the one hand, MDSR is presented as an instrument of accountability for maternal health—that is, a mechanism to reduce maternal mortality by generating information to guide corrective action.[15] On the other, health workers frequently perceive the same framing as assigning personal blame, where detailed case reviews may expose them to censure or liability.[16] As Vincent De Brouwere and colleagues noted early in the system's development, "because the focus is on creating changes by improving accountability … MDSRs might threaten confidentiality, essential for facility-based [maternal death reviews]."[17]

Three interrelated factors further entrench this interpretive tension. First, accountability is understood in divergent ways, including within the health sector. As Hunt observes, it is frequently reduced to either simple monitoring or punitive enforcement.[18] Second, although MDSR is intended as a confidential, non-punitive process under a strict "no name, no blame" principle, the absence of legal protections amplifies concerns about blame and liability.[19] Third, and closely related, the literature often frames MDSR as an internal performance monitoring tool, reinforcing its association with individual staff appraisal rather than systemic learning.[20] These concerns are supported by studies indicating that the system is often used to shift responsibility onto health workers, particularly those in lower-level facilities—a dynamic one study described as "sharp downward, blunt upward."[21] Such a narrow framing not only hollows out the concept but also shapes actors' behavior because "the way accountability … is discussed and disseminated by those intervening will have an influence on prospects for implementation."[22]

Against this background, I examine the potential of a human rights approach to reframe MDSR to enhance its potential as an accountability mechanism. In a way, this paper responds to the call by the former Special Rapporteur on the right to health to explore how maternal death review systems can be strengthened through a human rights-based approach. It does so by analyzing the objectives and structure of MDSR, clarifying the essence of accountability in general as well as human rights discourse, and assessing the relevance of this framework to efforts aimed at reducing preventable maternal deaths.

However, this short paper is principally conceptual and does not aim to provide empirical evidence or a detailed outline of the human rights accountability framing of MDSR that it advances. Rather, it aims to clarify the conceptual foundations of such a framing and to draw out its implications for how MDSR might more effectively serve accountability for maternal health.

The next section introduces the notion of accountability as it informs the analysis of MDSR. The following section offers an overview of the system as set out in WHO guidance. I then explore how a human rights-based understanding of accountability could offer a more relevant and potentially effective framework for interpreting MDSR. I outline its key elements, discuss potential challenges, and conclude with final reflections.

Accountability: Essence and controversies

Accountability is an elusive concept and "crops up everywhere, performing all manner of analytical and rhetorical tasks and carrying most of the burdens of democratic governance."[23] Broadly construed, it "embraces (or at least overlaps with) lots of other terms—surveillance, monitoring, oversight, control, checks, restraint, public exposure, punishment."[24] Its breadth has been a source both of its attractiveness but also of its limitation.[25] In his frequently cited work, Andreas Schedler describes accountability as follows: "A is accountable to B when A is obliged to inform B about A's (past or future) actions and decisions, to justify them, and to suffer punishment in the case of eventual misconduct."[26] Similarly, Messner notes that "to give an account means to provide reasons for one's behavior, to explain and justify what one did or did not do."[27] A similar understanding is shared in the health sector.[28]

While three components of accountability—namely, information, justification, and enforcement—appear to be the minimal elements of consensus about the notion, the status of the last element raises more questions.[29] According to Schedler, while the first two elements correspond to the etymological ambiance of the notion between bookkeeping (information provision) and storytelling (discursive or exploratory aspect), the element of enforcement (sanctions) seems to be a rational addition to make it bite.[30] Writing from a historical perspective, Richard Mulgan underscores that the original and widely accepted understanding of accountability refers to the process of being called to account by an authority for one's actions. While it aims at rectification, he notes that the role of sanctions remains contested.[31]

The tension among the three core components and the uncertainties regarding the appropriate balance in any given setting continue to challenge efforts to design effective accountability mechanisms. A notable dilemma in health governance is finding the balance "between accountability for control, with its focus on uncovering malfeasance and allocating blame, and accountability for improvement, which emphasizes discretion, embracing error as a source of learning, and positive incentive."[32] A further challenge is the tendency to reduce accountability to its third element—enforcement or sanctions.[33] This is evident in legal discourses, including civil and political human rights, where accountability is often equated with sanctioning violators, and in health systems, where lower-level health workers are frequently penalized for failures and become scapegoats for broader systemic problems.[34]

Despite these conceptual ambiguities, there is a broad consensus that the core purpose of accountability is to restrain power and help ensure its reasonable exercise.[35] This implies, among other things, that the design of an accountability mechanism must give careful consideration to the nature of the power it seeks to regulate. It also suggests that accountability should not be "reduced to a technical exercise; its essence remains … dialogue and debate."[36] Accountability needs to focus on highlighting "the *procedural* deficits that characterize many aspects of decision-making and the exercise of power."[37] This is particularly relevant given that "unsettling entrenched power dynamics is crucial to changing the patterns of health and ill health."[38]

The other implication is that, insofar as the objective of constraining power is achieved, the three elements of accountability—information, justification, and enforcement—need not operate simultaneously.[39] In some contexts, "accounting agents" primarily demand enforcement, as in elections; in others, enforcement may have little place, as in the South African Truth and Reconciliation Commission, where accountability for apartheid-era abuses rested on truth-telling and acknowledgment rather than punishment. More broadly, the role of enforcement varies across accountability settings—from a central feature in criminal proceedings to being largely absent in media and civil society, where constraint is discursive rather than coercive.[40] Accordingly, while all three elements remain essential, "how they are assembled is contingent on the type of activity, the level of uncertainty, [and] the ability to define agreed-upon measures of performance."[41]

This shift toward a more nuanced understanding of accountability is driven largely by the increasing diffusion of accountable power. In the context of preventable maternal deaths, the progressive nature of state obligations and the involvement of multiple nonstate actors influencing health outcomes mean that traditional approaches centered solely on identifying violations and violators provide an inadequate basis for accountability.[42] Reflecting this broader and more differentiated understanding, three main types of accountability strategies are commonly identified in the field of sexual and reproductive health and rights: performance, social (or community), and legal.[43] Performance accountability refers to "internal systems that governments hold service providers and health systems to account," with MDSR listed as a prime example.[44] Social or community accountability strategies broadly aim to "bolster the capacity of communities to demand improved services and provider responsiveness through community awareness and voice."[45] Legal accountability, by contrast, involves some form of litigation or hearing in response to alleged rights violations. As discussed below, a human rights-based approach to MDSR can strengthen its role as a social accountability mechanism, bringing it closer to exposing—if not restraining—power, while reducing its use for individual legal accountability.

Maternal death surveillance and response: Structure and objectives

The MDSR system is a continuous and structured process to identify, report, and review all maternal deaths, assess preventability, guide responses, and monitor effectiveness.[46] Its stated objective is to "count every maternal death, permitting an assessment of the true magnitude of maternal mortality," and "eliminate preventable maternal mortality by obtaining and using information on each maternal death to guide public health actions and monitor their impact."[47]

While the primary objective of MDSR is to generate evidence to prevent the recurrence of preventable maternal deaths, the WHO MDSR Guidance also identifies advocacy and accountability as complementary objectives. On advocacy, it notes that "the evidence and stories behind the maternal deaths are the ingredients for powerful and effective advocacy."[48] Regarding accountability, it emphasizes that "government accountability … requires the periodic and transparent dissemination and discussion of key results … among stakeholders, including the civil society at large," and that accurately assessing the magnitude of maternal mortality through MDSR helps "provide accountability for results" and "compels decision-makers to give the problem the attention and responses it deserves."[49] The guidance further suggests that "by investigating a woman's death, MDSR inherently places value on her life—an important form of accountability for families and communities."[50]

To operationalize these objectives, the WHO MDSR Guidance requires the identification and reporting of all suspected maternal deaths, whether they occur in facilities, in transit, or at home. It calls for making maternal deaths notifiable events, assigning coordinating health officers, establishing review committees, and engaging with communities and other stakeholders.[51] Review committees are expected to be multidisciplinary, bringing together clinical, public health, administrative, and community perspectives to ensure that medical and systemic factors are jointly analyzed. These committees should use medical records, accounts from care providers, and information from verbal autopsies with relatives or community members to establish the circumstances, causes, and contributing factors of each death and assess its preventability. Each review, along with aggregated trend data, is intended to inform further analysis regarding the causes, trends, and geographic patterns of maternal deaths.

To foster candid reporting and participation, the guidance and subsequent instruments emphasize confidentiality and the use of review findings exclusively for learning and improvement, separate from punitive processes.[52] This often requires establishing an enabling legal framework—a step that, by and large, has yet to be undertaken in many countries.[53] Owing to weak legal and institutional support, among other factors, MDSR implementation faces persistent challenges, including the underreporting of deaths, incomplete data, superficial reviews focused mainly on medical causes, limited community and civil society engagement, and the weak dissemination and translation of findings into action.[54] As one study observed, this creates a vicious cycle: weak implementation yields limited results, reinforcing demotivation and systemic dysfunction.[55] Key barriers include a limited understanding of MDSR's objectives and principles, together with a pervasive fear of blame, exacerbated by the absence of adequate legal protections.[56] This environment sustains a prevailing "blame culture" in which the intervention is used to appraise staff or assign individual fault and, more critically, fosters defensive practices that undermine its intended purpose.[57]

These challenges not only undermine implementation but also reveal a deeper limitation in how accountability is currently conceived within MDSR. A narrow operational focus—centered on generating evidence for action at the individual and facility levels while overlooking broader systemic and structural factors—appears to be a major cause. This limits the system's transformative potential and may perpetuate the vicious cycle described above.

This limitation is reflected in the WHO MDSR Guidance, which adopts a predominantly medical lens in attributing causes and contributing factors to maternal deaths. It prioritizes data collection on indicators such as skilled birth attendance and access to emergency obstetric care.[58] While acknowledging that "the problems leading to maternal death are frequently not all medical," reviewers are nonetheless directed to focus "only on those events that may have directly contributed to the maternal deaths."[59] Consequently, social and structural factors are often treated as secondary.

While the "three delays" model—a framework for understanding how delays in seeking, reaching, and receiving care contribute to maternal deaths—is recommended as an analytic tool, its application tends to emphasize clinical issues such as delayed recognition of complications or substandard care.[60] Although the WHO MDSR Guidance recognizes the need to consider household decision-making within the broader sociocultural context, it frames this instrumentally, as a means to "frame behavior-change strategies."[61] Reinforcing this medicalized approach, and to promote comparability, the guidance encourages assigning a specific cause of death in line with the ICD-Maternal Mortality classification, which broadly centers on identifying the single disease or event that led to the death.[62] The review's overarching aim, accordingly, is described as identifying "modifiable factors and behaviors and linkages with proven interventions and strategies to improve maternal survival."[63]

This emphasis on medical and procedural dimensions is further reflected in the assessment of avoidability, which plays a central role in shaping responses. A maternal death is considered avoidable "if it might have been avoided by a change in patient behavior, provider or institutional practices, or health-care system policies."[64] Although the guidance recommends including in the assessment "social and economic barriers related to the status of women, women's literacy level, and gender-based beliefs and practices that may be a root cause of poor service utilization," the response "should be specific and linked with avoidable factors," arguably reinforcing a focus on medical causes.[65] In addition, quality of care—assessed against "accepted local standards and best medical evidence," and within the limits of available resources—is central to this inquiry, though the guidance offers little direction on how resource constraints should be interpreted or applied.[66] By prioritizing responses to measures achievable at the facility level, the guidance further narrows the scope of analysis and action.[67]

This narrowing of focus also manifests in how responsibility is distributed. Strikingly, the state is largely absent as an actor, both in the analysis of causes and as an addressee of recommended responses. The focus remains on the family, local actors, and the health system. For instance, recommendations are to be addressed to the community, care sites, and providers.[68] This deflects attention from the structural determinants of preventable deaths, concentrating instead on implementers with limited capacity to effect meaningful change. This structural flaw arguably contributes to MDSR functioning as a performance review rather than a mechanism for systemic accountability. Evidence from a decade of global MDSR implementation also indicates a continued emphasis on quality of care, with little to no engagement with civil society, the media, or human rights organizations.[69]

This dynamic may also reflect a broader misalignment between MDSR's two core components—surveillance and review. The surveillance component focuses on generating data on the magnitude and trends of maternal mortality and primarily draws state interest, given its relevance to international performance metrics and reputational concerns. Particularly in authoritarian settings, this dynamic may invite political interference in reporting, discouraging candid participation by health workers and producing cascading effects throughout the system.[70] By contrast, the review component is intended to support learning and action across all levels of the health system—from individual providers and facilities to national policy makers. However, a narrow conception of accountability, reinforced by pressure to produce evaluative metrics, often leads administrators to use the data to assess staff performance rather than to drive systemic improvement. This, in turn, constrains the space for honest reflection and review. In other words, the evaluative and learning functions of surveillance and review, when combined with a reductive notion of accountability, risk rendering MDSR ineffective.

Framing maternal death surveillance and response through a human rights lens

Human rights accountability

Human rights law obliges states to reduce preventable maternal deaths as part of multiple rights, including the rights to life, dignity, reproductive autonomy, health, and equality.[71] Several international instruments also explicitly affirm special protections to ensure safe motherhood.[72] These rights entail both negative and positive obligations. The right to health—most relevant in the context of this paper—requires states to take appropriate measures to progressively eliminate preventable maternal mortality. This includes ensuring access to essential health services, such as skilled birth attendance, emergency obstetric care, and accurate health information, as well as implementing effective public health strategies.[73] Equally important, advancing gender equality by tackling discrimination embedded in laws and practices, harmful gender norms, sociocultural barriers, marginalization, and illiteracy is widely recognized as essential to addressing the root causes of maternal mortality.[74]

Accountability is an integral principle of human rights, as rights entail duties that are realized through systems of accountability. Accountability in human rights is a mechanism to provide rights holders "with an opportunity to understand how those with responsibilities have discharged their duties."[75] While there is no universally accepted understanding of human rights accountability, the essence is to ensure that duty bearers and others provide information regarding what duty bearers do, and fail to do, to comply with their obligations; duty bearers should also have to explain their decisions.

The Office of the United Nations High Commissioner for Human Rights, in its technical guidance on a human rights-based approach to reduce preventable maternal morbidity and mortality, presents accountability as a multidimensional duty extending beyond punishment.[76] Accordingly, accountability is a continuous process applied across all stages of the policy cycle—from conducting situational analysis and planning to budgeting and implementation. It involves monitoring through indicators and benchmarks that assess structural conditions, policy and budgetary efforts, and health outcomes. It also includes diverse forms of review and oversight to evaluate processes and results against human rights obligations, as well as remedies.

Another relevant source in which a human rights understanding of accountability is elaborated describes accountability as "the relationship of government policy makers and other *duty bearers* to the *rights holders* affected by their decisions and actions."[77] Accountability comprises three key elements: responsibility, which requires clearly defined duties and standards; answerability, which obliges public officials to justify their actions and devise effective oversight; and enforceability, which demands mechanisms to monitor compliance and apply sanctions when necessary.[78]

Beyond framing accountability as a continuous process of information, justification, and enforcement, which is crucial to "expose the hidden priorities and structures behind violations," human rights accountability grounds assessment in established legal obligations.[79] Most importantly, and relevant to eliminating preventable maternal deaths, a human rights framing—and the accountability systems it promotes—seeks to drive transformative change by empowering individuals and communities to reshape the power relations that underlie patterns of health and ill health. Furthermore, a human rights approach demands attention beyond biological factors to the social, political, historical, and economic contexts in which health is produced, experienced, and understood.[80] This, in turn, "forces us to see the suffering that is not the result of 'natural' biological causes but rather stems from human choices about policies, priorities, and cultural norms."[81]

Making the case for a human rights-based maternal death surveillance and response

Applying a human rights-based approach to maternal mortality is complex. It would broadly involve identifying and applying the key values, principles, and elements of the relevant right (health) and a mechanism in question (MDSR for accountability) into the six essential building blocks of the health system, which are critical for addressing maternal mortality.[82] While such an exercise is beyond the scope of this work and deserves further research, here I outline key aspects of human rights accountability and their implications for MDSR.

A central implication is the need to treat maternal deaths as potential violations of a state's human rights obligations. Promoting this understanding, including in technical guidance and among implementers and the public, has the potential to reshape how citizens perceive their relationship with the state, paving the way for stronger civic engagement and mobilization. This is crucial given that maternal deaths often persist not because effective interventions are unknown but because entrenched gender biases have naturalized such deaths as inevitable.

As part of a continuous process within the policy cycle, human rights accountability invites MDSR to examine how decision-making in policy and budgeting contributes to each death under review. Grounding the assessment in legal obligations further broadens the frame of analysis, extending it from immediate health needs and quality of care to structural barriers such as laws, social norms, and sociocultural conditions. These dimensions require an expanded scope of the MDSR review process, with questions formulated to interrogate relevant decision-making processes.[83]

By linking rights to duty bearers, a human rights accountability framework would also require the maternal death review process to identify the relevant duty bearers and clarify their respective obligations in progressively reducing preventable maternal deaths. Linking MDSR review to decisions by local, regional, or national authorities can expose deeper patterns of neglect or underinvestment. By focusing on the state rather than individual actors, a human rights-based approach also redirects attention from isolated errors or delays to broader structural drivers. Emphasizing duty may likewise counter the tendency to disregard MDSR recommendations. Moreover, the authoritative guidance developed by human rights monitoring bodies—including on standards for health services and goods, the notions of minimum core obligations, the progressive realization of rights, and the use of maximum available resources in assessing state obligations—can help structure the assessment of preventability and guide appropriate responses.[84]

A human rights-based accountability framework can further support MDSR implementation in at least three ways. First, human rights law requires states to establish mechanisms for remedying violations. Recognizing this can ease the pressure on MDSR to serve punitive ends by providing alternative avenues for redress. The fact that MDSR is not designed and should not be used for legal proceedings does not, however, mean that legal or judicial mechanisms have no role to play in addressing preventable maternal deaths. Indeed, evidence shows that litigation, when embedded in broader social and political mobilization, has advanced maternal health.[85] Properly conducted MDSR reports can even inform such litigation by identifying areas of persistent failure.

Second, framing MDSR as a tool for fulfilling states' human rights obligations to advance maternal health underscores the duty of implementing states to ensure that the process is carried out in accordance with human rights norms and that it achieves effectiveness.[86] This requires, among other things, establishing adequate legal frameworks and safeguarding the professional freedom of health workers, both of which are central to effective implementation. Such empowerment would help enable health workers to safeguard the integrity of the process. Furthermore, this framing implies that other relevant actors beyond the health sector, including civil society, the media, and human rights monitoring bodies, should be engaged. This way, MDSR can serve as a tool for social accountability, expanding the possibility of exposing deeper causes of preventable maternal deaths.[87] This calls for revising dissemination structures to ensure that relevant actors beyond the health sector are identified and engaged to fulfill their roles.

Third, by extending the inquiry to the deeper structures of power, a human rights-based accountability approach can foster more meaningful change that goes beyond improving care delivery. This shift could, in turn, encourage broader engagement and help break the vicious cycle that risks reducing MDSR to a procedural formality rather than a vehicle for transformation.

Challenges in applying a human rights-based approach

Recasting MDSR through a human rights-based lens presents several conceptual and practical difficulties. More broadly, operationalizing a human rights-based approach is challenging, and even its validity is questioned when "retroactively fitting human rights into health programs … that were not explicitly designed around rights," such as MDSR.[88] Similarly, while human rights accountability is about restraining and shifting power that underpins ill health, identifying where power lies and how it operates, including in the context of maternal mortality, is a daunting task because it often involves uncovering hidden and systemic forms of influence embedded in institutions, norms, and everyday practices.[89] Within this context, three major challenges can be identified.

The first relates to the tension between the transformative ambition of human rights accountability and the institutional inertia that resists it. While the normative appeal of such a transformation is strong, human rights accountability aims to disrupt entrenched systems and practices. Integrating human rights into MDSR involves identifying systemic injustices and interrogating established decision-making processes, which is often uncomfortable for those in power. One significant challenge, therefore, is resistance from power holders who resist applying the language of rights. The problem is particularly acute in settings with weak rule of law, common in many African countries where maternal mortality remains high. As Alicia Yamin and Rebecca Cantor have noted, human rights-based approaches aim to subvert existing power distribution and are often met with suspicion or pushback from those who benefit from the status quo.[90] Rosemary McGee also documents that resistance from anti-accountability forces is to be anticipated.[91] Strong resistance in the 1980s to incorporating social determinants—particularly race—into the UK Confidential Enquiry into Maternal Deaths provides a relevant example.[92]

One way to counter this challenge is to act strategically—using diverse approaches and enlisting reformers both within the state and in the community.[93] In the context of MDSR, this could involve engaging committed health workers, parliamentarians, civil society, the media, and human rights organizations to build broad-based support. It might also begin with expanding the composition of, at least, national MDSR steering committees. In the UK's Confidential Enquiry into Maternal Deaths, for instance, broadening the committee to include public health experts and drawing on human rights discourse helped overcome similar resistance, widening both participation and the understanding of accountability.[94]

The second challenge may be described as a data-quality paradox: How can a system that produces poor or even manipulated maternal mortality data be used as a tool to drive deeper, systemic change? While this remains a serious challenge—given that accountability, particularly for obligations to progressively reduce maternal mortality, depends on reliable data—it can be overcome. Misunderstandings about the objectives of MDSR contribute to this problem; clarifying its purpose and refocusing the inquiry may help. Because a rights-based approach aims to create a "dynamic of entitlement and obligation," it has the potential to encourage health workers not only to claim their rights but also to act as "local audits" in generating accurate and disaggregated data, thereby supporting the integrity of the MDSR process and improving data reliability.[95] External actors, including human rights monitoring bodies, can likewise play a role by examining the processes that produce maternal mortality—an emerging metric for assessing states' human rights obligations.[96] In this way, the misalignment between the surveillance and review components of MDSR, evident in its current implementation, can be eased.

The third, more practical challenge concerns the feasibility of implementation. Applying a human rights approach generally involves expanding the remit of MDSR. However, in many settings, the system already faces implementation hurdles, including resource constraints, limited coverage, and a lack of institutional support.[97] Adding layers of legal, policy, and sociopolitical analysis to an already fragile system—often implemented and managed by overstretched health workers—risks further overburdening them. A more feasible approach may involve conducting deeper human rights-based analyses in selected cases, while maintaining the surveillance component to capture and confirm all maternal death. This is reflected in emerging models in Kenya and Ethiopia, where complementary confidential inquiries are being introduced on the premise that they allow for more in-depth investigation.[98] Another human rights approach, as recommended by the Special Rapporteur on the right to health, is to establish national, regional, or global independent, transparent, non-statist bodies charged with responsibility for identifying, analyzing, and publicizing the structural injustices exposed by MDSR.[99]

In sum, the transition to a human rights-based MDSR is both necessary and complex. It calls for political will, institutional adaptation, and strategic engagement with actors at all levels to ensure that the transformative potential of human rights is not lost in implementation.

Conclusion

In discussing accountability within MDSR, two mutually reinforcing paradoxes merit attention. While accountability in both general literature and human rights discourse comprises elements of information, justification, and enforcement, it is often reduced to notions of blame and punishment. Similarly, although MDSR is intended as a confidential and non-punitive process, inadequate legal safeguards—and its framing as an internal performance tool—tend to reinforce its association with sanctions. These dynamics undermine both the system's intended function and trust among health workers and stakeholders. Combined with the narrow scope of data collection and use outlined in the WHO MDSR Guidance, the system risks ineffectiveness, perpetuating weak implementation and defensive practices that may further compromise care. This reinforces earlier critiques that questioned the feasibility of implementing MDSR in low-resource settings.[100]

Rethinking MDSR as a tool for fulfilling states' human rights obligations to eliminate preventable maternal deaths can help address implementation challenges and enhance effectiveness by reshaping what is investigated, how data are used, and for what purpose. It also requires the state to carry out these processes in accordance with principles such as due process, which often calls for an appropriate legal framework. While improving data quality and review, information alone cannot shift attitudes or drive action. The goal should be to expose "layers of systemic and structural norms that marginalize, disempower and dispossess."[101] A human rights framing of maternal deaths—and the accountability it demands—aligns more closely with this transformative vision. Crucially, MDSR must generate relevant data that actors beyond the health system can use to demand explanation and change, mainly targeting the state as the duty bearer.

However, applying a human rights approach requires significant changes and a fundamental refocusing of MDSR, which are likely to encounter various obstacles. It would thus require mobilizing support from activists, civil society, health professionals, parliamentarians, and human rights bodies to enable MDSR to play a more transformative role. As the Special Rapporteur noted, this may also call for a distinct yet complementary human rights accountability mechanism to address the structural injustices it routinely confronts.

Acknowledgments

I thank my PhD supervisors—Professors Henriette Aasen, Ingrid Miljeteig, Andrea Melberg, and Karen Marie Moland at the University of Bergen—for their valuable guidance and the productive discussions that shaped the ideas for this paper. I am also indebted to the anonymous reviewers, whose extensive and thoughtful comments offered valuable directions for further reflection and improvement, and to the editors of the special issue for their support. I further acknowledge members of the MATRISET research group at the University of Bergen for the engaging discussions, which contributed to improving the paper.

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PERSPECTIVE

Accountability Reimagined: Decolonizing Global Health Through Virtue and Subsidiarity

THANA C. DE CAMPOS-RUDINSKY AND DANIEL WAINSTOCK

Introduction

Accountability is widely recognized as a defining feature of human rights practice, including in the context of global health.[1] However, prevailing models of accountability remain deeply state-centric, structured around formal mechanisms that require power holders (governments, international organizations, and global health authorities) to justify their actions and remedy failures. While the demands of justification are essential for maintaining the legitimacy and trustworthiness of authorities, they often reinforce top-down structures that produce inflated bureaucracy, perfunctory transparency, and the marginalization of local voices. In many cases, they also reproduce colonial dynamics: concentrating evaluative authority in donors, experts, or international actors while diminishing the agency of local actors in setting priorities, defining success, or identifying harm.

We argue that effective and just human rights accountability requires an alternative, people-centered model, one that is not only structurally distinct but ethically reimagined. The alternative we propose is a relational approach that reconceptualizes accountability as a virtue and operationalizes it through the principle of subsidiarity. As a virtue, accountability is understood not as an external demand grounded in blame and shame but as an internal disposition: a moral and relational capacity marked by truthfulness, responsiveness, and a willingness to be answerable in ways that nurture mutual recognition, trust, and co-responsibility.[2] Operationally, we ground the virtue of accountability in the principle of subsidiarity, which affirms the moral and political authority of local communities while obligating higher-level institutions to provide support without displacing or abandoning them.[3]

This perspective essay focuses on the relationship between one defining feature of human rights—ac-

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Competing interests: None declared.

countability—and two concepts that can deepen its ethical and structural grounding: virtue and subsidiarity. While accountability and power have been extensively theorized, a comprehensive review of such scholarship lies beyond the present scope.[4] Our focus, instead, is to explore how virtue and subsidiarity can together reimagine accountability in global health as both a moral disposition and a structural principle. The upshot of our proposed account reinforces and resonates with well-established human rights dimensions—such as community engagement, empowerment, and equity—rendering them more conceptually robust. Although our argument dialogues with the human rights literature on accountability, sharing with it the view that accountability's true purpose is to empower local communities, our contribution lies elsewhere: in offering a virtue-centered and subsidiarity-driven reframing that complements rather than replicates existing analyses.

The limits of state-centric human rights accountability

While state-centric mechanisms of accountability remain the norm, their structure and logic have significant limitations, particularly in global health governance, where coloniality persists in the asymmetries of voice, knowledge, and authority that structure accountability relationships.[5] In these contexts, accountability is often reduced to periodic reporting, compliance checklists, or institutional audits. Real human rights accountability requires far more than this.

As Lynn Freedman emphasizes, genuine accountability entails more than the procedural routines of monitoring or bureaucratic oversight.[6] It demands a deeper, more nuanced understanding, one grounded in dialogue, responsiveness, and moral engagement. When reduced to technical compliance, accountability loses its transformative potential as a relational practice of trust, learning, and shared responsibility. These instruments may satisfy formal requirements of oversight, but they seldom disrupt entrenched power asymmetries or meaningfully engage the communities most affected by health policies and interventions.

This critique is increasingly echoed in human rights and global health scholarship. For example, Anuj Kapilashrami, Neil Quinn, and Abhijit Das argue that traditional models of political and bureaucratic accountability are inadequate for today's shifting health governance landscape.[7] They highlight the limitations of linear, top-down models and call for an expanded understanding of the accountability "ecosystem," one that includes community-led mechanisms, addresses corporate actors, and accounts for the sociopolitical contexts in which accountability is practiced.[8]

Yet the reality of most international systems of accountability, in being state-centric, remain tied to a narrow logic. They presume that the primary duty bearers are state actors and that legitimacy is preserved through upward-facing review. This is increasingly out of step with a global health landscape shaped not only by states but by powerful private actors: philanthropic foundations (donors), transnational corporations, and global health partnerships, whose influence often escapes formal accountability structures. For more than two decades, the international human rights system has sought to extend accountability to nonstate actors, for example, through the United Nations Working Group on Business and Human Rights and the development of the United Nations Guiding Principles on Business and Human Rights.[9] These mechanisms mark an important evolution in recognizing that corporate and transnational power must also be subject to human rights scrutiny. Yet their reach and enforcement capacity remain severely limited. The result is a fragmented architecture of accountability that continues to privilege state oversight while leaving significant sources of global health power insufficiently answerable to those most affected by their actions.

Moreover, state-centric models tend to reinforce technocratic norms: privileging quantitative metrics, formal procedures, and bureaucratic rationality over moral deliberation, relational trust, and contextual knowledge. Remedy, in this context, is often aimed at restoring functionality, ensuring that the system continues to operate rather than reimagining who should be accountable, how power is distributed, or what justice entails.

These mechanisms perpetuate the coloniality of knowledge and epistemic injustices that are inherent to global health governance. Knowledge is too often assumed to flow from evaluators in the Global North to recipients in the Global South. At the same time, the technical and phenomenological expertise of local communities is sidelined, extracted, or reinterpreted through external frames. Accountability, then, often risks becoming an instrument of blame, shame, and compliance rather than a space for shared reasoning, mutual recognition, and co-responsibility. When this occurs, it erodes the community's capacity to act and decide, subtracting and displacing local agency in the service of external interests, a dynamic that philosopher Caesar Atuire identifies as the moral wrong of colonialism.[10] While this critique does not deny that contemporary human rights accountability aspires to correct such an imbalance, our point is that practice too often reproduces the very hierarchies it seeks to overcome.[11]

To move beyond these limitations, an alternative model is needed, one that does not simply discard institutional mechanisms but grounds accountability in community agency, shared responsibility, and a horizontal dynamic of co-deliberation. The next section outlines the conceptual basis for such a model: accountability as a moral virtue.

Accountability as a virtue: From compliance to a reason-giving relationship

In many global health contexts, accountability is equated with oversight: a mechanism to ensure compliance, expose failure, or enforce transparency. But this framing, so common in reviews, donor contracts, and international partnerships, often reduces accountability to a tool of control. It emphasizes reporting over responsiveness, and output over moral engagement. As Lynn Freedman, Carmel Williams, and Paul Hunt have observed, this conflation of monitoring with accountability has long eviscerated the concept itself.[12] However, when accountability is reframed as a virtue (a cultivated disposition to offer justification to those with a legitimate moral claim), its logic shifts from blame, shame, and managerial control to relational trust, shared responsibility, and justice.

As philosopher C. Stephen Evans explains, to live accountably, in this sense, is to welcome appropriate moral expectations and offer meaningful explanation: not out of fear of sanction, but out of respect for those affected by them.[13] Accountability, then, arises from our shared moral standing. Since humans are accountable to other humans just because they are fellow humans, as philosopher Stephen Darwall argues, we have the authority or right to make certain demands on one another.[14] When accountability is viewed as shared authority, it is then not merely an obligation to submit to review, but a two-way moral exchange in mutual recognition.

We define accountability, therefore, as *a reason-giving relationship* in which both parties have a responsibility to answer and receive correction.[15] It calls for attentiveness to the other's concerns, a commitment to communicate with honesty and discretion, and the discipline to listen carefully and empathically in justifying one's actions in ways that are understandable and responsive to those affected.[16] This relational approach to accountability is not one-way. It emerges through mutual engagement, where both parties participate in building shared understanding and purpose moving forward. It is not a reaction to failure, but a proactive posture of relational trust. The accountable person speaks the truth with integrity, but also listens well. They recognize that being questioned is not an attack, but an invitation to grow. This shift in posture transforms accountability from a performance to a moral practice—from a burden to a form of moral care.

Defined as *a reason-giving relationship*, accountability depends on four interrelated dispositions: truthfulness, responsiveness, receptivity, and openness to correction.[17] These virtues resist both paternalism and passivity. Accountability thus construed avoids both the arrogance of imposed authority, which presumes to know better, and the irresponsibility of disengagement. It empowers communities to ask critical questions and to expect reasoned answers, not because they hold formal power but because they are moral participants in decisions that shape their lives. This vision resonates with recent calls for "human rights accountability from below"—an approach that seeks to democratize accountability by grounding it in community agency, moral reciprocity, and collective deliberation.[18] In doing so, accountability becomes not merely a mechanism of oversight but a practice of empowerment that redistributes moral and political authority toward those most affected.

In global health governance, this reframing would have far-reaching implications. Donors, international organizations, and national authorities are typically treated as the "accountors" (those who demand explanation). But from a virtue-based perspective, these actors also bear a responsibility to be accountable to communities: to justify their decisions in terms that are intelligible and assessable by those affected, and to listen with genuine openness to critique or dissent. This is not a procedural demand; it is an ethical and human rights requirement. It recognizes the standing of affected communities as moral equals and affirms their right to receive *truthful, intelligible, and timely justification*.[19]

This reframing orients accountability toward flourishing and interdependence rather than error correction alone. It opens space for solidarity, not surveillance, and for partnerships grounded in mutual care, not top-down compliance. In what follows, we offer a structural complement to this moral framework: the principle of subsidiarity, which gives institutional form to the ethic of shared authority and community agency.

Subsidiarity as a structural principle for decolonizing accountability

If accountability as a virtue offers a people-centered perspective that reframes how we stand in relation to one another (as co-participants in reason-giving relationships), then the principle of subsidiarity offers its structural complement. Subsidiarity holds that decision-making authority should reside at the most local competent level, unless there is a compelling reason for higher-level intervention.[20] It favors bottom-up governance, where local actors are empowered to take initiative, while higher-level institutions support rather than override them.[21] It is not simply a call for decentralization but a normative principle that seeks to align responsibility with contextual knowledge and capacity, and agency with proximity to need.[22] In this sense, subsidiarity offers a compelling alternative to both technocratic centralization and abandonment in the face of need.

By structuring responsibility along lines of proximity and capacity, subsidiarity ensures that accountability relationships remain horizontal, responsive, and contextually appropriate. It anchors the moral commitments of answerability, mutual recognition, and shared authority within the institutional architecture of global health governance, ensuring that these are not merely ethical aspirations but structural norms.[23]

In this context, subsidiarity becomes essential to global health. While solidarity is often invoked to promote shared goals across nations and communities, subsidiarity ensures that solidarity does not slip into colonialism or paternalism. It operationalizes solidarity through structures that protect community agency and foster mutual accountability. Rather than imposing "one-size-fits-all" solutions devised by centralized institutions, subsidiarity requires those institutions to support locally grounded responses, without abandoning their duty to assist when needed.[24]

The principle consists of two mutually reinforcing elements: agency and non-abandonment.[25] Agency refers to the freedom and responsibility of local actors to identify problems, determine priorities, and define appropriate responses based on their knowledge and lived experience. It recognizes that those most directly affected by injustice often have the clearest insight into what will work, and why.[26] Non-abandonment ensures that these actors are not left to fend for themselves, especially in contexts of structural inequity, corruption, or crisis. Instead, it obliges external actors to assist in ways that are proportionate, respectful, and explicitly invited.

Together, these two elements hold in tension the dual commitments of empowerment and care, resisting both domination and neglect. Practically, this means that higher-level institutions, including international organizations, donors, and multilateral agencies, should not act unilaterally or assume that formal or perfunctory consultation suffices as *meaningful inclusion*.[27] Instead, they must become accountable partners: answerable to communities for the rationale, timing, and terms of their interventions. They must be willing to listen to critique, adjust their actions in response, and support local priorities rather than assume or dictate them.

This form of shared authority reframes accountability not as vertical enforcement but as a reciprocal structure of care and justification.

Subsidiarity therefore refuses the model in which external experts arrive with ready-made solutions, indifferent to the lived realities they encounter. It also resists the extractive logic that often characterizes donor-driven systems, where communities are sites of implementation but not of co-deliberation. In many global health interventions, resources are conditioned by external metrics, predetermined indicators, or donor timelines.[28] These arrangements often reduce accountability to box-ticking exercises and marginalize local voices.[29] A subsidiarity-based framework challenges these hierarchies by prioritizing agency at the ground level and establishing accountability lines that run multi-directionally *across*, rather than merely *above*.

Therefore, subsidiarity makes space for this kind of horizontal correction without defaulting to external control. It offers a way to institutionalize the shared authority on which the virtue of accountability rests. It reinforces the idea that accountability is not only a virtue practiced by individuals but also a structure that shapes how institutions relate to one another. Together, the virtue of accountability and the principle of subsidiarity form the basis of a people-centered, decolonial approach to global health governance.[30]

Applied illustration: Donor pause and shared answerability

In early 2025, the United States Agency for International Development (USAID) ordered an immediate suspension and review of nearly all international humanitarian and global health assistance, leading to the temporary halt of approximately 90% of more than 6,000 active projects worldwide.[31] The abrupt decision, described by several observers as an act of "geopolitical vandalism," disrupted critical programs in pandemic prevention, maternal and child health, vaccination campaigns, food security, and disease surveillance, with ripple effects across more than 80 countries.[32] While humanitarian exemptions were later introduced, the sudden withdrawal revealed the structural dependency built into vertically organized aid systems and the fragility of donor-centered accountability mechanisms, which often position external funders as unilateral decision-makers rather than partners in shared deliberation.

Viewed through the lens of *accountability as a virtue*, the central question is not the attribution of blame but the construction of a broader system of answerability: Which priorities were shaped by donor logic rather than local needs? How were past funds allocated? And now that this external support has vanished, who is involved in rethinking the future? Local communities are not mere victims; they are primary agents with the human right to ask questions, receive answers, and co-determine the path forward. From the perspective of *subsidiarity*, an adequate institutional response cannot be limited to merely resuming financial flows. It requires a reordering of authority so that local providers, community councils, and ministries of health co-deliberate priorities, timelines, and monitoring frameworks.

Three operational implications follow: first, the need for *truthful accounting* of prior commitments and disbursements at the country level, ensuring clarity regarding both decisions and their underlying rationales; second, the establishment of *inclusive, locally led forums* to identify critical gaps, competing priorities, and context-sensitive trade-offs through deliberative engagement; and third, the adoption of *system-strengthening partnership terms* that condition renewed external support on demonstrable efforts to build sustainable domestic capacity rather than perpetuating fragmented or vertical programs.

Understood in this way, the 2025 USAID suspension is more than a moment of disruption; it serves as a revealing case of how the virtue of accountability and the structural principle of subsidiarity can jointly reorient global health governance. Therefore, it can serve as a catalyst for realignment: lines of accountability should begin to run horizontally (among domestic actors) and multidirectionally (with external partners), replacing unilateral control with shared authority and reciprocal answerability. This illustration thus substantiates our normative claim: that *virtue* (the cultivated disposition to speak truthfully, to listen, and to be corrigible) and *structure* (the principle of subsidiarity) should operate together to generate a more contextual, equitable, and resilient ecosystem of global health accountability.[33]

Conclusion

As new global health frameworks such as the Pandemic Treaty take shape, there is a risk that accountability will again be reduced to reporting obligations or centralized enforcement.[34] This paper has argued for a decolonial alternative: one that reframes accountability as a virtue and operationalizes it through the principle of subsidiarity. Together, they offer a people-centered model grounded in shared answerability, moral presence, and structural care. In a fragile world, accountability must move beyond metrics with an approach that resists both abandonment and dependency. Only when global health becomes genuinely accountable to those it claims to serve—by listening across borders, not dictating from above—can it fulfill its promise of justice. This requires more than transparency; it demands a fundamental shift in power, where local communities are not just consulted but recognized as co-authors of the future they inhabit.

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Chasing Accountability in Global Health: Reflections from Experience on the UN Secretary-General's Independent Accountability Panel on Women's, Children's, and Adolescents' Health

ALICIA ELY YAMIN

Abstract

The story of United Nations (UN) efforts to create an independent mechanism to foster greater accountability across global health is one of high hopes, missed opportunities and, ultimately, planned project failure. The creation of the UN Secretary-General's Independent Accountability Panel on Women's, Children's and Adolescents' Health (IAP) in 2016 was born out of the idea that accountability was the missing link to achieve progress on the Sustainable Development Goals related to women's, children's, and adolescents' health. The IAP produced four reports before it was dissolved in 2020. Subsequently, other independent accountability mechanisms have been proposed, such as for antimicrobial resistance. In this paper, I draw on my experience as a member of the IAP to examine the context for the creation of the IAP and share four lessons as to why meaningful accountability has been so elusive in global health and how future efforts might benefit from these insights. These lessons relate to the need for (1) normative grounding; (2) institutional legitimacy; (3) genuine independence; and (4) conceptual clarity with respect to the meaning of accountability. I conclude by arguing that the deeply neoliberal and colonial architecture of global governance for health constrains possibilities for transformative accountability. In telling this story, I do not pretend to represent the views of other IAP members, who may have very different reflections.

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Competing interests: None declared.

Introduction

The story of United Nations (UN) efforts to create an independent mechanism to foster greater accountability across global health is one of high hopes, missed opportunities, and, ultimately, planned project failure. At the dawn of the Sustainable Development Goals (SDGs) and the implementation of Agenda 2030, accountability-talk in global health was at its apex; "accountability" seemed to be mentioned at every global health summit, paraded as the highest of political virtues, and deemed the long-sought development jackpot. The creation of the UN Secretary-General's Independent Accountability Panel on Women's, Children's and Adolescents' Health (IAP) in 2016 was born out of this enthusiasm for the idea that accountability was the missing link to achieve progress on the SDGs related to women's, children's, and adolescents' health.

The IAP produced four reports while it existed. After its introductory report in 2016, the IAP's reports from 2017 to 2020 focused on accountability in the context of specific areas: adolescents' health in 2017; the private sector in 2018; and COVID-19 and universal health coverage in 2020.[1] At its inception, I was appointed by the UN Secretary-General to the IAP, along with initially eight, and later nine, other experts from diverse disciplines from around the world who each served in our individual capacities. Along with some of the original members, I was reappointed in 2018 and served until the IAP was terminated. In 2020, just as the COVID-19 pandemic began to ravage the world, the IAP was dissolved. It was determined that accountability would be instead centered around the UN High-Level Political Forum, a country-to-country peer review process that differed substantially from the concept of an independent accountability panel.[2] Subsequently, other independent accountability mechanisms have been proposed, such as for antimicrobial resistance.[3]

In this paper, I first set out the context for the creation of the IAP. Thereafter, I share four lessons as to why meaningful accountability has been so elusive in global health and how future efforts might benefit from these insights. These lessons relate to the need for (1) normative grounding; (2) institutional legitimacy; (3) genuine independence; and (4) conceptual clarity with respect to the meaning of accountability. I conclude by arguing that the architecture of global governance for health constrains possibilities for transformative accountability. In telling this story, I do not pretend to represent the views of other IAP members, who may have very different reflections.

Context for the IAP's establishment

The 2008 financial crisis that began in the United States and quickly spread throughout the world shook development finance, as well as domestic resources for health. The International Monetary Fund doubled down on austerity programs, which deeply affected health systems and development financing.[4] By 2010, two-thirds of the way through the Millennium Development Goals (MDGs), lagging progress on MDGs 4 and 5 led then-UN Secretary-General Ban Ki-moon to launch the Every Woman, Every Child Initiative (EWEC) to "intensify national and international commitment and action by governments, the UN, multilaterals, private sector and civil society to keep women's, children's and adolescents' health and wellbeing at the heart of development."[5] As part of this initiative, the UN Secretary-General set out a Global Strategy on Women's and Children's Health, which, among other things, identified accountability deficits as a principal obstacle to progress.[6] That first Global Strategy resulted in a World Health Organization (WHO)-led Commission on Information and Accountability. The commission elaborated a "unified accountability framework" that included "monitor, review, and act," which in turn led to the creation of the independent Expert Review Group on Information and Accountability in Women's and Children's Health (iERG), a *sui generis* "global oversight mechanism to ensure that commitments to women's and children's health were being delivered on time and with impact."[7]

The first Global Strategy focused on 74 low- and middle-income countries, with 49 "priority" countries that had high burdens of child and maternal mortality.[8] By the end of the MDGs, progress was still highly uneven, and the countries "furthest behind" were largely in Sub-Saharan Africa, where there was the weakest infrastructure.[9] Macroeconomic and structural constraints, however, did not factor into measuring progress in the MDGs. Moreover, while we should applaud progress on these scourges, the plainly colonialist dynamics of the knowledge and governance discourses established in the MDGs presupposed a particular kind of accountability. That is, many of the indicators, such as maternal mortality ratios (MMRs), were calculated using algorithms and monitored at a distance by global institutions as opposed to national statistical offices.[10] Further, arguably, in these highly aid-dependent countries, turning *global* goals and targets—for example, reduce global maternal mortality by 75%—into *national* planning tools (i.e., X country must reduce its MMR by 75%) perverted the meaning of the goals and actually diverted accountability from governments to donors and international institutions, away from their own citizens.

The architects of the Sustainable Development Goals sought to learn from some of the identified problems in the MDGs.[11] The SDGs addressed inequality, not just extreme poverty; explicitly noted intersectionality and links across goals; and applied universally to all countries. SDG 3 focused on health broadly, and on universal health coverage and health systems, as opposed to top-down siloed approaches to maternal health, child health, and certain infectious diseases.[12] In preparation for the SDGs, in 2015, the UN Secretary-General set out a second, bolder "Global Strategy on Women's, Children's *and Adolescents'* Health," through which the iERG mechanism was succeeded by the IAP.[13] The revised Global Strategy went beyond setting out goals with respect to "surviving" and "thriving" and in its third pillar called for "transforming" conditions that would allow women, children, and adolescents to enjoy the fruits of sustainable development.[14]

In its last report, the time-limited iERG had set the stage for the IAP, arguing for a more robust independent accountability mechanism and asserting that

> *there is vigorous debate about the details. Where should this group be hosted? What should be its exact terms of reference? Who will fund it? Who should it report to? How should its recommendations be acted upon? These details matter. But, much more importantly to us, the idea of independent accountability seems secure, at least in this one sphere of global health and in the short term.*[15]

In retrospect, those concerns were far from logistical details, and the idea of independent accountability was not so secure, even in this one area of global health.

Lesson 1: Accountability cannot be merely instrumental; it must have some normative *raison d'être*.

It was apparent from the outset that while, in global health, accountability was seen in instrumental terms—i.e., to address lagging progress and "improve the oversight of results and resources"—the capacious and somewhat slippery concept had to "earn adequate normative traction."[16] The technocratic, results-based management approach to the goals, targets, and indicators that permeates global health institutions was simply not going to be sufficient to meet the moment. As Danielle Rachad writes, accountability alone is merely "an empty container that structures and explicates a bilateral or multilateral power-relationship. Some substantive normative view, thus, must flesh out this skeleton."[17] The proverbial flesh that was to imbue the instrumental skeleton of accountability with life, and to make it desirable and attractive for its own sake, was good governance based on human rights, which had been highlighted in both Global Strategies. Moreover, Agenda 2030 itself was "to be implemented in a manner that is consistent with the rights and obligations of States under international law," which includes international human rights law.[18] Accountability has long been seen as the *sine qua non* of human rights, converting identified problems into violations to be remedied through standard setting and the creation of institutions and procedures to implement those standards.

In 2003, in light of the top-down approach of the MDGs, which contrasted sharply with the human development emphasized in the trans-sectoral UN development conferences of the 1990s, the UN Development Group had set out a "Common Understanding on Human Rights-Based Approaches to Development Cooperation and Programming," which highlighted accountability and rule of law among its pillars.[19] That Common Understanding subsequently led to efforts to set out intergovernmental agreements on human rights-based approaches to health at the UN Human Rights Council, the first two of which related to maternal health (2012) and child health (2014).[20]

The IAP drew heavily on these experiences, noting throughout our reports the relevance to accountability of human rights norms related to equality and nondiscrimination, meaningful participation of affected communities, freedoms of information and expression, and other democratic ideals necessary for social and legal accountability. However, we had neither the capacity nor the authority to assess specific countries' legal and policy frameworks, budgets, public policies, monitoring and evaluation standards, and remedies for violations, as these rights-based approaches had set out.

Moreover, while we rooted our normative legitimacy in human rights law, we were operating within a global health architecture that profoundly imbricated the unaccountable private power of transnational corporations, philanthropic foundations, and other private actors.[21] Further, the economic political power relations in the global order were structured through other bodies of international law; by the 2010s, neoliberal globalization had shaped international investment law, trade and intellectual property law, and tax law, among others.[22] The "obligations of States under international law" that were meant to guide actions under the Global Strategy included those set out under these other binding legal frameworks. This, in turn, stymied the implementation of many of our recommendations regarding, for example, curbing the power of pharmaceutical monopolies in order to ensure access to medicines, and stemming illicit financial flows in order to preserve domestic resources for health systems.

Far from oblivious to this context, from the very first report in 2016, the IAP attempted to leverage our status as experts to highlight what the 2014 Lancet–University of Oslo Commission on Global Governance for Health had labeled "global political determinants of health: The norms, policies, and practices that arise from global political interaction across all sectors that affect health."[23] Importantly, in our reports we addressed issues in high-income as well as lower-income countries, as well as systemic forces structuring global governance for health. For example, we included discussion of the taxation of corporate actors, both in terms of products harmful to health (such as sugary beverages) and in terms of international tax evasion.[24]

Yet, as a tiny panel of volunteers with a drastically underfunded secretariat, we had no way in which to foster allegiance to a set of normative expectations that often conflicted either with these other binding legal frameworks or with the growing conservative populist backlash to sexual and reproductive health and rights that was emerging forcefully at the time.[25]

Lesson 2: An independent accountability mechanism requires institutional legitimacy.

From the outset, the IAP struggled with institutional legitimacy, understood broadly as the perception that an institution rightfully exercises authority and can command obligations. The exceptionally broad remit given to the IAP by the Executive Office of the UN Secretary-General (EOSG) was explained to us at our first face-to-face meeting: "The Independent Accountability Panel (IAP) … is empowered to command attention from the global community across the full range of the updated Global Strategy's accountability framework … across the spectrum of issues that comprise the Global Strategy's 'Survive, Thrive, and Transform' themes."[26] From the start, it was unclear what "command attention from the global community" really meant, given that the IAP had no ability to sanction governments, global institutions, or private actors for poor performance—or to confer rewards for progress. Indeed, Agenda 2030, on which the SDGs drew, had called for a "robust, *voluntary*, effective, participatory, transparent and integrated follow-up and review framework," and it was immediately apparent that states understood compliance with the IAP's follow-up and review mechanism to be voluntary.[27]

The legitimacy stories of accountability institutions within states, even when contested or dismissed in practice, are reasonably well accepted in theory. However, accountability in global health is far more complex than in a domestic sphere with well-established institutions. As Ruth Grant and Robert Keohane note, without a centralized government, there are a variety of power-wielders who relate to one another in non-hierarchical ways.[28] For this very reason, in such a domain, "there is no single 'problem of global accountability'; there are many."[29] Given that, the lack of a clearly defined remit and legal authority posed a major problem for the efficacy of the IAP in holding states, global institutions, and private actors to account.[30]

States are generally the subjects or principals of international law, and international institutions, such as WHO, act as their agents.[31] Human rights law alters this relationship insofar as it sets out individuals as subjects of international law and asserts that sovereign authority cannot be exercised wholly independently from international standards. However, the institutional legitimacy of an international institution, such as a supranational human rights body, to issue judgments regarding a country's performance is based on the consent of states to be bound by specific treaties or membership in specific organizations. The rules regarding signature, ratification, and accession to human rights treaties, as well as interpretation of the permissible scope of reservations, understandings that are established under international law, did not exist with regard to the IAP.[32]

In our case, there was no formal consent from states and other duty bearers to be held to account, and the follow-up and review mechanism had explicitly been stipulated to be "voluntary."[33] Endorsing Agenda 2030 or the Global Strategy was a far cry from consent from a particular country to be judged by the IAP for (in)actions under specific treaties that it had ratified, or based on our interpretation of the *corpus juris* of international human rights law. We of course made efforts to socialize our reports with human rights treaty monitoring bodies, including the Committee on the Rights of the Child. However, the IAP, just as was the case with the iERG before it, did not have the authority to "name and shame" specific states for violations of human rights related to women's, children's, and adolescents' health. Likewise, despite holding civil society hearings and emphasizing the importance of civic space and freedoms of assembly and information, we did not have the authority to receive individual or group complaints from affected people and communities, as is possible through complaint procedures in human rights mechanisms, with all their limitations.

Our reports were limited to invoking standards, citing other well-established human rights authorities as well as reputable indexes, and using data to illuminate important comparisons and trends. Because we had no proverbial sticks, we sought to use carrots, praising certain countries for legislative, regulatory, judicial, and other efforts. For example, we praised Thailand's National Health Security Office for accountability in its strategic purchasing, including of benefits for women and children; Brazil's Supreme Court for banning corporate contributions to parliamentarians to influence food and other policies; and multiple countries' legislatures for instituting sugary beverage and alcohol taxes.[34]

Additionally, the IAP faced particular legitimacy challenges due to the subject matter that was a central domain of our work: sexual and reproductive health and rights. While extraordinary advances in gender equality and sexual and reproductive health and rights had been made in international human rights law and some domestic constitutional law since the 1990s, a growing conservative backlash was apparent during these years, which associated human rights guidance with illegitimate ideological global governance agendas.[35] Across our reports, we made evidence-based recommendations that aligned with emerging consensuses in international law. Nevertheless, in the context of growing conservative movements that used contestation in reproductive rights around abortion and LGBTQ+ rights to attack the broader legitimacy of global human rights institutions writ large, our inability to stand on firm institutional legitimacy proved challenging.

Holding donor states and global institutions to account proved equally difficult. When we attempted to act as a "monitor of monitors"—for example, pointing out major gaps in data availability across the 60 indicators for the second Global Strategy—and questioned whether the right indicators were being used to enable meaningful action, global health institutions were not always receptive.[36] This resistance to our independent review extended to arguing that the IAP's "dashboards" of indicators were duplicative of work that was already being done, which ignored the fact that the data were set out for quite a different purpose, such as delineation of responsibilities or concern for intersectional inequalities, which were key to accountability in the SDG framework. For example, the Institute for Health Metrics and Evaluation and Countdown to 2030 prepared special visualizations based on its own database as well as Demographic and Health Survey and Multiple Indicator Cluster Survey databases, which enabled us to show equity gaps in the financing of essential reproductive, maternal, newborn, and child health services.[37] While we were able to promote broad general agreement regarding the need for more disaggregated data and actionable information to address equity gaps, it is not clear to what extent sustained changes were made across these institutions' data collection and review processes, or in development financing, as a result of issues the IAP identified.

Perhaps the most disheartening were our efforts to hold actors in the private sector to account for pledges and activities.[38] At the time, the private sector and philanthrocapitalist solutions were being courted by leaders in global health, and championed as responses to the lack of public sector resources and capacity, to, among other things, mobilize "billions to trillions."[39] For our private sector report, given the complexities and diversity of private sector actors involved, we undertook additional efforts: we met with private sector stakeholders both in New York and at the World Economic Forum headquarters; we hired a consultant to conduct background research; and, most importantly, a subset of the IAP panelists, together with the then-director of the secretariat, spent an entire additional week of volunteer time holding meetings with an array of informants and deliberating about key themes.

The 2018 report we produced contained detailed findings and evidence-based recommendations regarding the private provision and financing of services; the pharmaceutical industry and access to medicines; the food industry; the UN Global Compact and EWEC partners; and donor and business engagement in the SDGs.[40] We strongly argued that increased monitoring and regulation of private sector actors across these industries and beyond was critical to ensuring accountability and in turn making progress on women's, children's, and adolescents' health. Indeed, in 2018, we stood out among international panels for arguing for extraterritorial obligations of donor states to regulate private sector actors headquartered in their own countries, given the influence of the transnational food, pharmaceutical, and other industries affecting health.[41] Nonetheless, the lack of institutional legitimacy meant that corporate and private actors were able to ignore or dismiss our conclusions and recommendations, and continue to trumpet discrete actions of voluntary largesse.

Lesson 3: Meaningful accountability requires genuine independence of the oversight mechanism.

In the context of independent judiciaries and other national oversight mechanisms, independence generally refers to two concepts: (1) *autonomy*, which relates to freedom from political influence at the domestic level and (2) decision-making *authority*, which, as noted above, depends on both normative and institutional legitimacy. These two concepts are equally relevant to the independence of oversight mechanisms at the global level, which is why many global panels (e.g., supranational human rights tribunals) operate within a set of rules intended to safeguard independent judgment.

As noted above, the IAP's authority was challenged from the outset because it was not rooted in a legal framework that would enable the sanctioning of relevant actors. Autonomy was also hindered from the beginning. Structurally, the IAP was created by the EOSG and reported directly to the UN Secretary-General, not WHO as the iERG had done. We presented our reports to the UN Secretary-General at the UN General Assembly, not the World Health Assembly, which underscored that meaningful accountability issues extended beyond the remit of health ministers. However, from the beginning, the IAP faced challenges in terms of its independence from the EWEC ecosystem.

The iERG had not been created to be independent of WHO.[42] From 2012 to 2015, it attempted to assert its small "i" independence from the rest of the EWEC ecosystem with regard to its recommendations. However, noting the lack of independence as a major flaw in the iERG, the IAP was established as independent from WHO from the outset, at least in theory. Nonetheless, in practice the IAP's secretariat was situated within the Partnership for Maternal Neonatal and Child Health (PMNCH), a "partnership" hosted by WHO for which WHO provides a legal, administrative, and fiduciary platform. The IAP received its very small funding as a percentage of the PMNCH budget and was therefore legally accountable not just to the EOSG but also to the Board of PMNCH, which includes 30 members from among the partnership's membership.[43] The initial secretariat staff had even been hired by PMNCH, although we quickly replaced those personnel with direct hires by the IAP and insisted on exclusive control over staffing decisions. Further, despite a theoretical firewall between PMNCH and the IAP secretariat, being physically and administratively hosted by PMNCH frequently meant obtaining budgetary approvals and sharing information.

In addition to funding and physical positioning, another aspect of autonomy relates to the appointment process to the IAP. The EOSG appointed each of us to serve in our individual capacities, based on a diversity of experience, gender, professional background, geographic representation, and age (we had two "youth" representatives who served respectively from 2016 to 2018 and 2018 to 2020). Some members had previously held high positions within the UN system; many if not all of us had participated in WHO, PMNCH, and other panels previously and were well known in that orbit; two of our co-chairs, Carmen Barroso and Joy Phumaphi, had previously served on the iERG. Those backgrounds may be entirely justified for a panel of the nature of the IAP, which had to navigate a complicated global health institutional architecture and also required some institutional continuity with the iERG experience. However, it is not clear what pool of possible candidates was drawn on by the EOSG, nor the role of WHO and PMNCH in the shaping of that pool or the ultimate selection of panelists. Likewise, it was unclear how those actors shaped the selection and remits of the chairs in particular, who exercised substantial control over the IAP's internal governance and external representation, as well as communications with other actors in the EWEC ecosystem.

To be clear: this is not a personal critique of anyone. I greatly admired many of my esteemed co-panelists' commitments to promoting equity in global health, in addition to their formidable technical expertise. It was a privilege to serve with them, and many of us have stayed in touch, united by our shared concern for women's, children's, and adolescents' health. Nonetheless, the processes for appointment—and especially for reappointment in 2018—were not sufficiently transparent to assess the IAP's structural autonomy from other actors in the EWEC ecosystem.

Further, meaningful autonomy also requires being protected from retaliation from powerful stakeholders after critical reports are issued. The IAP was accountable not just to the EOSG, which would have been complicated enough. It was also legally answerable to PMNCH Board, whose members represented different constituencies, including donor governments and foundations, "partner governments," UN agencies, the private sector, and nongovernmental organizations. This arrangement placed us in the impossibly complicated position of trying to hold accountable actors that held sway over our financing and continued ability to function. Such a structural arrangement invariably affected the boundaries of our permissible critique.

Genuine independence and institutional legitimacy are closely related. At a minimum, the IAP would have required a direct, clearly articulated mandate and accompanying budget directly from the EOSG that was legally rooted in state consent, with transparent selection processes. Without those conditions in place, the hard-won capital "I" of the IAP compared with the aspirational "i" in the iERG ended up being less of an achievement than we had hoped.

Lesson 4: The concept and implications of accountability remain deeply contested in global health.

What complicates accountability discourses in global health is not only the various contexts they must address but also the multiplicity of concepts they imply and their more or less pronounced normative undertones.[44] Because so much of the global health community viewed accountability in a very narrow limited way of *monitoring* data, much of the IAP's work entailed explaining what *human rights* demanded in terms of accountability. In a 2017 article, Carmel Williams and Paul Hunt explained the importance of going beyond monitoring:

> *if the SDGs are simply monitored, using the agreed indicators, human rights failings can be overlooked, intentionally or otherwise. For example, if a state were to introduce punitive measures against women who fail to give birth in approved facilities, they would likely show improvement on SDG 3.1.2, with an increased number of births taking place under supervised care. However, if this indicator is achieved without women's consent or in the absence of culturally acceptable care being provided, then it breaches women's human rights entitlements.*[45]

The IAP took as a starting point the "monitor, review, act" framework articulated by the Commission on Information and Accountability and used by the iERG, but immediately noted that it would additionally include *remedies*—in other words, monitor, review, act, *and remedy*. Our reasoning in adding judicial and other remedies was that to be consistent with human rights law and meet commitments to the bolder second Global Strategy and the SDGs, national legislation and regulations were required, policies and national plans of action needed to be devised and implemented, and priority-setting mechanisms for universal health coverage needed to be instituted. All of these require the use of law and are issues overseen by courts in democratic societies.

As the High-Level Working Group on Health and Human Rights of Women, Children and Adolescents recognized in 2017, accountability for rights in and through health requires legal review as part of democratic governance.[46] Likewise, General Comment 22 on the right to sexual and reproductive health, which the UN Committee on Economic, Social and Cultural Rights issued in 2016, underscored far more strongly the need for judicial remedies in relation to health than had its earlier General Comment 14 in 2000, noting that it was imperative that

> *the right to sexual and reproductive health … be fully justiciable at the national level, and that judges, prosecutors and lawyers be made aware of that such a right can be enforced. When third parties contravene the right to sexual and reproductive health, States must ensure that such violations are investigated and prosecuted, and that the perpetrators are held accountable, while the victims of such violations are provided with remedies.*[47]

Judicial and quasi-judicial remedies are equally important at the international level for accountability in global health and within efforts to achieve the SDGs. For example, in its 2017 report, the IAP highlighted the International Centre for Settlement of Investment Disputes tribunal case in which Philip Morris had sued the government of Uruguay for plain packaging on cigarette containers, in keeping with the WHO Framework Convention on Tobacco Control, and lost. The tribunal specifically noted the margin of appreciation (i.e., scope of permissible policy action) afforded to states for the protection of public health.[48] In its 2018 report, the IAP noted the increasing frequency of concluding recommendations from UN treaty monitoring bodies relating to the regulation of private business enterprises, in relation to health and beyond.[49]

The addition of judicial remedies in the IAP framework had a fundamental epistemic purpose as well; it underscored that when they are addressed by courts, failures to address health issues are transformed from being lapses in quality of care to questions of dignity and nondiscrimination, violations of bodily integrity, and the like. This epistemic change was essential to undergirding our normative claim that accountability was about more than improvements in health indicators and required a whole-of-government response, including sanctions, which "independent review" was simply too weak to trigger. In a real-world example, when an estimated 272,000 women were forcibly sterilized in Peru between 1996 and 2000 under Alberto Fujimori's administration, an independent review was performed by the Population Council, which found serious deficiencies in the quality of care and informed consent. By contrast, human rights activists mobilized politically and brought litigation, initially domestically and later internationally, arguing that violations of bodily autonomy had to be understood in the context of systemic discrimination against Indigenous women and the weaponization of the health system under Fujimori.[50]

When supranational tribunals or forums are involved, the institutional response shifts as well. That is, when a supranational forum offers recommendations or a judgment, ministries of foreign affairs, justice, finance, and women and family are involved, not just the ministry of health.[51] For example, Brazil created an interministerial committee when the Committee on the Elimination of Discrimination Against Women found it in violation of rights regarding maternal health in *Alyne da Silva Pimentel v. Brazil*.[52]

At the time, the enormous effort we made to explicate accountability's dimensions seemed an appropriate, even strategic, response to the IAP's lack of capacity and authority.[53] We were committed to using our platform to make meaning out of the ubiquitous disparities and deprivations faced by women, children, and adolescents regarding their health and to explain how such injustices could be legally remedied and not merely lamented. Because we were a tiny volunteer panel, and could not ourselves sanction behavior, our efforts were rightly intended to catalyze the strengthening and implementation of systems at the national level and to reaffirm the importance of existing systems at the international level.

This focus on effective systems of democratic governance was a departure from an idea proposed in the final report of the iERG, which called for all countries to "establish and implement transparent, participatory, democratic, and independent national accountability mechanisms to monitor, review, and act on results and resources for women's, children's, and adolescents' health, with special attention to the translation of recommendations into action and reporting to Heads of State."[54] Rather than promoting the creation of mini-IAPs filled with technical specialists, the IAP instead chose to emphasize that accountability in women's, children's, and adolescents' health was a matter of regulating and transforming power through institutional arrangements, which both uphold and require functioning democracies. It was critical for the IAP, both epistemically and politically, to repeatedly break through the tendency to focus on the health sector, and delineate the roles of many institutions—from national statistical offices to health providers, and from parliaments to judiciaries—in protecting and promoting the health and rights of women, children, and adolescents.

On the one hand, it was the IAP's insistence on judicial remedies that, perhaps more than any other change from the iERG, garnered the enormously positive feedback some of us received from human rights advocates who were in the trenches fighting to advance the justiciability of health-related rights and hold their governments and other actors accountable. On the other hand, powerful actors that may have bristled at the possibility of facing sanctions and other legal remedies either rejected the idea that judicial remedies should play a part in advancing accountability under the SDGs or chose to elide the significance of emphasizing remedies.

Although the IAP hoped to "command the attention of the global community" regarding the normative importance of all of these dimensions of accountability, including remedies, in well-functioning governance, in retrospect the time spent on justifying evolving explanatory frameworks did not prove as helpful as we hoped in attempting to shore up our legitimating toolbox. Despite significant efforts—including the creation of a brief video created at Harvard University on a pro bono basis—in its short existence, the IAP had neither the necessary resources nor the authority to catalyze a broader acceptance of the justiciability of health rights related to women's, children's, and adolescents' health at national and international levels.[55]

Conclusion

In 2019, an independent evaluation of the IAP was commissioned for the EWEC ecosystem. Among the principal recommendations was to evolve the remit of the IAP to include accountability for "who is being left behind, where and why" across health and well-being in the SDGs, with the idea that women, children, and adolescents would be among the most left behind. However, there was no appetite to address the extent to which the global political economy itself perpetuates the exclusion of certain populations in certain countries. Nor was there readiness to acknowledge the dramatically different legal mandate and institutional configuration that such a remit would have required. In early 2020, rather than set up a successor panel, the IAP was dissolved and accountability efforts were centered on the country-to-country peer review High-Level Political Forum for Sustainable Development.[56]

At a time when the Trump administration has upended global governance for health and we are seeing a disastrous retrogression on women's, children's, and adolescents' health, among many concerns, the need to revive discussions of accountability in global health could not be more urgent. However, the questions raised here bear serious consideration before additional panels are set up that are destined to fail. I have argued here that the IAP faced at least four challenges in promoting accountability for advancing women's, children's, and adolescents' health in the SDGs, which involved the lack of effective normative grounding, institutional legitimacy, genuine independence, and conceptual agreement regarding elements of accountability and why they matter.

All of these factors in turn must be understood within a neoliberal global order permeated by enormous economic and political power asymmetries, which constrained transformative accountability. Truly transforming the conditions that perpetuate ill-health for women, children, and adolescents, as the third pillar of the 2015 Global Strategy had set out, calls for changing tax, sovereign debt, investment, and trade and intellectual property rules; adding leaders from the Global South to decision-making multilateral institutions; changing the obsolete model of charity and crisis-based development finance; and curbing the power of private actors in the global health architecture. It is those structural factors and "rules of the game" that consign women, children, and adolescents to being left behind in, if not excluded from, progress in human development.

Even as we need to mitigate the devastation that the Trump administration's shambolic destruction has created, this inflection point also offers an opportunity to consider how we might genuinely transform global governance for health, including the production and distribution of resources, the construction of knowledge and epistemic authority, leadership criteria, control over agenda setting, and possibilities for accountability.[57] Hard-won lessons from the IAP should inform that thinking. There is no room for nostalgia for the status quo ante, nor for the empty invocation of new mantras—such as the newly popular "country ownership"—without situating such calls in the reality of macroeconomic constraints and alignment with technology transfer and other legal reforms. To recover lost trust in institutions and advance global health justice requires nothing less than a radical reimagining of global governance that addresses the political determinants of global health and reanimates hope for realizing dignity, equality, and well-being for swaths of people across the world.

Acknowledgments

I am enormously grateful to Monica Dey for her help with the preparation of this manuscript.

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EDITORIAL

Examining Institutional Corruption in Mental Health: A Key to Transformative Human Rights Approaches

ALICIA ELY YAMIN, CAMILA GIANELLA MALCA, AND DANIELA CEPEDA CUADRADO

Introduction

At a time of unprecedented upheaval in the world order triggered by the Trump administration's withdrawal of funding and institutional engagement, this special section adds to broader conversations regarding how human rights praxis might contribute to a more democratic political economy of global health, particularly global mental health. These conversations are occurring against a backdrop of dramatically reduced policy space across global health, as a result of cuts in development finance from the United States and other countries, as well as debt servicing and illicit financial flows. Today, the Global South loses more than US$1.7 trillion annually to tax evasion, avoidance, and illicit financial flows, and as of 2024, developing countries' external debt was almost US$12 trillion, which translates into 90% of export revenues. The United Nations Conference on Trade and Development estimates that 54 countries spend more on debt servicing alone than on health care.[1] In this context, when there are strong pushes to increase private financing and provision, and to implement cost-cutting in health systems, the papers collected here present a cautionary tale for policy makers and human rights activists alike.

Looking back at the last 40-plus years, the pieces in this special section make clear that the architecture of global governance in mental health has long been marked by the concentration of economic and epistemic power in private actors, driven by knowledge hierarchies favoring biomedical approaches, and trapped in colonialist dynamics and mentalities.[2] Despite significant progress in creating enforceable normative standards, especially since the entry into force of the landmark United Nations Convention on the Rights of Persons with Disabilities, and in elaborating the contents of human rights-based approaches

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Competing interests: None declared.

(HRBAs) to health, these efforts have not produced transformative change in practice. There are many factors that have stymied progress, but here we identify *institutional corruption* as a significant barrier to the promotion of rights related both to mental health and psychosocial disabilities.

In human rights praxis, corruption is often framed in terms of "leakage," or abuse of entrusted public power for private gain, which leads to mapping perpetrators, victims, and potential reforms. The underlying presumption is that corruption is an illicit deviation from the legal norm. In the context of neoliberal globalization, an uncritical focus on corruption in the public sphere has been aligned with global and national policies promoting the privatization of health services, including mental health services. At a time when human rights are under attack not just from conservative populists but also progressives who argue that the human rights movement has been either complicit in the rise of neoliberalism or ineffectual at constraining its devastating consequences, we should take the consequences of these inadvertent alignments seriously.[3]

In analyzing the connections between mental health, human rights, and corruption, the papers collected in this special section adopt a different starting point that does not take as a given that the problem of corruption lies exclusively in public officials' conduct—or that the obvious remedy is to privatize to diminish opportunities for such malfeasance. Here, we focus on *institutional corruption*. We adopt Lawrence Lessig's definition of institutional corruption as

> *manifest when there is a systemic and strategic influence which is legal, or even currently ethical, that undermines the institution's effectiveness by diverting it from its purpose or weakening its ability to achieve its purpose, including, to the extent relevant to its purpose, weakening either the public's trust in that institution or the institution's inherent trustworthiness.*[4]

When applied to mental health, focusing on institutional corruption allows us to better understand how public and private organizations alike may "deviate from their mission by engaging in activities that endanger it, even if these activities are not illegal."[5]

Highlighting institutional corruption in mental health in no way negates the rampant problem of regular corruption. It does, however, call for a critical examination of prevalent recommendations of best practices for public policies made without due consideration of socioeconomic context and health system capacity. These include scaling up mental health coverage without adequate attention to the content and quality of that care; privatizing services for mental health that may produce unequal treatment through dual practice, among other things; and proliferating "cost-effective" pharmaceutical approaches in a global context in which the social determinants of mental health, as well as public funding for health systems, are being hollowed out.

Reexamining the application of human rights to mental health today could not be more urgent, given the widespread attention placed on a global mental health crisis. Alarm bells over the "crisis in mental health" have been ringing for some time. For example, suicide rates in the United States rose 30% from 1999 to 2016, representing an increase among both sexes, all racial and ethnic groups, and all urbanization levels.[6] After the COVID-19 pandemic, *The Lancet* published a study finding an additional 53.2 million cases of major depressive disorder and 76.2 million cases of anxiety disorder globally due to the pandemic.[7] In recent years, *The Lancet* has devoted a commission to global mental health and has published multiple series, including on adolescent psychiatry, transforming mental health implementation research, and climate change and mental health.[8] While structural issues are often mentioned, the focus in these reports and in the Movement for Global Mental Health still tends to be on scaling up and securing equitable access to care within and across countries. Frequently, the human rights principles of nondiscrimination and equality have been invoked in these calls.

HRBAs also highlight the need to address how the social determinants of health and well-being impact the prevalence of mental health issues, which are distinct from but overlap with some psychosocial disabilities. A key insight of HRBAs is that institutional arrangements, and the laws that structure them, can be changed to modify the social determination of mental health, as well as the social creation of disability. The papers collected here go a step further, focusing on the role of evolving political economies that have fostered institutional corruption and prevented such changes from being implemented in practice. In so doing, they denaturalize the economic order as a given and examine how it interacts with mental health policy and the practice of psychiatry in middle-income and lower-middle-income countries.

For example, in the United States, prolonged declines in wages, barriers to education (and the instrumentalization of education as the sole key to social mobility), the deterioration in job quality, and subsequent alienation from the labor force are all underlying determinants of the increase in suicides and "deaths of despair," and they are simultaneously consequences of the United States' political economy as increasingly dominated by the interests of the wealthiest and a discourse of meritocracy that blames poverty on moral failure.[9] While human rights analyses on mental health that focus on socioeconomic issues directly related to treatment or health care access, or specific policies on issues such as housing, are important, they fail to capture the broader structural drivers that shape the possibilities for well-being.

If we extend this broader focus to the rest of the world, it becomes even more urgent to situate our human rights analyses and claims in the context of neoliberal economic orders and examine how they institutionalize, legitimate, and reproduce regimes that drive systemic mental health issues—as well as individualized biomedical remedies for those problems.

As detailed in several papers in this special section, the prioritization of medication as treatment for mental health—which began in the 1980s and has greatly expanded treatment in high-income and middle-income countries alike—exists in this broader context of the hegemonic neoliberal ethos that pervades academic and public conceptions of mental health care, and which magnifies narratives of mental health as a biological issue and an individual responsibility.[10] The special section further considers who the actors are that are promoting and profiting from these global discourses, which are then transferred to local contexts. Analyzing how the multinational pharmaceutical industry has profited from the guild interests of professional psychiatry calls attention to how specific actors systematically extract gains that may be unrelated to or even undermine the health and well-being of patients and the public in general. Those entrenched interests, and the political control they exercise, help explain the systematic marginalization of social determinants of mental health in setting priorities for action, and hold lessons for moving forward.

Different regions, disciplinary perspectives, and issues

The collected papers span geographic contexts and histories, as well as aspects of psychosocial and mental health. To explicate the political economy of mental health, which is concerned with both institutions and governance (i.e., formal institutions and informal rules; capacity of public administration), almost all the papers situate their arguments in the structural and socio-historical context in which particular national mental health systems were constructed. Former Eastern Bloc countries with histories of Soviet psychiatry, such as Serbia, naturally differ substantially from other countries such as South Africa or Peru. Other papers address specific issues within mental health to examine the dynamics of economies of influence exercised by the pharmaceutical industry, such as obesity medications and drugs to treat postpartum depression.

It is not a coincidence that many of these papers are written by authors from different disciplines or deploy multidisciplinary methods, including empirical studies and normative frameworks. Challenging disciplinary orthodoxies—not just in biomedicine and public health but also in human rights praxis—frequently calls for an external or fresh gaze in order to unsettle ways of understanding the world that are taken for granted within a specific professional tribe. While these papers adopt different approaches to considering how HRBAs might contribute to meaningful reform, they collectively point to the need to situate our human rights analyses and advocacy in specific contexts, and to render visible the global and national forces that have shaped those particular settings when designing reforms.

In the first piece, "Institutional Corruption in the Political Economy of Global Mental Health: Challenges for Transformative Human Rights Praxis," Alicia Ely Yamin and Camila Gianella Malca set out the theoretical anchor for the special section, in which they challenge the standard understanding of HRBAs in three ways. First, they suggest that transformative human rights approaches need to be attentive to the epistemic architectures of both biomedicine and neoliberal economies in which mental health rights are advocated. Improving technical interventions is crucial, but broader structural and institutional arrangements that entrench asymmetries at the micro level between clinicians and patients and at the macro level in national health systems are too often not just displaced by biomedicine but obscured or distorted by the premises built into the model. Second, accepting the prevalent human rights construction of corruption as "bad apples" that engage in bribery or the embezzlement of public funds destines remedies to reinforce structures that systematically privatize wealth and deprive states of the capacity to uphold mental health rights. If those premises are accepted in HRBAs, applying rights to mental health may stymie more than facilitate structural reforms. Rather, our understanding of corruption in mental health needs to extend to institutional corruption that entails structural and systemic drivers of private gain at the expense of the public good, which are imbricated in economies of influence between academic psychiatry and the pharmaceutical industry and spread through the globalization of Western biomedical frameworks and the neoliberal consensus across the globe. Third, they add to the literature on the psychiatrization of the world by placing it in historical context, noting the intertwined impacts of the spread of biomedical approaches to mental health and neoliberal globalization since the 1980s and the differential impacts across the world.

This anchor piece, together with the remainder of the papers, suggests that human rights needs to be attentive to both universal trends in global and national political economies and the plurality of lived experiences in national settings. A series of papers then delve into greater detail with respect to how institutionalized corruption spreads discourses and practices across borders. In "Addressing the Global Mental Health Crisis: How a Human Rights Approach Can Help End the Search for Pharmaceutical Magic Bullets," Lisa Cosgrove argues for a shift away from the dominant pharmaceutical paradigm in global mental health, advocating instead for an HRBA that recognizes how emotional distress is often rooted in social, political, and economic conditions. Using the specific example of zuranolone, a recently approved treatment for postpartum depression, Cosgrove argues that institutional corruption, manifested through conflicts of interest and guild influence, undermines scientific integrity and public trust. She situates this critique within the broader context of neoliberal frameworks that medicalize distress and obscure structural drivers such as inequality, discrimination, and lack of social support. Cosgrove emphasizes the importance of moving beyond binary debates (pro- or anti-psychiatry) and fostering more nuanced narratives that critically examine who benefits (and who does not) from current models of care.

In "Without Informed Consent: The Global Export of a Failed Paradigm of Care," Robert Whitaker argues that the way in which the US biomedical model of psychiatry was exported globally alongside psychiatric medications failed to provide patients and the broader public with adequate information about the limitations and risks of this approach, which would have been necessary for "informed consent." He argues that the chemical-imbalance narrative, used to justify the disease model, was never scientifically validated and that research consistently fails to demonstrate long-term improved recovery with psychiatric drugs.

Whitaker contends that institutional corruption, which is rooted in guild interests, led US psychiatry to misrepresent its own evidence base and that this misrepresentation influenced World Health Organization-endorsed global mental health frameworks. As a result, he asserts, a paradigm of care grounded in inaccurate claims of efficacy and safety was disseminated worldwide, contributing to worsening public mental health outcomes.

Ximena Benavides's paper, "Too Big to Lose Weight: How Pharmaceuticalization Corrupts the Right to Health," considers the political economy of health through the lens of obesity and comorbidities in mental health, arguing that "the pharmaceuticalization of obesity carries wide-ranging implications for public health—from its intersections with mental health and diabetes to its structural effects on the health care system." Noting that reliance on glucagon-like peptide-1 receptor agonists has generated market distortions, Benavides examines the financialization of health care, focusing on how policy choices allocate power to dominant pharmaceutical manufacturers operating in highly concentrated markets. She then describes institutional corruption as the transfer of governance to private actors that favors self-interested exercises of governing power in drug commercialization and redefines medical progress in terms of market expansion and control. Benavides argues that these dynamics disregard the social determinants of obesity and weaken the protection of fundamental rights to health and health care.

The remainder of the special section focuses on middle-income countries and regions with very different historical trajectories regarding mental health: Eastern Europe, Peru, and South Africa.

In "Reflections on Institutional Corruption in Mental Health Policy Implementation: Global Insights and the Eastern European Experience," Dainius Pūras and Julie Hannah reflect on the missed opportunities for transformation in Eastern Europe following the fall of the Soviet Union. Hannah worked closely with Pūras while he was the United Nations Special Rapporteur on the right to health, and much of their focus at the time was on mental health and the obstacles posed by the biomedical model. In this piece, they recount—based on the authors' own experiences—that although the collapse of totalitarian regimes brought hope for more human rights-centered mental health systems, the convergence of neoliberalism with remnants of totalitarian institutional cultures instead led to the renewed medicalization of mental health challenges. Their paper highlights this experience in Central and Eastern European countries and raises important questions about authoritarian dynamics in many mental health care institutions that play out between providers and patients. By underscoring the critical role of institutions as a major barrier to the adoption of truly human rights-based mental health reforms, the authors call on the global mental health movement to move beyond a narrow focus on mental health goals such as reducing treatment gaps and to recognize the need for transformation of the system itself—ensuring that care is accessible, non-coercive, and rights based—and to address institutional corruption as both a consequence and a cause of institutional flaws.

Milutin Kostić and Danilo Vuković, the authors of "Regression of Hard-Won Advances in Socialized Medicine: The Emergence of the Private Sector in Health Care in Serbia," examine how the emergence of dual practice in post-socialist Serbia, where the majority of physicians work simultaneously in public hospitals and private clinics, has weakened the public health system and produced conditions that foster institutional corruption. They argue that dual practice creates direct financial incentives for physicians to conserve time and effort in the public sector and to encourage patients to seek care privately, which turns access to timely and respectful treatment into a matter of ability to pay. As the authors explain, this model "breaches equality and access to rights and services" by producing a two-tiered system in which wealthier patients often receive more care (and sometimes unnecessary care, including prescriptions), while those dependent on the public system encounter declining quality and access. Limited state investment in public health facilities further exacerbates this dynamic, accelerating the shift of patients who can afford to do so toward private providers. Kostić and Vuković propose eliminating dual practice in mental health and beyond in order to address structural inequity and protect the right to health.

The two papers on Peru—written by Alberto Vásquez and Camila Gianella, respectively—illustrate what happens when global mental health discourses are transferred into local contexts with weak institutional capacity that refracts the steep socioeconomic inequalities and social fragmentation of the broader society. Each study examines different aspects of the implementation of an ambitious mental health reform over the past decade. While both authors highlight some positive outcomes of the reform, they also note how structural factors—such as a weak and underfinanced health system, the dominance of a biomedical approach to mental health, the lack of regulation of private actors, and weak oversight of the commercialization of drugs, including psychiatric medication—can undermine the effects of mental health policy reforms and contribute to maintaining and even reinforcing institutional corruption.

Vásquez's paper, "A Hard Pill to Swallow: Pharmacy Chain Dominance and the Commodification of Mental Health in Peru," examines how chronic underinvestment and uneven implementation of community-based reforms have allowed private pharmacy chains to become central providers of mental health care in Peru. He argues that persistent medication shortages and limited access to public services lead many people to self-medicate and rely on pharmacies as their primary point of care. Further, in this context, pharmacy conglomerates shape which psychotropic medications are available and at what price, often prioritizing high-profit products and limiting access to affordable generics. This model exemplifies institutional corruption in that it privileges profit over the public purpose of health institutions. Using the framework of institutional corruption, Vásquez shows how these dynamics undermine the availability, accessibility, acceptability, and quality standards required by the right to health. He calls for stronger public investment and rights-based reforms to ensure "that private actors operate within clearly defined legal and ethical boundaries."

In "When Scaling Up Isn't Enough: The Impacts of Peru's Mental Health Care Reform on Adolescents," Camila Gianella Malca also deploys the human rights framework of availability, accessibility, acceptability, and quality of facilities, goods, and services to examine the effectiveness of Peru's mental health reform with respect to a specific population: adolescents. Gianella notes that the reform was intended to incorporate a human rights-based approach. Yet based on a qualitative study conducted across four regions of Peru, Gianella is able to provide granular insights into where the rhetoric of human rights has fallen short in practice. Through a combination of policy analysis and qualitative interviews, Gianella shows how the reform's focus on scaling up access to pharmaceutical treatment neglects critical issues such as health system capacity, the availability of trained personnel, the need for intercultural and youth-centered approaches tailored to diverse adolescents, and information systems that adequately monitor policy impact. Gianella's analysis also highlights how a reform that promotes pharmacological treatment creates risks of abuse by private actors involved in the marketing of psychiatric medications.

Finally, Sasha Stevenson's paper, "South Africa's Life Esidimeni Disaster and the Institutional Corruption That Opened the Door to It," offers a chilling case study on the impacts of institutional corruption on human rights, including the rights to health and life. Stevenson examines the Life Esidimeni case, which shows how a policy reform portrayed as aligned with international standards, in a country with expansive human rights protections in its constitution, can still cause enormous damage to vulnerable populations when private nongovernmental actors are engaged without sufficient oversight. In this case, 144 patients in the care of nongovernmental organizations died in grotesque conditions of neglect—undernourished, dehydrated, unmedicated, and sometimes suffering from bedsores and gangrene. Stevenson argues that the Life Esidimeni tragedy "must be seen as a large-scale human rights violation within the context of institutional corruption: caused by inappropriate political involvement in the administration of health and the drive for cost-saving, disguised as deinstitutionalization." As with the papers from Peru, the Life Esidimeni case reveals the shortcomings and potential harms of involving private actors in the supply and administration of health services in contexts characterized by weak state capacity to oversee the quality of care and by structural violence against vulnerable populations. Stevenson's paper also goes on to document the "public and legal processes undertaken to expose the disaster, to secure accountability, and to begin to deconstruct the conditions that allowed one of South Africa's most shameful human rights violations of the democratic era."

Conclusion

The papers in this special section offer three important contributions at a time when there is simultaneously a renewed focus on the "crisis in mental health" and a major disruption in global health governance, including in mental health, as a result of changes in US policy and their follow-on effects. Amid the intensifying calls to move toward greater private financing and provision of health services to fill gaps created by sharply reduced development finance as well as renewed austerity, the papers collected here suggest the need for different approaches.

First, these papers make a compelling argument that addressing corruption as a barrier to progress in mental health systems requires moving beyond narrow understandings of illegal misconduct by public officials to also consider the role of private actors (including the pharmaceutical industry's interactions with academic and professional psychiatry), the adoption of dual practice models and public-private partnerships, the role of trade liberalization and intellectual property regimes, and the increasing financialization of aspects of health care systems, including pharmaceutical medications. The papers here collectively explicate how this *institutional corruption* is embedded within broader political, economic, and historical contexts that shape priorities, allocate resources, and determine experiences of care.

Second, taken together, the pieces in this special section call for a rethinking of the architecture of global mental health through a political economy lens that recognizes how epistemic and economic power at the global level operates to legitimate specific forms of mental health care in middle-income and lower-middle-income countries. Evidence presented here of how these models are transferred to specific country contexts suggests that the increasingly frequent rhetorical incantations regarding the importance of "decolonizing mental health" or "social determinants of mental health" are unlikely to produce meaningful change without challenging both the narrow frameworks and authority of Western psychiatry and the neoliberal globalization that facilitates the spread of that individualized, abstracted understanding of emotional distress.

As should be clear from the data presented throughout the special section, this is in no way an anti-scientific stance or a simplistic rejection of psychopharmacology. It is rather an acknowledgment that while the health sciences are often taken as technical and accessible only to specialized expertise, the frameworks in which they operate are not free of cultural premises and interact with the political economies that we inhabit and which deeply affect our diverse lived realities.

Finally, the pieces collected here call for us to reflect on how human rights approaches can meaningfully contribute to confronting the structural conditions that sustain institutional, as well as regular, corruption and systematically perpetuate violations of dignity and well-being across social determinants of mental health as well as in care. Facing this challenge in human rights could not be more urgent in our current period of radical upheaval. Applying human rights to any health issue in transformative ways requires destabilizing ways of framing the world that stem from disciplinary orthodoxies and naturalized practices in medicine and public health. But a robustly transformative praxis of human rights equally calls for recognizing that the meaning—and meaningfulness—of applying human rights to mental health cannot be autonomous from our socioeconomic contexts—or abstracted from the colonial and other socio-historical processes that have created them.

Acknowledgments

This project received support from the Brocher Foundation. The Brocher Foundation's mission is to encourage research on the ethical, legal, and social implications of new medical technologies. Its main activities are to host visiting researchers and to organize workshops and summer academies. More information on the Brocher Foundation is available at www.brocher.ch. We are grateful for the additional support provided by the Harvard Global Health Institute, which was crucial for enabling both a pre-workshop convening and travel to a workshop at the Brocher Foundation, as well as the Chr. Michelsen Institute, which provided both financial and project management support.

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Institutional Corruption in the Political Economy of Global Mental Health: Challenges for Transformative Human Rights Praxis

ALICIA ELY YAMIN AND CAMILA GIANELLA MALCA

Abstract

Through an exploration of the impacts of institutional corruption in global mental health, we argue here that deploying human rights-based approaches to health must go beyond rhetoric regarding equity in access to treatment to address power structures that systematically perpetuate harm against diverse people in specific contexts. First, applying human rights to mental health in transformative ways requires upending the biomedical paradigm that both locates mental health within people's brains and imbues psychiatric expertise as an unchallengeable authority in defining mental health conditions. Second, such change in approaches to mental health has proved challenging due in significant measure to institutional corruption, defined as a systemic, legal influence that diverts the institution from its purpose. We focus on institutional corruption driven by financial influences of the pharmaceutical industry in combination with the guild interests of the psychiatric profession. Third, we sketch the relation between institutional corruption and the spread of neoliberal policy imperatives on the financing and organization of mental health services in lower-middle and middle-income countries. Finally, we question the metrics deployed in global health that reaffirm existing presumptions in mental health systems, such as coverage, which can foster institutionalized corruption. We conclude that focusing on institutional corruption allows us to understand the need for new forms of health governance aligned with transformative human rights praxis.

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Competing interests: None declared.

Introduction

Through an exploration of the impacts of institutional corruption in global mental health, we argue in this paper that deploying human rights-based approaches to health (HRBAs) must go beyond rhetoric regarding equity in access to treatment to address power structures that systematically perpetuate harm against diverse people in specific contexts. First, we assert that applying human rights to mental health in transformative ways requires upending the biomedical paradigm that both locates mental health within people's brains as a stochastic phenomenon and imbues psychiatric expertise as an unchallengeable authority in defining mental health conditions. Likewise, the landmark United Nations (UN) Convention on the Rights of Persons with Disabilities, which 191 states and the European Union have ratified, explicitly rejects the medical model of disability in favor of a social model.[1] Under this convention, psychosocial disability is understood to be created through the interaction between a person's impairment and the social, civic, political, and economic environments that contain physical, attitudinal, and communication barriers.[2]

Mental illness and disability overlap to some degree but are not synonymous. However, the effective enjoyment of health and disability rights always requires a just arrangement of institutions, and in both cases the need to move beyond a biomedical model and acknowledge the role of laws, policies and practices has been repeatedly emphasized by various UN bodies and human rights institutions.

Second, we assert that although normative standard-setting has proceeded rapidly in both health and disability rights, implementation and systemic change in approaches to mental health have proved challenging due in significant measure to institutional corruption, which is directly related to the privileging of psychiatric expertise in the biomedical model. Following Lawrence Lessig, we define institutional corruption as

> *a systemic and strategic influence which is legal, or even currently ethical, that undermines the institution's effectiveness by diverting it from its purpose or weakening its ability to achieve its purpose, including, to the extent relevant to its purpose, weakening either the public's trust in that institution or the institution's inherent trustworthiness.*[3]

In this context, Lisa Cosgrove and Robert Whitaker have used the term "economies of influence" to describe the institutional corruption in psychiatry that is driven by financial influences of the pharmaceutical industry in combination with the guild interests of the psychiatric profession.[4] Thus, institutional corruption is not a glitch in current mental health systems but a feature that is woven into their design.

Third, noting that the rise of an understanding of mental illness as an imbalance of chemicals naturally found in the brain overlaps with political economies shaped by coloniality in global health, together with the neoliberal globalization that began to sweep the world in the 1980s, we sketch some of the dramatic impacts of structural adjustment programs and successive implementation of neoliberal policy imperatives on the financing and organization of mental health services in lower-middle and middle-income countries. Here, we focus on two processes. First, the coloniality of knowledge production in global health enabled the research premises advanced through the National Institute of Mental Health and the categories of the DSM (Diagnostic and Statistical Manual of Mental Disorders) and ICD (International Classification of Diseases) to spread throughout the rest of the world.

This dimension of the paper contributes to other critical accounts of psychiatrization by emphasizing the significance of neoliberal globalization's impact on social determinants and health care reforms worldwide, which has exponentially expanded the reach of biomedical and pharmaceuticalized approaches and, in turn, institutional corruption.[5] The application of neoliberal policy imperatives drove health reforms that included targeting the needy and reducing universal services. These reforms also involved cutting social protections that support psychosocial needs, expanding intellectual property protections for pharmaceuticals, and privatizing or engaging in public-private partnerships to provide mental health care. Moreover, throughout, we emphasize that human rights principles have often been invoked to spread psychiatric treatment and pharmaceuticalization to lower-middle and middle-income countries out of concerns for equal access to pharmaceutical treatment.

Finally, looking ahead to what can be done, in addition to suggesting the need for broader systems change, we question the metrics deployed in global health—particularly the focus on coverage abstracted from context—which reaffirm existing presumptions in mental health systems and which can foster institutionalized corruption. We conclude that focusing on institutional corruption allows us to understand the need for new forms of health governance aligned with more transformative human rights praxis.

In proposing changes to human rights theory and practice, this paper draws on two non-exhaustive reviews of public health research (PubMed), social science and legal databases, and gray literature on (1) corruption and mental health, and (2) human rights (including disability rights) and mental health. These reviews were performed during 2023–2024. Although most of the secondary literature dates from the last 10 years, key legal and institutional documents from as early as the 1970s were essential to examine to establish the context for the arguments we make. Further, additional literature reviews on privatization and public-private partnerships in health, as well as on the use of global indicators, were performed by this paper's authors for other studies and, in turn, inform this work as well.

Beyond the biomedical model[6]

The starting point for applying human rights to mental health in a transformative way requires understanding how defining mental health and psychosocial disability in terms of rights challenges the biological individualism of mainstream psychiatry, which defines conditions in terms of personal defects or abnormalities.

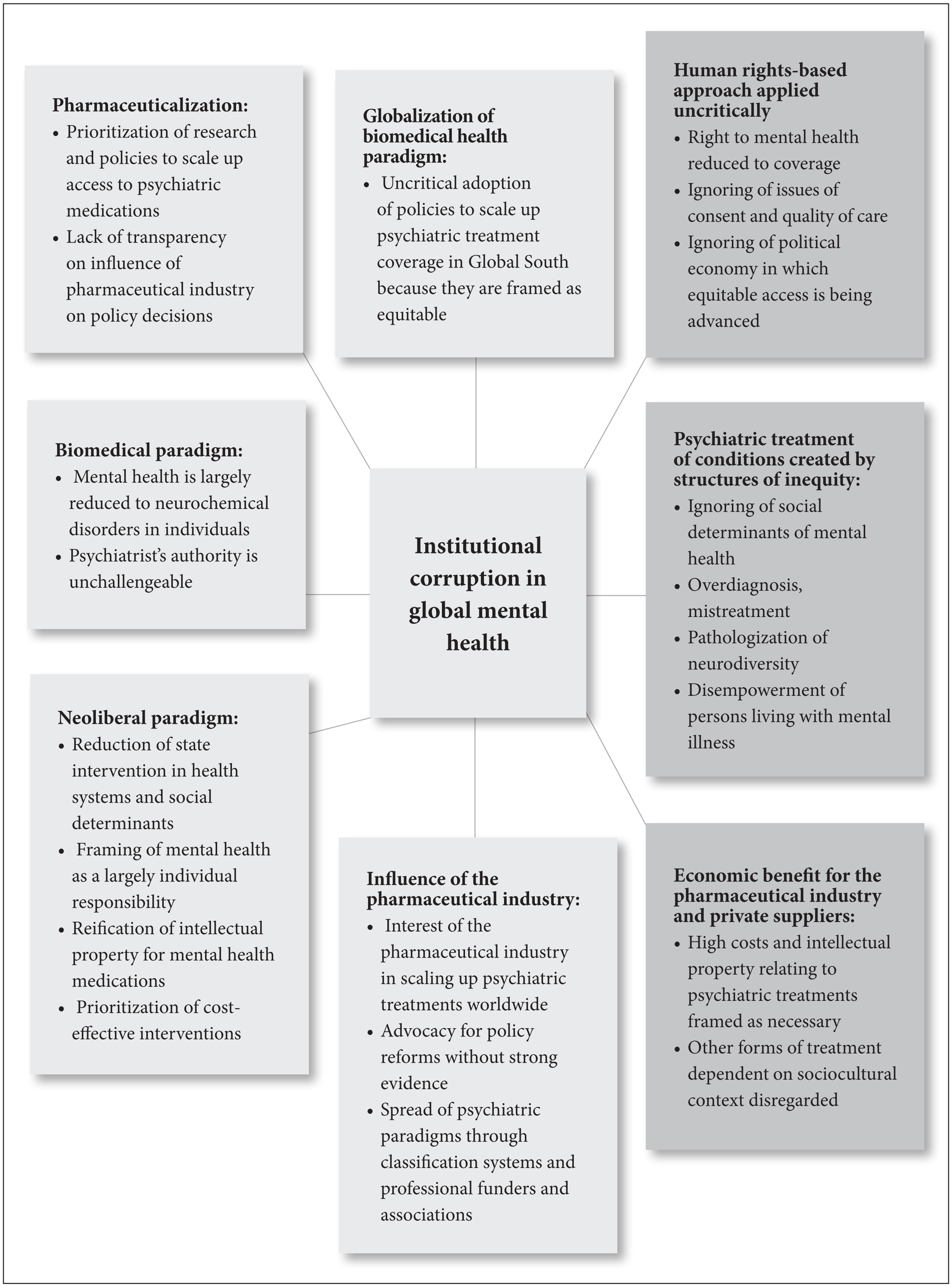
In the biomedical paradigm, health is defined as the absence of disease—for example, a "normal" result on a cholesterol or other function test. This negative definition of health, including mental health, is simultaneously (1) abstracted from social context (and therefore permits standardization in research and classification of disease, however questionable that is in mental health); and (2) appraised exclusively through a specialized scientific expertise. In the case of mental health, many mental health problems have been reduced to an imbalance affecting neurotransmitters, and psychiatric drugs as the solution to balance the chemicals naturally found in the brain.[7]

By contrast, conceptualizing mental health as a right requires accepting that (1) mental health has special moral value because of its relationship to dignity—variously and not mutually exclusively understood as self-governance, a preservation of a range of opportunities, and the ability to participate fully in one's community and society; and (2) mental health is *not* merely an individual biological or biochemical issue. On the contrary, understanding mental health in terms of rights requires recognizing health, including mental health, not as a natural good but as a social good dependent on the just arrangement of essential social institutions, including health systems.[8] Just as with disability in a rights paradigm, our conception of mental (ill) health in a rights framework is also constructed in interaction with social and cultural norms.[9]

This broader understanding has been well-diffused in international legal frameworks since the entry into force of the UN Convention on the Rights of Persons with Disabilities. In 2017, the UN Special Rapporteur on the right to health argued for a more expansive understanding of mental health that encompasses social determinants.[10] In 2023, the UN General Assembly adopted a resolution underscoring the need to frame mental health not only as the presence or absence of a psychiatric disorder or cognitive condition but rather as the result of

> *an environment that enables persons to live a life in which their inherent dignity is respected, with full enjoyment of their human rights, and in the*

Figure 1. Institutional corruption in global mental health



Pharmaceuticalization:
- Prioritization of research and policies to scale up access to psychiatric medications
- Lack of transparency on influence of pharmaceutical industry on policy decisions

Globalization of biomedical health paradigm:
- Uncritical adoption of policies to scale up psychiatric treatment coverage in Global South because they are framed as equitable

Human rights-based approach applied uncritically
- Right to mental health reduced to coverage
- Ignoring of issues of consent and quality of care
- Ignoring of political economy in which equitable access is being advanced

Biomedical paradigm:
- Mental health is largely reduced to neurochemical disorders in individuals
- Psychiatrist's authority is unchallengeable

Institutional corruption in global mental health

Psychiatric treatment of conditions created by structures of inequity:
- Ignoring of social determinants of mental health
- Overdiagnosis, mistreatment
- Pathologization of neurodiversity
- Disempowerment of persons living with mental illness

Neoliberal paradigm:
- Reduction of state intervention in health systems and social determinants
- Framing of mental health as a largely individual responsibility
- Reification of intellectual property for mental health medications
- Prioritization of cost-effective interventions

Influence of the pharmaceutical industry:
- Interest of the pharmaceutical industry in scaling up psychiatric treatments worldwide
- Advocacy for policy reforms without strong evidence
- Spread of psychiatric paradigms through classification systems and professional funders and associations

Economic benefit for the pharmaceutical industry and private suppliers:
- High costs and intellectual property relating to psychiatric treatments framed as necessary
- Other forms of treatment dependent on sociocultural context disregarded

> *equitable pursuit of their potential, and that values both social connection and respect through non-violent and healthy relationships, and recognizing that discriminatory laws policies, practices and attitudes undermine well-being and inclusion.*[11]

In addition to focusing on the social determinants of mental health, transformative human rights praxis calls for changing the epistemic paradigm of biomedicine that privileges the technical expertise of psychiatrists. In the biomedical model, the technical language of scientific "expertise" cloaks the deeper political implications of decisions made in biomedical research and clinical practice, guiding narratives of social beings, human bodies, sexuality, (dis)abilities, race, and the like. In the case of mental health, this dominant model feeds on and facilitates harmful stereotypes: people with mental conditions "continue to be falsely viewed as dangerous," they are "labelled incompetent," "their capacity to make decisions is questioned," and they are "denied the right to make decisions for themselves."[12]

While power asymmetries between health professionals and health care users are prevalent across health services and conditions, in the case of mental health, they are exacerbated. Historically, in psychiatry, objective "scientificity" as a form of categorization has served as a pretext to regulate populations in society for deviance from norms and standards of being or behavior.[13] In some places, political dissent was defined in terms of mental disorders (e.g., "sluggish schizophrenia" under Soviet psychiatry); in others, feminist discontent with social roles was labeled "hysteria." These categorizations have changed over time, and with context.

When the DSM-3 conceptualized psychological disorders as primarily brain-based diseases, psychiatrists' special medical expertise became essential to diagnose and treat these conditions, despite dissent from the beginning as to the appropriateness of categorizing mental distress in this way.[14] Over the last 40 years, the American Psychiatric Association and academic psychiatry in the United States and other countries have touted pharmaceutical treatments in addressing mental illness, which has greatly expanded markets for psychiatric medications.[15]

The ICD, the most widely used classification of diseases for low- and middle-income countries, also quickly adopted the neurochemical account of mental disorders. While many have pointed to the lack of diagnostic reliability and the lack of cultural appropriateness, and disability rights activists have argued that the medical model pathologizes neurodiversity, the predominant approach to mental health has been the biomedical one. And pharmaceutical interventions have been prioritized as a first-line therapy worldwide.[16]

The medicalization of mental illness has had direct effects on widespread diagnoses of mental illness as institutional responses to "deviant behavior."[17] Making mental illness into an issue largely of brain chemistry and presenting psychopharmacology as a solution enabled an extraordinary arrogation of power to psychiatrists to control both the supply and demand of mental health care. Mental health diagnoses based on genetics and neuroscience captured the fervor of academic and clinical psychiatry in the late 20th century and the beginning of the 21st century around the world, even after they were shown to have limited clinical utility and began to be questioned in the Economic North.[18]

Institutional corruption

The standard approach to corruption in human rights is to treat it as a leakage—that is, a drain on resources that could otherwise go toward fulfilling, in this case, mental health care. Traditionally, that leakage is construed as misfeasance or malfeasance by *public* officials. In some legal regimes, such as the United States, corruption is explicitly limited to quid pro quo cases—for example, where there is a direct exchange between a public official and some kind of donor, where an official takes a specific official action in return for a benefit, or where a donor's influence can be proven to have impacted the official's judgment unduly, or if there is a strong appearance of such influence.[19] Dennis Thompson argues that *institutional corruption* can be applied more generally to "political gain or benefit by a public official under conditions that in general tend to promote private interests."[20] However, this focus on public officials is unduly narrow. Just as we have expanded our understanding of infringements of rights beyond the direct actions of state agents, it is time to broaden our view of corruption beyond actions by state officials, and explore how institutional arrangements across both public and private sectors foster a more insidious form of *institutional corruption*.

As noted above, we adopt Lessig's definition of institutional corruption: "a systemic and strategic influence which is legal, or even currently ethical, that undermines the institution's effectiveness by diverting it from its purpose or weakening its ability to achieve its purpose, including, to the extent relevant to its purpose, weakening either the public's trust in that institution or the institution's inherent trustworthiness." Cosgrove and Whitaker identify the release of the DSM-3 as an inflection point in mental health care, after which pharmaceuticalization exponentially expanded. Subsequent versions of the DSM and ICD have generally reinforced this trend.[21]

Nonetheless, the drivers of inappropriate measures go far deeper than isolated bad practices, as the default becomes pharmaceuticalization.[22] Normative guidance that fails to account for institutional corruption is likely to be ineffective. That is, the inherent indeterminacy of international standards, the prioritization of a biomedical understanding of mental health, an overemphasis on scaling up treatment coverage, and the incompleteness of formal human rights norms regarding mental health care open the space for informal and background rules to play a significant role in everyday behavior within mental health systems.[23] In this context, informal rules relate to how conditions for exercising entitlements to mental health care are deliberately restricted to impose a default of pharmaceuticalization, as well as coercion. Background rules, in turn, relate to how health institutions function with respect to such factors as staffing and information sharing, which also play a significant role in erecting barriers to non-pharmaceutical, non-biomedical forms of mental health care in practice.[24]

The current for-profit schema of research and development has strengthened the ties between academic researchers and pharmaceutical companies, as well as the prevalent sponsorship of clinical trials by the industry, imbricating institutional corruption ever more deeply into practice.[25] Since DSM-5, the American Psychiatric Association has had an official policy of declaring conflicts of interest (defined as receipt of US$10,000 from pharmaceutical companies per year, with the exception of unconditional grants). However, in practice, more than half of psychiatrists on review committees maintain close relationships with the pharmaceutical industry, in particular in relation to mood, sleep, and psychotic disorders, and research on randomized controlled trials has found evidence in support of conflicts of interest as a potential bias in the outcomes of such trials conducted for antidepressants.[26]

In turn, the permeation of pharmaceuticalization in medical knowledge and training has become so normalized that its impact on clinical treatment is not generally questioned by individual patients, providers, or the general public in most of the world.[27] Indeed, the pharmaceuticalization of mental illness has been so widely exported around the world that even where social causes, such as austerity, are understood to cause emotional distress (including depression and anxiety), the response is still too often to treat this distress at a biochemical level.[28]

The WHO currently explicitly recommends that national action plans "evaluate and monitor the use and costs of psychotropic medication, psychological interventions, and other treatments in mental health and social services in primary care" and calls for "a significant increase in investment in research and evaluation" of alternatives to psychopharmacology.[29] Yet the biomedical framework is still disseminated through prominent medical and public health journals, at universities, at academic and professional conferences, and through the direct lobbying of the pharmaceutical industry worldwide.

Research agendas have been crucial to propagating this epistemic framework, and agencies such as the National Institute of Mental Health (NIMH) in the United States have played a significant role in shaping the global understanding of mental health issues. Until the Trump administration took office in 2025, the NIMH, and its parent institution the National Institutes of Health, funded more basic research on mental health than any other institution in the world. The NIMH has overwhelmingly prioritized the funding of biomedical research over social science research on structural causes or population effects over time.

Institutions that frame thinking as well as funding in global health have also contributed to these policies. For example, in 2007, *The Lancet*, a leading global health journal, published an influential series on mental health, which further disseminated the idea of pharmaceutical treatment as cost-effective worldwide.[30] In 2016, the World Bank published a report estimating global burdens of mental illness and disability and calling for making mental health a global development priority.[31]

Professional associations such as the World Psychiatric Association have also urged scaling up the availability and use of psychiatric drugs and adopting standardized approaches and categories of diseases.[32] In this regard, the ICD, the most widely used system of medical classification worldwide, provides practitioners with a universal, free, and accessible classification system that can be utilized by non-psychiatrists working even in low-income settings and which has been critical for spreading the Western biomedical model of mental health around the world.

Human rights arguments have often been key in spreading the biomedical model of psychiatry beyond the United States and Western Europe to the rest of the world. Article 25 of the Convention on the Rights of Persons with Disabilities calls for state parties to take all appropriate measures to ensure access for persons with disabilities to health services, which include providing persons with disabilities "the same range, quality and standard of free or affordable health care and programmes as provided to other persons," as well as "*those health services needed … specifically because of their disabilities*, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities."[33] Although it has shifted positions, WHO itself encouraged the global dissemination of psychopharmacological treatments in its 2001 edition of its flagship *World Health Report*—whose title was *Mental Health: New Understanding, New Hope*—as a response to the vast unmet need for mental health care in lower-middle and middle-income countries.[34] In arguing for redressing discrimination in mental health, prominent human rights advocates have pointed to WHO studies that have shown "a huge and growing proportion of morbidity and mortality from mental disorders with significant underdiagnosis and treatment compared to physical disorders."[35]

The Movement for Global Mental Health has consistently used nondiscrimination and human rights arguments to argue for "scaling up" access to psychiatric treatments worldwide, including pharmaceuticals, available in the Economic North.[36] For example, Vikram Patel, a leading proponent, analogizes the situation to inequitable access to HIV/AIDS drugs:

> *Consider the moral argument that persons with HIV/AIDS in developing countries had the right to access antiretroviral drugs, that the state has to provide them for free, that drug companies had to reduce prices … that discrimination against people with HIV/AIDS had to be combated vigorously, and that knowledge about HIV/AIDS was the most powerful tool to combat stigma. These arguments were human rights based … We believe that the time is ripe for such a [global mental health] advocacy initiative that makes the moral case for the mentally ill.*[37]

Of course, a human rights framework requires that access to treatment be universally available, and there is no question that in too many countries the lack of access to appropriate mental health care causes tremendous suffering. However, the actual quality of care and agency of persons must be part of the equation. The reductive analogy fails on multiple dimensions, including the unreliability of diagnostic categories, the lack of evidence regarding the effectiveness of psychotropic medication, the displacement of social determinants, and the equally important right of persons across the world to refuse treatment. Health rights cannot be constructed in a vacuum; in this case, a psychiatrized vision constructed through colonialist architectures of knowledge production has been applied through ostensibly universal models that omit and distort important features of the experience of emotional distress in specific local contexts.

The push to spread a pharmaceuticalized model of psychiatric treatment to the rest of the world has not been without critique. It has been accused of psychiatric colonialism—of "exporting western illness categories and treatments that would ultimately replace diverse cultural environments for interpreting mental health."[38] Others have pointed out that prevalent models in mental health care are based on neocolonial power structures that permeate public health, effectively marginalizing traditional Indigenous knowledges in favor of allopathic health treatments. As China Mills writes, "to export psychiatry globally is to begin to reframe an enormous variety in expression of personal and social distress into an illness model, treatable by drugs." She concurs with other scholars who have argued that because this approach is devised in a particular Western culture that is alien to many, it constitutes a kind of psychiatric imperialism that may be less stark than military domination but is no less destructive to the populations around the world.[39]

Neoliberal globalization and the political economy of global mental health

Epistemic frameworks travel through the arteries of power. Sometimes these are professional associations and journals; sometimes they are rooted in the economic ordering of societies. Just as the biochemical understanding of mental illness was becoming embedded in mental health practice in the 1980s, neoliberal globalization began sweeping the globe, with extraordinary impacts on health systems, including mental health systems. The two processes were deeply intertwined. Divorcing all health, including mental health, from social meaning enormously facilitated the commercialization of health care.[40] It is not just that in isolation, the answer to depression was to prescribe a psychotropic medication, and the answer to the side effects of that medication was then to prescribe yet another pharmaceutical. Health systems came to be understood as apparatuses for delivering technical interventions to address individuals' biological conditions—as determined by clinical judgments—as opposed to social institutions at the interface of society and the state. Furthermore, those apparatuses were to be reformed in the most cost-effective way, which often facilitated the privileging of pharmaceuticals over talk therapy and relational approaches to psychosocial health in traditional medicine.

The web of negative experiences that deeply affect both mental and physical health includes historical experiences of colonization, enslavement, and marginalization, as well as adverse early life exposures, such as exposure to family and community violence, discriminatory employment patterns, economic insecurity, poverty, lack of education, and homelessness. But in a highly individualized technical health care delivery system, these social, political, and historical determinants could be shunted aside.[41]

Various guidelines from WHO, as well as its Comprehensive Mental Health Action Plan 2013–2030, now call for actions across health, education, labor, housing, and other arenas to deliver a coordinated response as opposed to merely increasing access to psychiatric medications.[42] Yet the past four decades have driven health systems across most of the world in precisely the opposite direction.

The diffusion of a menu of neoliberal policies to lower-middle and middle-income countries proceeded rapidly from the 1980s onward through various social processes, including policy imitation, the adoption of new ideas, and the need to compete in global markets.[43] Additionally, as Alex Kentilkenis and Sarah Babb argue, "Coercion was also a key diffusion mechanism: powerful global institutions could use their resources to leverage free-market reforms."[44] The World Bank and International Monetary Fund—

pushed by powerful shareholders, particularly the United States—developed a set of interventions in the internal governance and economies of countries across the Global South to address perceived debt default threats. In exchange for rescue from default, countries were forced to adopt "structural adjustment policies," which generally included privatization and deregulation; trade liberalization to open markets to foreign investment; and the reduction or elimination of social subsidies to balance budgets, which then entailed imposing user fees for health services, among other things.[45]

In the logic of neoliberalism, the public sector was cast as the locus of corruption in overseeing clientelistic and poor regulatory practices, and shrinking that potential for abuse through privatization has been a prevailing response from international financial institutions.[46] Spreading the understanding of corruption as bad apples "abusing entrusted power for private gain" has been a key pillar of promoting privatization and deregulation, which, not ironically, has fostered conditions for the appropriation of public power for private economic and political gain.[47]

Given limited space, we highlight two prominent effects of neoliberal globalization: (1) the shrinking of public health capacity and turn toward private provision of care or public-private partnerships; and (2) the role of trade liberalization, and heightened protections for intellectual property, in propelling expansion of the pharmaceutical industry into the Global South.

First, these market-friendly reforms prioritized fiscal discipline and balanced budgets, and almost always involved replacing broad universal social programs in health and beyond (often largely aspirational at the time) with targeted programs for the neediest, to meet "basic needs." More than 40 years later, waves of adjustment and austerity have been imposed on much of the Global South, which have hampered the capacity of states to adequately fund health systems, as well as invest in social protection, education, and other common goods that are directly related to psychosocial well-being.[48]

Responding to gaps in public finance and capacity in health systems, lower-middle and middle-income countries governments often expand privatized care alongside public health care for the poor, seeking partnerships with the private sector and establishing public-private partnerships (PPPs) in mental health, long-term care, and other aspects of health delivery. In the logic of neoliberalism, PPPs are often politically attractive for moving public spending off the government balance sheet. Yet evidence on health PPPs is patchy at best; PPP contracts can be expensive and inflexible, and PPP facilities can systematically exclude "expensive patients" to limit costs and meet targets.[49] Further, contrary to arguments about privatization reducing abuse-of-power corruption, PPPs are often unaccountable to the public and are involved in egregious violations of patients' rights in mental health facilities.[50] Despite the lack of robust evidence on the positive impacts of health PPPs, and evidence of corruption on health infrastructure PPPs, neoliberal ideology has displaced public policy debates about whether the private sector is needed and whether it is more efficient; instead, the sole question is when and how private funding can be sourced and de-risked.[51]

Another key structural aspect of privatizing public goods for private gain occurred through neoliberal trade liberalization and the expansion of intellectual property protections, including for pharmaceuticals. The Agreement on Trade-Related Aspects of Intellectual Property Rights required the adoption of far more invasive rules for patents on medications, among other things, which largely did not exist in the Global South, in contrast to "freeing up" trade in goods by eliminating tariffs.[52] Intellectual property became a major source of wealth transfer from the Global South to pharmaceutical corporations in the North.[53]

The liberalization of trade and the introduction of greater intellectual property protections for pharmaceuticals opened vast markets for the industry, as clinicians were being introduced to the biomedical view of psychological distress and governments were reducing budgets for social protections and non-pharmaceutical care in health systems. Pharmaceutical companies modified some of their marketing techniques in situations where it was clear that people understood their distress to be caused by economic austerity, such as in Argentina, so that anti-anxiety and antidepressant medications were promoted as biochemical interventions for social problems.[54]

Currently, neoliberal imperatives of privatization and increasing financialization of health care and commodities, including pharmaceuticals, reinforce both the biological individualism underpinning psychiatrization and the social inequalities that foster emotional distress.[55] On a global level, the effects of receding fiscal space and, in turn, the political capacity of many states—especially those in the Global South—hollow out the possibilities for fulfilling meaningful claims for health and social protection by persons with mental illness and psychosocial disabilities, and more broadly.

If we understand corruption in mental health as institutional, HRBAs have to address not only how neoliberal globalization has shaped legal and policy frameworks that deprive states in the Global South of the capacity to construct other forms of mental health treatment, but also how neoliberal social policy has exacerbated gaping wealth gaps.[56] This includes reforming intellectual property regimes, advancing an international framework for tax cooperation to stem massive interstate tax avoidance and evasion, and addressing unsustainable sovereign debt. Without concrete measures that address institutional capacity and political economy factors, invoking the importance of social determinants in scholarly articles and national policy documents offers hollow hope.

Measuring progress in health systems: The need for new metrics

Addressing institutional corruption calls for a broad set of legal and policy reforms at national and international levels and change in educational approaches and training incentives for providers. It also calls for different metrics. Metrics drive funding and priorities; they create incentives for behavior change and performance standards. In neoliberalism, the performance standards and behaviors are individualized. By changing metrics, we can begin to redefine the framework for understanding mental health and illness, and the goals of health systems in addressing mental health can begin to be more aligned with demands from people with lived experience.[57]

Both the Sustainable Development Goals, which set out universal health coverage as a principal target under the goal of "improvement of health and well-being," and national planning targets emphasize *coverage* as an indicator of progress in health, including mental health.[58] The use of coverage under universal health coverage has been successful in cultivating a sense of urgency and shared understandings of the aims of health systems across many countries, including catalyzing a sense of urgency around a Movement for Global Mental Health, to which some HRBAs have contributed.

However, as noted above, HRBAs in the context of mental health can actually foster pharmaceuticalization by focusing on measurements of equity of access without interrogating the relationship between accessibility of treatment and outcomes.[59] If our starting presumption is that over-pharmaceuticalization is a manifestation of institutionalized corruption, we cannot rely on the traditional public health measures of inputs (e.g., drug supply) and outputs (e.g., patients attended or medications distributed) to assess progress in mental health, much less in combating corruption in mental health.[60]

Increasing coverage in mental health in isolation from quality of care and adequate evaluation of outcomes is not a solution and may drive institutionalized corruption further. Let us recall that providers determine both the supply and demand for pharmaceutical treatments, and the evidence that expanding coverage improves population mental health is not robust. Data on psychiatric conditions over time on a population-wide basis reveal that the number of people taking antidepressants has risen exponentially and continues to rise; for example, antidepressant prescriptions virtually doubled in England in the last decade, rising from 47 million in 2011 to more than 85 million in 2022/23, and these trends are set to continue.[61] Further, the average duration that any one person takes an antidepressant has also doubled over the last 15 years or so, with approximately half of patients being classified as long-term users. These data should raise alarm bells over how we assess "progress."

Further, qualitative research reveals that prioritizing pharmacological interventions over other types of interventions has often been based on questionable evidence.[62] The truth is that the little information we have on the connections between prescription coverage and outcomes from varied contexts does not support widespread pharmaceuticalization as the adoption of "all appropriate measures" under international law.[63] Systematic reviews of studies that attempt to model the clinical and cost effectiveness of various treatment forms have uncovered difficulties in evaluating such effectiveness, given contested assumptions regarding the nature of clinical benefits of multiple treatments.[64] Further, significant disparities in studies that measure clinical versus cost-based effectiveness underscore the difficulty in evaluating treatment based on such siloed efficacy metrics.[65]

In short, if we want to meaningfully assess progress in mental health, and combat institutionalized corruption, an important first step is to adopt different metrics, which in turn would suggest adopting different understandings of the aims of mental health care. Indicators that are fit for purpose would ideally combine issues relating to institutional practice (e.g., numbers of health facilities with protocols for supported decision-making; staffing of social workers) with outcome indicators (e.g., percentage of patients treated for psychological conditions who finish treatment and do not relapse within a certain period; suicide rates). In keeping with human rights concerns about nondiscrimination, these data should be disaggregated by sex, race, ethnicity, socioeconomic class, region, and age, and include both PPPs and private facilities. Further, quantitative indicators should always be supplemented by qualitative research to assess people's lived experiences at the national and subnational level, and to account for cultural differences as well as socio-historically constructed understandings of emotional distress from colonialism. To advance systems that uphold the rights of diverse persons suffering from psychosocial distress, we require far more data that are reliable and actionable, and tailored to specific social and cultural realities. Finally, legal and regulatory frameworks have been included previously in Sustainable Development Goal indicators (e.g., indicator 5.6.2); in this case, it is imperative for transparency laws regarding the pharmaceutical industry's support to universities, health authorities, and providers to be incentivized through monitoring processes that can drive actions.

Conclusion

In this paper, we have challenged the standard understanding of HRBAs in relationship to mental health in three ways. First, we have suggested that transformative human rights approaches need to be attentive to these epistemic architectures of biomedicine and neoliberal economies in which mental health rights are advocated. Improving technical interventions is of course essential, but asymmetries at the micro level between clinicians and patients and at the macro level in national health systems are too often not just displaced by biomedicine but obscured or distorted by the premises built into the model. Second, accepting the prevalent human rights construction of corruption as "bad apples" that engage in bribery or embezzlement of public funds destines remedies to reinforce structures that systematically privatize wealth and deprive states of the capacity to uphold mental health rights. If those premises are accepted in HRBAs, applying rights to mental health may stymie more than facilitate structural reforms. We have argued here for a conception of institutional corruption in mental health that entails structural and systemic drivers of private gain at the expense of the public good, which are imbricated in economies of influence between academic psychiatry and the pharmaceutical industry and spread through the globalization of Western biomedical frameworks and the neoliberal consensus across lower-middle and middle-income countries. Third, we have added to the literature on the psychiatrization of the world by placing it in socio-historical context, noting the growing impacts of neoliberal globalization, which began to colonize our collective imaginations just as the Cold War was thawing and other modes of mental health practice began to wane in power.

Rethinking epistemic paradigms in science as well as economic organization may appear to be an overwhelming task, but, along with legal and policy advocacy, we have argued that shifting our measurement of progress in mental health can facilitate such reimagining and foster consideration of different sorts of governance. Coverage in access to psychiatric treatment, while important, cannot be the gold standard for assessing health systems and the right to health. Governments should produce disaggregated data—both qualitative and quantitative—focusing on measuring successful outcomes rather than inputs. These different forms of data are critical to understanding and assessing the real effectiveness of prioritized interventions and to being accountable to local populations, especially marginalized ones, regarding what interventions are useful in specific contexts.

Ultimately, effectively addressing institutional corruption in mental health requires different forms of global governance for mental health, understood as the mechanisms through which various historical configurations of actors utilize legislation, economic incentives, direct coercion, and epistemic framings to produce, monitor, and control behaviors and practices related to mental health and well-being. Biomedicine depends on what Sheila Jasanoff has termed "technologies of hubris" to "keep the wheels of science and industry turning," whereby a series of predictive methods are designed to facilitate management and control by experts invested with technical authority, even in areas of high uncertainty, such as mental health. Neoliberal globalization has relied on other technologies of hubris, whereby economic policies are dictated from afar by international financial institutions based on abstract metrics, such as fiscal discipline and debt-to-GDP ratios. Development frameworks, such as the Sustainable Development Goals, similarly rely on abstracted indicators that determine knowledge and governance discourses about the meaning of progress in mental health, and health more broadly, across widely varying cultural and social contexts. Addressing institutional corruption and advancing mental health *rights* for all calls for shifting to technologies of humility, which Jasanoff describes as "social technologies [that] would give combined attention to substance and process, and stress deliberation as well as analysis." Such technologies of humility would "engage the human subject as an active, imaginative agent, as well as a source of knowledge, insight, and memory."[66] As Jasanoff suggests, these concepts alone are insufficient to drive serious institutional change. However, they can offer starting points for a deeper public debate on addressing the scope of institutional corruption and the future of human rights in mental health.

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Addressing the Global Mental Health Crisis: How a Human Rights Approach Can Help End the Search for Pharmaceutical Magic Bullets

LISA COSGROVE

Abstract

Although there is a seductive neutrality to calls to end the "mental health crisis" and develop more effective psychotropics, these calls are grounded in a neoliberal sensibility. Such rhetoric deflects attention away from the lived realities of people's lives and from the human rights violations that are often the cause of mental ill-health. Moreover, the undue influence of both industry and organized psychiatry in the mental health field create a perfect storm in which mental health research, policy, and clinical practice are driven by the search for pharmaceutical magic bullets. This search is facilitated by medicalized tropes, academic-industry relationships, an anti-regulatory climate, and guild interests, to the detriment of public health considerations. Indeed, an overly medicalized response to emotional distress violates patients' human rights, including the rights to health and to informed consent. Using the conceptual and normative framework of institutional corruption, this paper identifies the various economies of influence that have paved the way for the fast-tracking of psychotropics with "novel" mechanisms of action. I discuss the marketing of postpartum distress (PPD) as a disorder of the hypothalamic-pituitary-adrenal axis and the "first ever" pill to treat PPD, zuranolone, as a case illustration of medicalization. I conclude by offering solutions for reform that are embedded in a human rights framework.

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Competing interests: None declared.

Introduction

> *"Half of World's Population Will Experience a Mental Health Disorder"*[1]
>
> — Queensland Brain Institute

> *The [United States'] national economic burden of TRD [treatment-resistant depression] was estimated as $43.8 billion annually.*[2]
>
> — M. Zhdanava et al.

> *"Globally, one in seven 10-19-year-olds experiences a mental disorder, accounting for 15% of the global burden of disease in this age group … yet these remain largely unrecognized and untreated."*[3]
>
> — World Health Organization.

In light of these alarming statistics and headlines, it is no wonder that there are calls for increasing access to psychiatric screening and treatment and for speeding up the regulatory process so that countries can get new psychotropic medications approved more quickly. Certainly, large swaths of the population in all age cohorts are distressed, and mental ill-health is a pressing public health issue. However, calls to end the "mental health crisis" are grounded in a seductive neutrality. Such calls deflect attention away from the lived realities of people's lives and from the human rights violations that are often the cause of mental ill-health. Unfortunately, the pharmaceutical industry has taken good advantage of the rhetoric and of the mental health disease burden estimates. Commercial entities that manufacture psychotropics have co-sponsored international events promoting the movement and have funded researchers who report on the high prevalence of mental illness and the need for greater access to treatment.[4] Matthew Roberts reports that the Gates Foundation did not offer financial support for global mental health projects because the pharmaceutical industry already provides funding.[5]

Against this backdrop, and using the conceptual and normative framework of institutional corruption, this paper discusses the various economies of influence that have paved the way for the continued search for psychotropic magic bullets. I explore the marketing of postpartum distress (PPD) as a disorder of the hypothalamic-pituitary-adrenal axis, and a resulting deficit in allopregnanolone, and the "first ever" pill to treat PPD, zuranolone, as a case example of pharmaceuticalization. I then offer solutions for reform that are embedded in a human rights framework.

The mental health crisis and medical neoliberalism

> *Medicalization and individualism go hand in hand, thus giving more power and political ammunition to the view that health is individual and autonomous and thus outside the purview of governmental authority and action.*[6]

Neoliberal capitalism both requires and sustains the medicalization of distress. This is due in part to the fact that medicalization ignores the context and conditions in which emotional distress is embedded—such as poverty, discrimination, isolation, and oppression—and makes these human rights violations seem inevitable. Although mental ill-health is inseparable from capitalism and racism, a distinguishing feature of medical neoliberalism is the assumption that emotional distress is best conceptualized and treated as a disease. Such conceptualizations take suffering out of its "moral and political context" and lead to one-size-fits-all psychological and psychotropic interventions.[7] The medicalization of distress also encourages policy makers to use simplistic symptom-reduction models and to focus on the economic cost of mental ill-health. Metrics such as "disability-adjusted life years" (DALYs) were introduced by the World Bank and the World Health Organization in the 1990s. DALYs are based on an incidence approach that can be used (with other metrics) to calculate, per country or globally, the financial burden of having disease or disability. For over two decades, there has been ever-increasing documentation of, attention to, and rhetoric about the "burden" of mental disorders; biostatisticians identify the days, months, or years that one "loses" (economically speaking) to mental ill-health. Not surprisingly, critical psychiatrist Derek Summerfield has noted that applying the DALY metric to depression is "epistemologically lamentable."[8]

An increasing number of researchers are documenting the ways in which neoliberal ideology and policies have contributed to the increasing rates of mental illness.[9] This scholarship provides important data that can be used to develop policies that are grounded in a human rights framework. For example, there is a substantial body of literature emphasizing the need to address economic and employment issues (e.g., through "housing first" programs) in order to prevent mental ill-health. Relatedly, researchers have found that farmer suicide in India is best predicted by cash crop production and level of debt; to significantly reduce suicide, they recommend policy-level interventions addressing the economic realities of farmers' lives.[10] Thus, in order to stop the medicalization of despair and improve population mental health, there needs to be a concerted effort to address the *drivers* of medicalization. As described below, the conceptual and normative framework of institutional corruption can assist in identifying and addressing these drivers.

The normative and conceptual framework of institutional corruption

> *Kindergarten ethics sees the world in black and white. There are good people. There are bad people. Good comes from the former, bad from the latter … The field of "institutional corruption" was launched to help ethics grow up.*[11]

The ways in which academic-industry relationships can have a biasing effect on the scientific literature and undermine evidence-based practice have been well-documented. Although all medical specialties have come under scrutiny, psychiatry could be described as being at the epicenter of this "crisis of credibility." Much of the literature revealing the pro-industry habits of thought that are engendered by financial conflicts of interest focuses on the payments that individuals receive from industry. For example, in the United States, the Open Payments database was developed to create "a more transparent and accountable healthcare system."[12] It provides the public with information on how much money, and for what services (e.g., consulting), prescribers have received from commercial entities. Yet as physician and bioethicist Carl Elliot notes, the focus on conflicts of interest may deflect attention away from the more pernicious problem—institutional practices:

> *The difficulty with conflict of interest as a way of framing the problem of industry funding is that it directs our attention to individuals … This way of framing the issues makes it sound as if these financial ties are a purely individual problem—that an individual has a problem and we need to manage it.*[13]

Indeed, an acontextual focus on the amount of money individuals receive from pharmaceutical companies may give the erroneous impression of wrongdoing or quid pro quo corruption. In contrast, the framework of *institutional* corruption is oriented toward solutions, not blame, and avoids a focus on individuals. As legal scholar Larry Lessig puts it, "Institutional corruption is manifest when there is a *systemic and strategic* influence which is legal, or even currently ethical, that undermines the institution's effectiveness by diverting it from its purpose or weakening its ability to achieve its purpose … weakening either the public's trust in that institution or the institution's inherent trustworthiness."[14]

Certainly, the health care sector is exposed to quid pro quo corruption, and girls and women are particularly vulnerable. As Farzana Nawaz and Marie Chêne note, "the consequences of expensive, ill-tailored, inaccessible or unsafe health products and services hit women particularly hard."[15] However, the conceptual and normative framework of institutional corruption broadens the scope of the problem. In so doing, it can help us better identify, understand, and mitigate the "economies of influence" that have undermined the trustworthiness of organized psychiatry—influences that reinforce medicalization and pharmaceuticalization. For example, organized psychiatry, in particular the American Psychiatric Association, has developed a financial dependence on Big Pharma. This is evidenced not only by monies given to individual psychiatrists but also by the monies given to support the organization itself, its conferences, its journals, and even its philanthropic arm, the American Psychiatric Foundation. In fact, each year, the foundation thanks its "corporate alliance" (which includes a myriad of pharmaceutical companies) for their generous support.[16]

It is not surprising that commercial entities provide financial support to organized psychiatry. Industry benefits from an overemphasis on chemical, neurobiological, and hormonal theories regarding the etiology of distress and from medicalized diagnostic conceptualizations of mental ill-health. The Diagnostic and Statistical Manual of Mental Disorders *(*DSM*)* is often referred to as the "bible" of psychiatric disorders. Since the publication of DSM-3, when psychiatry officially adopted the medical model, industry has exerted an undue influence on organized psychiatry. This was made abundantly clear by Robert Spitzer, who chaired DSM-3; when asked by a reporter from the *New Scientist* what pharmaceutical companies thought of the revised manual, he said, "the pharmaceuticals were delighted!"[17] This is not to suggest that there was any wrongdoing or quid pro quo corruption on the part of the DSM panel or task force members. Rather, the former chair of the DSM was acknowledging the fact that the paradigm shift to the medical model that occurred with the publication of the manual in 1980 resulted in an industry-friendly psychiatric taxonomy. It is also important to note that, in a unique and significant way, psychiatry benefits from its dependence on commercial entities: industry creates a climate that sustains the ontological status of psychiatry and psychiatric conditions. Because of the lack of biological markers for any disorders listed in the DSM, psychiatry is unique in its need to have industry legitimize its existence as a medical subspecialty.

Guild interests

> *Although it is true that individual medical providers care deeply about their patients, the guild of health care professionals—including their specialty societies—has a primary responsibility to promote its members' interests … it is a fool's dream to expect the guild of any service industry to harness its self-interest and to act according to beneficence alone—to compete on true value when the opportunity to inflate perceived value is readily available.*[18]

Congruent with Kerianne Quanstrum and Rodney Hayward's insight, the framework of institutional corruption reveals the biasing effects of guild interests. Such interests undermine psychiatry's ability to acknowledge the poor harm-benefit ratio of many psychotropic medications and to acknowledge that despite greater access to these agents worldwide, we have not seen improvements in population mental health. The combination of guild and industry interests also explains why organized psychiatry continues to search for pharmaceutical magic bullets and continues to export to both low- and middle-income countries an overinflated sense of efficacy about currently approved psychotropics. To paraphrase Upton Sinclair, it is difficult to get people to understand something when both their salary and allegiance to their profession depend on their *not* understanding it.[19]

Psychologists are also implicated in promoting their guild interests, having more confidence in psychological interventions than the empirical evidence supports, and in exporting an overly optimistic view of Western intra-individual interventions to non-Western settings. Exporting Western diagnostic models risks perpetrating epistemic injustice, can result in over- or mis-diagnosis, and is a clear example of colonial global health "aid." For example, psychologists as well as psychiatrists were involved in developing and implementing one of the World Health Organization campaigns on depression awareness, titled "When sadness doesn't stop: Helping Syrians talk about depression."[20] Five years after the Syrian conflict began, the United Nations described it as the "biggest humanitarian and refugee crisis of our time."[21] Although the campaign was well-intentioned, and acknowledging pain and sadness can certainly help heal broken communities, it nonetheless reflects a US-centric and biomedical perspective. The assumption is that the displacement and violence experienced by refugees is best understood as a psychiatric disorder and treated with talk therapy.

Fortunately, there are some signs that even the most passionate guild supporters are walking back their claims that the psychiatric conditions codified in the DSM are best understood via medicalized tropes. In 2017, Martine Hoogman, a leading international ADHD researcher who published a high-powered analysis of brain scans comparing patients with and without ADHD, stated, "patients with A.D.H.D. have altered brains; therefore A.D.H.D. is a disorder of the brain." Eight short years later, she regretted this claim and called for a more nuanced view. As quoted in a *New York Times* article, Hoogman acknowledged, "'We emphasized the differences that we found (although small), but you can also conclude that the subcortical and cortical volumes of people with A.D.H.D. and those without A.D.H.D. are almost identical.'" The article added, "[Hoogman said] it wasn't fitting to conclude from her findings that A.D.H.D. is a brain disorder."[22]

Yet the pull of medicalization remains strong in psychiatry in part because of its guild interests. The next section discusses the marketing of PPD as a disorder of the hypothalamic-pituitary-adrenal axis and the "first ever" pill to treat PPD, zuranolone, as a case example of the ways in which commercial influences sustain the medicalization of PPD.

The first-ever pill to treat postpartum distress: Caveat emptor

> *Childbirth is one of the most powerful triggers of psychiatric illness in a woman's life.*[23]

The assumptions embedded in the above quote—a contemporary version of a very old trope (women's reproductive capacity and organs cause mental illness)—are being exported to both low- and middle-income countries. Giving birth to a child is a life-altering event that is certainly stressful, and there is a biological basis to all distress, including that which is experienced after childbirth. However, promoting the view that PPD is a homogeneous psychiatric disorder that can be explained in terms of DSM criteria and identified via the use of acontextual survey instruments (e.g., HAM-D; Edinburgh postnatal depression scale) is problematic and leads to the pharmaceuticalization of that distress. Yet women and their health care providers are being told that PPD is a psychiatric disorder with a distinct biological and hormonal cause.[24] In the publications based on the clinical trial data assessing zuranolone's efficacy, the authors—who have financial conflicts of interest or are employees of Sage or Biogen (the pharmaceutical companies that manufacture zuranolone)—emphasize the role that low levels of allopregnanolone play in the etiology of PPD.[25] For example, the authors focus almost exclusively on the "connection between neuroactive steroid levels [i.e., allopregnanolone], network connectivity, and symptom severity in PPD."[26] From a human rights perspective, it is important to ask, What gets erased when we make hormonal dysregulation the primary site of intervention?[27]

Additionally, health care providers and the public are being told that PPD is significantly "underdiagnosed and undertreated," and thus there is a "silent health crisis."[28] In late 2023, Sage received regulatory approval in the United States for zuranolone, the "first ever" pill for PPD. The cost of this new pill is almost US$1,600 for a two-week supply, and Sage will likely be able to grow its global market. In fact, a 2024 marketing report, "Postpartum Depression Drugs Market Trends," optimistically reported:

> *The global postpartum depression drugs market size was estimated at USD 838.4 million in 2023 and is projected to expand at a CAGR [compound annual growth rate] of 9.63% from 2024 to 2030. The increasing prevalence of postpartum depression, growing research and development efforts, and a rise in new product launches are supporting the market expansion for postpartum depression drugs (PPD). Furthermore, an increase in awareness about the treatment options for PPD is driving market growth … The postpartum depression drugs market in Latin America is expected to grow rapidly.*[29]

A critical question remains: Will Sage and Biogen be exporting an effective and safe medication for new mothers struggling after childbirth? As discussed by Vinay Prasad and David Allely, the short answer is no.[30] Unfortunately, despite regulatory approval, an assessment of the clinical trial data suggests that zuranolone barely outpaced the placebo statistically and likely offers little clinically meaningful benefit. In fact, the small difference on the outcome measure (the HAM-D) between the zuranolone and control group could be explained by either the placebo effect or regression to the mean.[31] There are also significant safety concerns. Although zuranolone is being marketed as a "neurosteroid," the integrated summary review from the US Food and Drug Administration (FDA) notes that it is an allosteric modulator of GABA_A, which is the same pharmacodynamic action of benzodiazepines.[32] The FDA also reports that it carries the same potential for abuse and dependence as alprazolam, a benzodiazepine, and it is not known whether it is safe to breastfeed while taking zuranolone.

Returning to the framework of institutional corruption, it is helpful to ask, What are the economies of influence that are facilitating the exportation of a drug with limited efficacy data and significant safety concerns? The suggestion that PPD is the result of a chemical or hormonal imbalance—one that a magic-bullet medication can fix—is supported by organized psychiatry (with its attendant guild interests) and by researchers who are Sage employees or who have other financial conflicts of interest (e.g., holding patents on synthetic analogues of allopregnanolone).[33] Additionally, financial support of both the American Psychiatric Association and FDA by the drug industry has led critics to question whether these financial relationships have opened the door for "disease mongering."[34] Indeed, the overemphasis on a neurobiological explanation of PPD, together with the drug narrative, "readily meld[s] scientific credibility and commercial imperatives."[35]

Such is the case with Sage's new drug application (NDA) for zuranolone: the FDA effectively lowered the regulatory bar by allowing Sage to compare zuranolone only to a placebo, despite the fact that Sage received Fast Track designation. This designation, according to the FDA, requires pharmaceutical companies to provide data that show some advantage over available treatments. However, as Prasad and Allely point out, selective serotonin reuptake inhibitors and psychotherapy are considered standard therapies for PPD and are recommended as interventions in many clinical practice guidelines, yet the FDA did not require any head-to-head comparisons with either antidepressants or psychotherapy.[36]

It is also instructive to more closely examine the etiological narratives that the authors of the clinical trial data are using in the published medical literature. What one finds is a story similar to that of Prozac. The marketing of Prozac reinforced the gravitas of "major depressive disorder" and the chemical-imbalance theory of depression—that is, the idea that low serotonin levels cause depression. In much the same way, zuranolone-qua-magic-bullet depends on a conceptualization of PPD as a deficit of allopregnanolone. It is noteworthy that the manufacturer did not get its NDA approved for zuranolone for major depressive disorder. The fact that the FDA did not grant regulatory approval of the drug for depression is particularly interesting because PPD could be seen as a subset of major depressive disorder; in the DSM, the condition is codified as "Major Depressive Disorder, peripartum onset." In light of the FDA's rejection of zuranolone for depression, heavily promoting the allopregnanolone-deficit hypothesis for PPD, and zuranolone as a novel new agent—a "neurosteroid"—is a successful marketing technique.

Additionally, medicalized conceptualizations deflect attention and resources away from addressing PPD as a *public* health issue. Women are encouraged to overlook the context in which their emotions are manifest and regard feelings of sadness or anxiety as by-products of hormonal changes or allopregnanolone deficiencies. Emma Tseris summarizes this point well, noting that the PPD label "renders invisible a broad array of social contexts and gendered power relations and their impacts on new mothers during the perinatal period."[37] For example, a recent meta-analysis of studies from 56 countries found a clear relationship between wealth inequality and PPD.[38] Level of debt is also strongly associated with maternal depression, and the United States is the only one of 41 OECD nations that does not mandate paid family leave.[39] Numerous studies, including a recent systematic review, found that paid maternity leave was significantly correlated with beneficial mental health effects on both mothers and children and that there was a relationship between restrictive maternity leave policies and rates of postpartum depression.[40] The authors called on the United States to mandate a national paid leave policy of at least three months.

Unfortunately, as reported in a 2023 *Lancet* editorial, because both breastfeeding prevalence and breastfeeding duration are highly correlated with paid maternity leave, "some CMF [commercial milk formula] lobby groups have cautioned against improved parental leave."[41] As described earlier, paid parental leave is associated with better maternal health and a lower incidence of PPD. Thus, CMF lobbying groups can be seen as a distal, but important, economy of influence that may contribute to the distress many women experience postpartum. The marketing of zuranolone as a "magic bullet" is an example of the promotion of pharmaceutical solutions to what are also public health issues.

A robust human rights approach as a solution for reform

> *The juggernaut of medicalization is a complex and powerful social and historical process that cannot be stopped with a pithy set of recommendations for cultural shifts, systemic and institutional changes, and policy reform.*[42]

Although Lantz and colleagues are correct that we must be cautious about finding an easy "cure," I agree with epidemiologist and public health activist Devra Davis, who said, "Those of us who indict past failures have a duty to develop new solutions."[43] Toward that end, I offer the following ideas as a means to facilitate a discussion about how a human rights approach can address the drivers of medicalization and stop the resource-draining search for pharmaceutical magic bullets.

As scholars such as Amartya Sen and Martha Nussbaum describe, a human rights approach invigorates our ethical imaginations and encourages thinking about the promotion of well-being not just within individuals but *within societies*. Critical thinking about the mental health crisis must start with the recognition that the field of global mental health has been subsumed by the medical model. Thus, what is needed is nothing short of a "moral renaissance," a paradigm shift, and the development of new narratives.[44] Such a suggestion may seem overly ambitious and perhaps even impossible. However, the policy reset recently suggested for suicide prevention, where the focus shifts "from health departments to all parts of government," provides both hope and a road map.[45] This policy reset is grounded in a population health approach and has a clear human rights impulse. Specifically, the focus is on addressing and ameliorating the upstream and often sociopolitical and economic precipitants of suicide. Because many social determinants can best be addressed by creating economic safety nets (e.g., a universal living wage), this public health approach to suicide prevention involves a "whole of government and whole of society" approach where there is a "strong commitment from a range of government sectors, many of which fall outside of health."[46]

However, making a similar commitment for tackling the mental health crisis will come to fruition only if researchers and clinicians develop and promote less medicalized narratives about mental health. As neurologist and Alzheimer's expert Peter Whitehouse astutely notes, "He/she/they that control language also control resources and manipulate the sources of hope."[47] Thus, in order to facilitate a commitment from a wide range of government sectors and engender a more robust human rights approach in the field of global mental health, there will need to be a marked shift in the language we use about mental well-being and the narratives we use to understand the "mental health crisis." Nick Chater and George Lowenstein, two leading behavioral social scientists, eloquently argue for the need to shift from individual (i-level) to society (s-level) theoretical frameworks:

> *An influential line of thinking in behavioral science, to which the two authors have long subscribed, is that many of society's most pressing problems can be addressed cheaply and effectively at the level of the individual, without modifying the system in which the individual operates. We now believe this was a mistake, along with, we suspect, many colleagues in both the academic and policy communities … behavioral scientists [have framed] policy problems in individual, not systemic, terms: To adopt what we call the "i-frame," rather than the "s-frame." The difference may be more consequential than i-frame advocates have realized, by deflecting attention and support away from s-frame policies.*[48]

A human rights approach, as articulated by psychiatrist Dainius Pūras, former United Nations Special Rapporteur on the right to health, focuses on the "global burden of obstacles" rather than the global burden of mental disorders.[49] As such, a human rights approach is congruent with and extends this s-level focus. Fortunately, there are increasing efforts to transform the global mental health movement from a top-down, individualized, and treatment-oriented approach toward a rights-based conception that accounts for the political, and economic conditions that produce distress and disability.[50] These efforts will be enhanced to the degree that we genuinely center the insights and ideas of individuals with lived experience in mental health research, policies, and practices.

It is clear that addressing the sociopolitical determinants of mental health and mitigating industry and guild interests will require more nuanced narratives about mental ill-health—ones that focus on how to prevent it and help people flourish. Publishing critiques of medicalization in the scientific literature is helpful, but more innovative efforts are also needed. For instance, human rights scholars and activists can assist the media in learning how to frame the story of the "mental health crisis" with more nuance, complexity, and appreciation for the upstream causes of distress. Indeed, a human rights framework can facilitate greater public scrutiny about the iatrogenic consequences of taking emotional suffering out of its moral, ethical, and political context.[51]

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Without Informed Consent: The Global Export of a Failed Paradigm of Care

ROBERT WHITAKER

Abstract

The discourse around health as a human rights issue usually focuses on access to medical treatment. However, the "right to health" begins with the right to informed consent about the merits of a treatment, which has been lacking as a US-constructed "disease" model of psychiatric care has been exported around the globe. The narrative that supported the adoption of the disease model told of how major psychiatric disorders were due to chemical imbalances in the brain, which could be treated by a second generation of psychiatric drugs that fixed those imbalances, much like "insulin for diabetes." Randomized clinical trials had proven that antidepressants, antipsychotics, and other psychiatric drugs were safe and effective. However, missing from this narrative of medical progress were three key facts: that investigations failed to validate the chemical-imbalance theory of mental disorders; that studies of long-term outcomes regularly failed to show a benefit for the medicated patients; and that this model of care has led to poor public health outcomes in the United States and other developed countries. The principle of informed consent in medicine can be expanded to include the obligation of a medical specialty to be a reliable narrator of its own research, which provides a framework for understanding the violation of human rights that occurred with the exporting of a disease model of care to a global population.

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Competing interests: None declared.

Introduction

The legal right to informed consent arose out of the horrors of Nazi experiments. The Nuremburg Code stated that volunteers in research studies needed to be informed about the risks of a study before they could give consent. In the 1950s and 1960s, this principle of informed consent was extended to regular medical practice in the United States. In the 1972 case *Canterbury v. Spence*, the US Supreme Court ruled that a doctor must provide the patient with "enough information to make an intelligent choice" regarding the merits of a proposed treatment. As for the information to be disclosed, the court set this standard: "What would a reasonable patient want to know with respect to the proposed therapy and the dangers that may be inherently or potentially involved?"[1]

This obligation is codified in the American Medical Association's Code of Ethics, which states that "informed consent to medical treatment is fundamental in both ethics and law."[2] Similarly, the European Charter of Patients' Rights and the World Medical Association's Code of Medical Ethics list informed consent as a fundamental right.

While this obligation is imposed specifically on the individual doctor, it also imposes an ethical duty—by proxy—on the medical specialty to provide the public with an accurate and full summary of its research findings, because a society will organize its care around that public narrative. A medical specialty needs to be a reliable source of information about what is known about the biology of a disorder, as well as the risks and benefits of a proposed therapy. In essence, it is the medical specialty that provides society with "informed consent" for its therapies.

Moreover, the right to informed consent is a primary element of the individual's right to health as set forth by the United Nations International Covenant on Economic, Social and Cultural Rights. The covenant states that the right to health includes "access to health-related education" and that an "important aspect is the participation of the population in all health-related decision-making at the community, national and international levels." In other words, the individual's right to health is dependent on the public being properly informed about scientific findings regarding the risks and benefits of any proposed treatment.

As can be shown, American psychiatry failed to meet its informed consent obligations as it promoted its disease model to the public, and this failure continued as this model was adopted in other high-income countries and exported to low- and middle-income countries.

The American Psychiatric Association adopts a disease model of care

Prior to the publication of DSM-3 (the Diagnostic and Statistical Manual of Mental Disorders, third edition), American psychiatry had conceptualized psychiatric disorders as arising from multiple factors: family and social tensions, social inequalities (poverty, racism, and so forth), and, on occasion, biological illnesses. However, this was a diagnostic medley that lent credence to the criticism that psychiatrists were not "real doctors," and in the 1970s, the American Psychiatric Association (APA) faced criticisms from so many quarters that its leaders spoke of their field as being under siege. Ex-patients formed psychiatric survivor groups; popular movies suggested that psychiatrists were crazier than their patients; psychiatrists' diagnostics were seen as unreliable; and outcome studies failed to show that psychoanalysis was more effective than less-expensive therapies provided by psychologists and other mental health counselors.

With psychiatry's public image in freefall, the APA created a task force to produce a new DSM. As this effort took hold, APA leaders spoke about how adopting a disease model could serve to remake psychiatry's public image. The shrink tending to a patient on a couch would be replaced by a doctor in a white coat, treating "diseases" of the brain. With this new model, APA leaders stated, the focus would be on "the symptoms and signs of illness … the medical model is clearly related to the concept of disease."[3]

In 1984, Nancy Andreasen, who would later become editor-in-chief of the *American Journal of Psychiatry*, presented the field's new thinking in a best-selling book, *The Broken Brain: The Biological Revolution in Psychiatry.* "Major psychiatric illnesses are diseases," she wrote. The thought was that each "different illness has a different specific cause … there are many hints that mental illness is due to chemical imbalances in the brain and that treatment involves correcting these chemical imbalances."[4]

This was the soundbite that was used to sell the disease model to the American public. In 1988, Eli Lilly brought Prozac (fluoxetine) to market, and it was touted as a breakthrough medication that fixed a serotonin imbalance in the brain. Other pharmaceutical companies brought selective serotonin reuptake inhibitor (SSRI) antidepressants to market, and throughout the 1990s the American public was informed, both through pronouncements from leaders in American psychiatry and pharmaceutical advertisements, that these drugs fixed a chemical imbalance in the brain.

As APA President Richard Harding wrote in a 2001 *Family Circle* article, "We now know that mental illnesses—such as depression or schizophrenia—are not 'moral weaknesses' or 'imagined' but real diseases caused by abnormalities in brain structure and imbalances of chemicals in the brain."[5] In that same issue of *Family Circle*, Nada Stotland, who subsequently became president of the APA, informed the public that antidepressants "restore brain chemistry to normal."[6]

During the mid-1990s, pharmaceutical companies also introduced a second generation of "atypical" antipsychotics, which were said to fix the dopamine imbalance that caused schizophrenia, while also fixing irregularities in the serotonergic system. As psychiatrist Peter Weiden wrote in a book titled *Breakthroughs in Antipsychotic Medications*, the newer antipsychotics "do a better job of balancing all of the brain chemicals, including dopamine and serotonin."[7]

This narrative told of an astonishing medical advance. Researchers had discovered the very molecules that caused depression, psychosis, and other major disorders, and the field now had drugs that corrected those chemical imbalances. Patients diagnosed with such disorders now understood that they suffered from a known pathology and that psychiatric drugs provided an antidote.

Indeed, in 2005, an APA survey proved that this understanding had taken hold in the public mind. The APA announced that "75% of consumers believe that mental illnesses are usually caused by chemical imbalances in the brain." A psychiatrist, the APA added in its press release, is "a specialist specifically trained to diagnose and treat chemical imbalances."[8]

The APA continued to tell this story in the years that followed, with visitors to its website in 2014 able to read, in a section titled "Let's Talk Facts" about depression, that "antidepressants may be prescribed to correct imbalances in the levels of chemicals in the brain."[9] Other mental health organizations, such as the National Alliance for the Mentally Ill, the Depression and Bipolar Support Alliance, and the Child and Adolescent Bipolar Foundation, told this to the public as well.[10] These organizations had scientific advisory councils composed of prominent American psychiatrists, and so the public had reason to conclude that the chemical-imbalance story was a well-established fact.

Economies of influence

Any study of institutional corruption requires identifying the "economies of influence" that can lead an institution to betray its public duties. In this instance of institutional corruption, there were two such influences that led American psychiatry astray.

The first was that American psychiatry had an evident guild interest in promoting the chemical-imbalance story, as it told of an extraordinary medical advance that elevated the prestige of psychiatry and its influence on American society. It also provided psychiatry with superiority in what might be dubbed the therapeutic marketplace. Psychiatrists had prescribing powers, while other mental health providers—psychologists, counselors, and so forth—did not.

The second was that pharmaceutical companies were eager to help the APA sell the disease-model story to the public. Drug companies provided funding for the APA through grants, advertisements in APA journals, and fees for display booths, and they sponsored talks at the APA's annual conferences. With pharma money flowing into its coffers, the APA's annual revenues increased from US$10.5 million in 1980 to US$65.3 million in 2008, with 30% of this 2008 revenue coming from pharmaceutical companies.[11]

Pharmaceutical companies also began paying academic psychiatrists to serve as their advisors, consultants, and key opinion leaders, with this financial influence so complete that in 2000, when the *New England Journal of Medicine* sought to commission a review on the efficacy of antidepressants, it found it difficult to find an expert in mood disorders who was not receiving money from industry.[12] A subsequent investigation by Senator Charles Grassley revealed that prominent thought leaders had received six-figure payments from industry, with several reaching the million-dollar club.[13]

With pharmaceutical companies providing the funding and academic thought leaders the scientific legitimacy for the disease-model narrative, spending on psychiatric drugs in the United States dramatically increased—from US$2.4 billion in 1986 to US$58 billion in 2012.[14] In 2020, one in six adults in the United States was treated with a psychiatric medication.[15]

Without consent: The science that belies the disease model

The chemical-imbalance story lies at the heart of the disease-model narrative that was told to the American public and subsequently the world. However, decades of research failed to find such chemical imbalances, and it is the disparity between those findings and what was told to the public that reveals psychiatry's failure to provide informed consent to the public.

The chemical-imbalance hypothesis arose in the 1960s based on an understanding of the mechanism of action of antipsychotics and antidepressants. Antipsychotics were found to block dopamine receptors in the brain, thereby decreasing dopamine transmission, and this led researchers to hypothesize that schizophrenia was due to too much dopamine. Both classes of the new antidepressants—monoamine oxidase inhibitors and tricyclic antidepressants—increased monoamine activity, prompting researchers to hypothesize that depression was due to a monoamine deficiency (serotonin is a monoamine).[16]

With these hypotheses in mind, researchers then sought to determine whether patients diagnosed with schizophrenia or depression actually suffered from such chemical imbalances prior to being medicated. In neither instance did they find compelling evidence that this was so, and that was particularly true regarding the low-serotonin theory of depression (also known as the monoamine theory of depression).

Even by the early 1970s, researchers were reporting that they were not finding evidence that low serotonin was a cause of depression.[17] In a 1984 report, National Institute of Mental Health (NIMH) researchers came to the same conclusion, writing that "elevations or decrements in the functioning of serotonergic systems per se are not likely to be associated with depression."[18]

Still, the hunt for a chemical imbalance continued, and over the next 15 years, researchers utilized a number of methods for assessing serotonergic activity in depressed patients, but none bore fruit. The 1999 edition of the APA's *Textbook of Psychiatry* traced this research history and pointed out the faulty logic that had led to the hypothesis in the first place:

> *Inferring neurotransmitter pathophysiology from an observed action of a class of medication availability is similar to concluding that because aspirin causes gastrointestinal bleeding, headaches are caused by too much blood and the therapeutic action of aspirin in headaches involves blood loss. Additional experience has not confirmed the monoamine depletion hypothesis.*[19]

The following year, Stephen Stahl, in his textbook *Essential Psychopharmacology*, put this conclusion even more bluntly: "There is no real clear and convincing evidence that monoamine deficiency accounts for depression; that is, there is no 'real' monoamine deficit."[20]

The history of research into the dopamine hypothesis of schizophrenia is a bit more complicated, but it too began to fall apart in the 1970s and 1980s. In 1994, John Kane, who was a leader in schizophrenia research, concluded that there is "no good evidence for the perturbation of the dopamine system in schizophrenia."[21] Seven years later, Eric Nestler, former NIMH director Steven Hyman, and Robert Malenka, in their book *Molecular Neuropharmacology,* echoed this conclusion, writing that "there is no compelling evidence that a lesion in the dopamine system is a primary cause of schizophrenia."[22]

With both pillars of the chemical-imbalance theory of mental disorders having been investigated and found wanting, other prominent figures in the research community pronounced the chemical-imbalance theory dead. In 2005, Kenneth Kendler, coeditor-in-chief of *Psychological Medicine*, summed it up this way: "We have hunted for big simple neurochemical explanations for psychiatric disorders and not found them."[23]

Such were the conclusions that could be found in psychiatric texts. However, the public heard little of this, and many were shocked in 2022 when UK psychiatrist Joanna Moncrieff and colleagues published an exhaustive review of research on the serotonin theory of depression and concluded that there was "no convincing evidence that depression is associated with, or caused by, lower serotonin concentrations or activity."[24]

Moncrieff said in an interview:

> *People were staggered, really surprised. I went on one television program and the presenter said it blows your mind that this is not true. It revealed that the general public has been persuaded by the pharmaceutical industry and medical propaganda that depression had been established to be caused by a deficiency of serotonin. That's what people thought, and so people were blown away to find out that it wasn't true.*[25]

Yet as Tufts Medical School psychiatrist Nassir Ghaemi wrote after Moncrieff and colleagues published their 2022 paper, "nothing is new here. And the fuss surrounding the paper reveals much ignorance about psychiatry. The serotonin hypothesis of depression, which became popular from the 1990s until now, is false, and has been known to be false for a long time, and never was proven to begin with."[26]

Ghaemi was accurately summarizing the history of research into the chemical-imbalance theory of mental disorders. The APA had been telling the public one story, and scientific research had been telling another, and that disparity tells of a medical discipline that failed to fulfill its public duty to be a reliable narrator of its own research.

The efficacy of psychiatric drugs

There are three principal types of evidence present in the scientific literature regarding the efficacy of antidepressants and antipsychotics. First, in randomized clinical trials, both of the two classes of drugs reduced symptoms of the disorder better than placebo, with the difference statistically significant. Second, in randomized controlled trials (RCTs) conducted in patients who had responded well to the drug, those who were withdrawn from the drug relapsed at higher rates than those who were maintained on it, which was seen as evidence that the drugs help prevent relapse.

Together, these two types of RCTs became the pillars for assertions that the use of psychiatric drugs was evidence based, which enabled the globalization of the disease-model of care. The relapse studies, in particular, fit neatly into the chemical-imbalance narrative that antidepressants and antipsychotics needed to be taken on a continual basis, because they provided evidence for this practice.

However, the deficiency of the relapse studies, as a source of evidence supporting maintenance use of the drugs, is of a fundamental sort. As Ghaemi noted, the design of these studies "is biased from the start by excluding acute symptomatic non-responders" and thus is not a "scientifically valid design."[27] Moreover, the studies do not tell how patients are faring over the long term, particularly in regard to functional and quality-of-life outcomes, and in comparison to unmedicated patients.

There is a third line of research that exists in the literature that can provide insight into that last question. The research is of several types—a few randomized studies, research comparing the change in the course of the "disorder" following the introduction of psychiatric drugs, and naturalistic studies—which together have raised arguments, made within the research literature, that both of these classes of drugs, in the aggregate, have worsened long-term outcomes. Much of this research consists of landmark NIMH investigations into the long-term impact of these two classes of drugs.

Depression

In the 1970s, mood experts in the United States told of how depression was an episodic disorder. Various studies in the pre-antidepressant era found that at the end of one year, around 85% of hospitalized patients had recovered.[28] However, after antidepressants were introduced, studies began to find that depression was now running a more chronic course, with only about 15% of patients remitting and staying well.[29] In 1994, Italian psychiatrist Giovanni Fava raised the question of whether antidepressants were the cause of this increased chronicity:

> *Within the field of psychopharmacology, practitioners have been more cautious, if not fearful, of opening a debate on whether the treatment is more damaging [than helpful] … I wonder whether the time has come for debating and initiating research into the likelihood that psychotropic drugs actually worsen, at least in some cases, the progression of the illness which they are supposed to treat.*[30]

A number of NIMH studies conducted between the late 1980s and early 2000s provided reason to bring this "debate" to the public. For instance, in a one-year NIMH study of 108 real-world outpatients, only 6% remitted and stayed well until the end of the study, whereas in a NIMH study of 85 unmedicated depressed patients, 85% were well at the end of one year.[31]

With such questions about antidepressants swirling in the research literature, in the early 2000s the NIMH launched the STAR*D study, which it touted as the largest and longest trial of antidepressants ever conducted. The results from this study in "real-world" patients would guide future clinical care in the United States. "Given the dearth of controlled data [in real-world patient groups] results should have substantial public health and scientific significance, since they are obtained in representative participant groups/settings, using clinical management tools that can easily be applied in daily practice," the STAR*D investigators wrote.[32]

The STAR*D study had two phases. In the first, or "acute," phase, patients were given up to four tries to remit. If they did not remit on a first antidepressant, they could try a second one, and so on. In the second, or follow-up, phase, those who remitted would be treated with the best possible clinical care for one year. This would provide a final count of patients who remitted and then stayed well and in the trial to its end.

In 2006, the STAR*D investigators announced the study results.[33] They reported that nearly 70% of the patients had remitted after the four rounds of acute treatment, and this became the result that was promoted to the media, cited within the profession and by *The New York Times* and other media as evidence of the real-world effectiveness of antidepressants.[34]

However, a team of independent investigators, led by psychologist Ed Pigott, relied on Freedom of Information requests to review these findings, and in a series of articles, they reported that the STAR*D investigators had violated the protocol in various ways to inflate the announced remission rate. If the protocol had been followed, Pigott and colleagues concluded, the remission rate at the end of the acute treatment would have been 35%.[35] Moreover, they reported on the one-year results from the second stage of the study, which the STAR*D investigators had failed to do. Of the 4,041 patients who entered the trial, only 108 remitted and then stayed well and in the trial to its one-year end. The remaining 3,933 patients either never remitted, remitted and then relapsed, or dropped out.[36]

There have been a number of government-funded studies from other countries, including the Netherlands, France, Switzerland, and Canada, that have similarly told of better long-term outcomes and lower disability rates for depressed patients off medication compared to those who took antidepressants.[37] Such results have led Fava and several others to publish articles exploring the possibility that antidepressants might worsen long-term outcomes and positing a biological explanation for why this might be so. Antidepressants increase serotonergic activity, and in response, the brain dials down its own serotonergic machinery as it tries to maintain a homeostatic equilibrium. "Continued drug treatment may induce processes that are the opposite of what the medication originally produced," wrote Rif El-Mallakh and his two co-authors. This may "cause a worsening of the illness, [may] continue for a period of time after discontinuation of the medication, and may not be reversible."[38]

Although it takes a little sleuthing to find this history in the scientific literature, it is easy to see that if the STAR*D results had been honestly reported, and if the public had been advised of the evidence that antidepressants were turning an episodic disorder into a chronic one, then the public's understanding of the risks and benefits of antidepressants would have been profoundly altered.

Schizophrenia

While this may seem surprising, a similar counter-narrative can be dug out from the research literature regarding the long-term impact of antipsychotics.

In the 1970s, the NIMH funded three studies that assessed the impact of antipsychotics over longer periods of times, and the results led NIMH researchers to worry that antipsychotics induced brain changes that made schizophrenia patients more biologically vulnerable to psychosis over the long term.[39] Canadian researchers then posited an explanation for why this could be so, telling of how antipsychotics could induce a "dopamine supersensitivity" that could lead to more severe and persistent psychotic symptoms.[40] Next, in the 1990s and early 2000s, MRI studies showed that antipsychotics shrink brain volumes and that this shrinkage is associated with a worsening of negative symptoms and functional impairment.[41]

In 2007, Martin Harrow announced the 15-year results from a NIMH-funded longitudinal study of schizophrenia. Most of the patients enrolled in the study were young, suffering from a first or second episode of psychosis, and all were treated in the hospital with antipsychotics and discharged. Harrow then periodically assessed their status over the next 15 years. Those who stopped taking antipsychotics were eight times more likely to be in recovery at the end of 15 years (40% versus 5%) and, as a group, had better cognitive function, were less anxious, and much more likely to work.[42]

Harrow and colleagues pointed to drug-induced dopamine supersensitivity as a possible explanation for the poor outcomes for patients who remained medication compliant: "How unique among medical treatments is it that the apparent efficacy of antipsychotics could diminish over time or become ineffective or harmful? There are many examples for other medications of similar long-term effects, with this often occurring as the body readjusts, biologically, to the medications."[43]

Other studies of various types—in the Netherlands, Australia, Germany, Denmark, and Finland—have reported higher long-term recovery rates for those off antipsychotic medication.[44] Yet little of this information, while available in the research literature, is told to the public. The standard of care is to maintain schizophrenia patients on antipsychotics indefinitely, and if patients resist taking the drug, they are said to do so because they lack "insight" into their illness. This is the narrative that governs psychiatric care in most of the developed world, which becomes a justification for forced treatment.

The spread of the disease model to high-income countries

Although the World Health Organization has its own classification system for medical disorders—the International Classification of Diseases—the NIMH is by far the largest public funder of psychiatric research, and at least in the 1980s and 1990s, the majority of trials of psychiatric drugs were conducted in the United States. This outsized influence led psychiatric journals throughout the developed world to require researchers to use DSM categories to report their results, which in turn led to a reification of the APA's disease model.

At the same time, the APA turned its annual conference into an international gathering of psychiatrists. Pharmaceutical companies provided grants to psychiatrists from high-income countries (and to psychiatrists from middle-income countries with large populations) to attend the conference, where they would enjoy free lunches and dinners that featured presentations by academic "thought leaders" telling of advances in treating psychiatric diseases.

The foreign attendees could then be expected to return to their home countries and promote the disease model to their colleagues. And just as they had done in the United States, pharmaceutical companies paid academic psychiatrists in Europe, Canada, and Australia to serve as their advisors and consultants and to speak at conferences throughout the developed world.

In a 2002 article titled "The Going Rate on Shrinks," psychiatrist E. Fuller Torrey told of how the 7th World Congress of Biological Psychiatry in Berlin included 23 symposia sponsored by pharmaceutical companies:

> *Each [symposium] brought in two to four psychiatric experts, whom the sponsoring pharmaceutical company usually gave business-class air tickets, four-star hotel accommodations, and an honorarium, typically $2,000 to $3,000 … Honoraria and future invitations are directly dependent on how experts present their data. Emphasizing adverse effects of a drug, for example, may well cost the expert a trip to future congresses. Some of the psychiatric experts sponsored by a pharmaceutical company are also on the company's speakers bureau; many own stock and thus have a direct financial interest in the success of the company's products.*[45]

With pharmaceutical money putting its thumb on the scale, psychiatric associations in high-income countries embraced the disease model that had originated in the United States, which produced the same commercial result. Websites in developed countries around the world now told of psychiatric drugs that fixed chemical imbalance in the brain, and psychiatric guilds promoted the RCT results from short-term studies and the relapse studies as evidence of the efficacy of psychiatric drugs.[46] The third line of research that told of drugs worsening long-term outcomes was not introduced into that story of medical progress, but rather conveniently forgotten or dismissed as not having come from RCTs.

In Europe, the prescribing of antidepressants rose 250% from 2000 to 2020, a commercial marker of the disease model taking hold.[47]

Public health outcomes in high-income economies

At a societal level, the public—if the principle of informed consent in medicine is applied—should have been told that the chemical-imbalance hypothesis never panned out and that the biology of mental disorders remained unknown. It also should have been informed of public health outcomes associated with the disease model of care. Here is a brief summary of public health outcomes:

- In 2013, Finnish investigators reported that long-term recovery rates for schizophrenia patients had declined since the introduction of the atypical antipsychotics in the mid-1990s, with only 6% "recovering" from the illness.[48] That is worse than any recovery rate reported since the schizophrenia diagnosis first appeared in asylum medicine 100 years earlier.
- Recovery rates for depressed patients worsened after the adoption of this disease model. The same is true for bipolar disorder.[49]
- The number of people receiving disability payments due to mood disorders soared in the United States following the introduction of SSRIs, increasing threefold from 1987 to 2007. A sampling of disability rates in other high-income countries shows a similar increase in disability payments, an increase that correlated with a rise in antidepressant prescriptions.[50]

- Standard mortality rates for patients with schizophrenia and bipolar disorder have worsened in high-income countries.[51]

In a 2025 article, Dost Öngür, editor of *JAMA Psychiatry*, validated this description of outcomes, writing that "life expectancy and long-term functional outcomes have worsened in recent decades for those with severe mental illnesses, including schizophrenia, severe mood disorders, and obsessive-compulsive disorder, despite greater availability of treatments."[52]

Öngür did not blame the worsening outcomes on the medications. However, the general public, having organized its use of psychiatric drugs for the past 40 years around a narrative of great medical progress, would surely be stunned to learn of this worsening of outcomes in modern times.

Exporting the disease model to low- and middle-income countries

As pharmaceutical companies marketed their drugs to middle-income countries, they once again relied on the same formula that had been successful in the United States and high-income countries. They paid academic psychiatrists to serve as their speakers and key opinion leaders, and paid for psychiatrists to attend conferences, where pharmaceutical freebies flowed.

Paulo Amarante, a well-known psychiatrist in Brazil, described the scene at one such conference in his country, where psychiatrists lined up at a pharmaceutical exhibit to get industry handouts:

> *There, they received vouchers for free dinners at restaurants with their families, and even other benefits for non-family members, according to the proud account of a department head who boasted of being "sponsored" by a [pharmaceutical] laboratory, along with his "lover." The laboratory had paid for the airfare, the luxury hotel, and other perks. All with great honor and pride! They also received various gifts, such as CDs, ice cream cones named after psychotropic drugs. There were raffles for flights to Europe and the US, laptops, and many other things. There were so many gifts! So many that the [department head] had a suitcase with wheels and a long handle, one that can be carried on the plane. This was so he could collect more gifts, as the bags distributed by the laboratories were considered too small for him.*[53]

As for the symposia, Amarante wrote, "many of the speakers were funded by pharmaceutical companies, and their speeches were blatant advertisements for the drugs."

Beyond such commercial influences, the globalization of mental health proceeded under the banner of science. After Prozac was brought to market, US and European researchers began reporting that mental disorders were quite common in low- and middle-income countries and that in the absence of access to "evidence-based" treatments, many patients resorted to "traditional or spiritual healers and healing," which were said to be useless or even harmful. "The impact of mental illness in these settings can be devastating, in terms of symptoms, stigma and functional impairment," researchers wrote.[54]

With this argument in place, in 2007 *The Lancet* issued an "urgent call for action to scale up services for people living with mental health problems and to close a substantial treatment gap, especially in low-income and middle-income countries, where the proportions of people receiving treatment are lowest."[55]

This was a clarion call by Western psychiatry to export the medical model to all corners of the world. The World Health Organization, for its part, urged countries around the world to pass legislation that would increase access to mental health treatment, with psychiatric drugs presented as a first-line treatment in its "intervention guide."[56]

The title of Ethan Watters's 2010 book *Crazy Like Us: The Globalization of the American Psyche*, neatly summarized the results of this medical crusade, telling how it supplanted Indigenous methods for treating psychiatric difficulties with DSM diagnoses and treatments.[57] From 2008 to 2019, the prescribing of psychiatric drugs rose at an annual rate of 8% in upper-middle-income countries and 3% in lower-middle-income countries—evidence, once again, of the disease model taking hold.[58]

Global mental health outcomes

The expectation was that the adoption of a Western model of care, together with greater access to psychiatric drugs, would lead to a drop in suicide rates and improved mental health outcomes in countries around the world. However, that has not proven to be the case in high-income countries, and outcomes have been similarly dispiriting in low- and middle-income countries.

In 2004, Australian researchers, in a study of 100 countries, found that "contrary to the hypothesized relation," the "introduction of a mental health policy and mental health legislation was associated with an increase in male and total suicide rates."[59] They quantified the negative impact of specific initiatives:

- The adoption of mental health legislation was associated with a 10.6% increase in suicides.
- The adoption of a therapeutic drugs policy designed to improve access to psychiatric medications was associated with a 7% increase in suicides.

"It is a concern," the researchers concluded, "that national mental health initiatives are associated with an increase in suicide rates."

In 2008, Ajit Shah and Ravi Bhat found higher rates of suicide among elderly patients "in countries with greater provision of mental health services, including the number of psychiatric beds, psychiatrists and psychiatric nurses, and the availability of training mental health [programs] for primary care professionals."[60]

In 2009, Shah and colleagues reported on suicide rates for people of all ages in 76 countries and once again found that suicide rates were higher in countries with mental health legislation. They also reported that there was a correlation between higher suicide rates and a higher number of psychiatric beds, psychiatrists, and psychiatric nurses; more training in mental health for primary care professionals; and greater spending on mental health as a percentage of total spending on health in the country.[61]

Finally, in 2013, Rajkumar and researchers in Denmark assessed the level of psychiatric services in 191 countries, with a combined population of more than six billion people. This was a comprehensive global study, and, like Shah, they found that "countries with better psychiatric services experience higher suicide rates." Both the "number of mental health beds and the number of psychiatrists per 100,000 population were significantly associated with higher national suicide rates (after adjusting for economic factors)," they wrote.[62]

Discussion

The principle of informed consent in medicine tells of a basic human right: patients have a right to be told what is known about the pathology associated with a medical diagnosis and to be informed of the risks and benefits of any proposed treatment. The honoring of this obligation requires that the medical specialty overseeing a domain of medicine provide a reliable accounting of research findings to the public and to the larger medical community. However, American psychiatry never fulfilled this obligation, and that failure remained present as the disease model took hold globally.

The informed consent failure was twofold. Although research in the 1980s and 1990s regularly failed to validate the chemical-imbalance theory of mental disorders, with the APA's own textbook in 1999 telling of this failure, the APA publicly doubled down on that story, and like a medical meme, it spread around the globe.

The other failure was that American psychiatry never publicized the studies that told of poor long-term outcomes and poor public health outcomes associated with this paradigm of care. This was information that belied the narrative of progress that American psychiatry was telling the public, and as the disease model of care was exported to the rest of the world, the public narrative remained much the same. This was a story of medical progress, and the exporting of this model of care was touted as an effort to bring this new standard of mental health treatment to a global public.

However, the disease model of care is now 45 years old, and that false narrative of medical progress is now falling apart. American psychiatry has stopped promoting the chemical-imbalance story, and there is increasing recognition, within the United States and abroad, that the disease model has failed. In a 2017 interview, former NIMH director Thomas Insel drew this very conclusion:

> *I spent 13 years at NIMH really pushing on the neuroscience and genetics of mental disorders, and when I look back on that I realize that while I think I succeeded at getting lots of really cool papers published by cool scientists at fairly large costs—I think $20 billion—I don't think we moved the needle in reducing suicide, reducing hospitalizations, improving recovery for the tens of millions of people who have mental illness.*[63]

Indeed, in 2025, the World Health Organization called for a "paradigm shift" in mental health care, one that moved away from historic "over-reliance on the biomedical approach and psychotropic drugs," and toward "approaches that are more person-centred, recovery-oriented, and grounded in human rights."[64] That is an approach that would honor the principle of informed consent, which should be the centerpiece of global mental health.

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Health and Human Rights

Too Big to Lose Weight: How Pharmaceuticalization Corrupts the Right to Health

XIMENA BENAVIDES

Abstract

Treating obesity with weight-loss medications has redirected clinical attention toward health conditions long stigmatized as personal failings, while potentially benefiting comorbidities such as mental health. Yet this "pharmaceuticalization" is deeply intertwined with the broader financialization of health care, enabling extractive practices by dominant drug makers operating in highly concentrated markets. These dynamics unfold under limited public oversight, ultimately undermining the realization of the right to health and redefining medical progress through corrupted practices of market expansion and control. This paper adopts a moral and political economy perspective to examine the pharmaceuticalization of obesity and its intersections with mental health, revealing its implications for health systems in the United States and low- and middle-income countries.

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Competing interests: None declared.

Introduction

The treatment of obesity through pharmacological and surgical interventions gained prominence in the United States about two decades ago, when the medical community formally recognized obesity as a disease. Among available treatments, the use of weight-loss medications accelerated in the early 2010s and drew widespread attention as obesity rates surged during the COVID-19 pandemic. Between 2019 and 2023, this "pharmaceuticalization" of obesity expanded dramatically—by more than 700%—with glucagon-like peptide-1 (GLP-1) receptor agonists leading among therapies for weight and eating disorders. By 2024, about one in eight US adults had tried one of these blockbuster prescription drugs.[1]

The medical treatment of obesity has reshaped societal perceptions of eating disorders—from personal failures to legitimate health conditions deserving clinical attention. Beneath the surface excitement surrounding a clinical innovation that appears to reduce blame and stigma by empowering patients, however, lies a political economy that exposes corporate practices undermining the very realization of the right to health and health care. Obesity today is not only medicalized but also financialized: pharmaceutical manufacturers with dominant market power and ownership ties to financial actors pursue investor expectations, prioritize commercial interests over disease prevention, and engage in value-extraction practices under limited public oversight.

The pharmaceuticalization of obesity carries wide-ranging implications for public health—from its intersections with mental health and diabetes to its structural effects on the health care system. Studies estimate that up to 70% of individuals with obesity also experience psychiatric comorbidities. Reliance on specific medications, particularly GLP-1 receptor agonists—has generated market distortions affecting access to diabetes treatments. These include constraints on human insulin manufacturing capacity, artificial drug shortages, soaring insulin prices, and mounting financial pressure on state-funded insurance programs. The ramifications extend beyond US borders: the decline of human insulin production in the United States exacerbates fragile health care infrastructures in low- and middle-income countries (LMICs), skews national strategies for addressing obesity and mental health, and compromises access to essential medicines.

While scholarship on the financialization of health care continues to expand, its implications for the life sciences and access to medicines remain comparatively understudied.[2] This paper addresses that gap in two ways. First, it examines the medicalization of obesity and its comorbidities through the lens of the political economy of health care financialization, focusing on policy choices that allocate power to dominant drug makers operating in highly concentrated markets. Second, it advances a distinct understanding of institutional corruption as the transfer of governance to private actors, favoring self-interested exercises of governing power in drug commercialization that redefine medical progress in terms of market expansion and control. These dynamics ultimately dismiss the social determinants of obesity, threatening the advancement of public health objectives and weakening the protection of fundamental rights to health and health care.

The discussion unfolds across five sections. The first section explores the interconnections between obesity, mental health disorders, and chronic diseases such as diabetes. The second section examines how the focus on pharmacological treatments sidesteps social determinants of health and, instead, reinforces corporate control over related industries. The third section offers a political economy analysis of obesity in the United States and globally, illustrating how market concentration among a handful of pharmaceutical firms producing insulin and obesity drugs epitomizes the financialization of research and development (R&D) of medical treatments. The fourth section identifies the transnational consequences of pharmaceuticalization, particularly in Africa and Latin America. The last section concludes by urging health policy makers and legislators to reassess the implications of inadequately monitored pharmaceuticalization, consider its effects on mental health and chronic diseases, and integrate a right to health approach into future policies on access to medicines.

Obesity and mental health

According to the World Health Organization (WHO), more than one billion individuals experience obesity.[3] The World Bank estimates that nearly 70% of them reside in LMICs.[4] Among high-income countries, the United States consistently reports the highest prevalence of adult obesity.[5] In the United States alone, obesity affects at least one-third of the population.[6] According to the US Centers for Disease Control and Prevention, prevalence rates in the US adult population have risen to 40% over the past decade.[7] Obesity among children and adolescents (ages 2–19) has also steadily increased, reaching 19.7% in recent years.[8] Despite obesity's longstanding and widespread prevalence in the United States and globally, official recognition of obesity as a disease deserving of medical treatment emerged only two decades ago—a shift influenced by factors beyond scientific evidence.

Obesity emerged as a significant public health concern only in the mid-20th century, when WHO officially recognized obesity as a disease in the 1948 International Classification of Diseases. Yet it was not until 1997, coinciding with escalating medical costs associated with managing overweight globally, that the organization declared obesity a complex, incompletely understood, serious, and chronic disease and a global epidemic.[9] In 1998, the US National Institutes of Health, the largest funder of biomedical innovation worldwide, declared obesity a chronic disease. This decision was informed by decades of physiological research on the mechanisms governing body weight, acknowledging obesity's multifactorial nature and its profound public health implications.[10]

Today, a number of medical societies classify obesity as a chronic medical condition. The American Obesity Society recognized obesity as a disease in 2008, but it was not until the American Medical Association classified it as a disease in 2013 that obesity was formally medically recognized and treated in the United States.[11] The American Medical Association's decision was not based solely on new scientific evidence—it was significantly influenced by industry interests, particularly those of the pharmaceutical and weight-loss sectors, which saw market expansion as medical progress.[12]

US health agencies consistently define obesity primarily through body mass index (BMI)—a measure of body fat, with thresholds varying by age and sex. While this measure provides a standardized diagnostic criterion, it inadequately captures the complex and multifaceted nature of obesity, particularly its strong association with mental health issues and its high prevalence among psychiatric populations. Comorbidities between obesity and psychiatric disorders, such as depression and anxiety, are well-documented and suggest shared risk factors. Individuals with a mental health illness exhibit a two- to three-fold increased risk of obesity, whereas the risk of mental illness in individuals with obesity ranges between 30% and 70%.[13] Adolescents with depression, for example, are more likely to develop elevated BMI later in life, and individuals with obesity also report higher incidences of major depressive episodes relative to their healthy-weight counterparts.[14] The prevalence of obesity among psychiatric populations is also significant. Estimates suggest that up to 60% of individuals with bipolar disorder, 70% with schizophrenia, and 50% with depression experience obesity. Obesity in women in particular has been associated with symptoms of serious psychological distress, posttraumatic stress disorder, and depression, while in men, obesity correlates with generalized anxiety disorder and distress.[15] Studies show that psychological conditions such as posttraumatic stress disorder can influence BMI trajectories, further entrenching the bio-directional relationship between mental health and obesity.[16] Among patients seeking surgical interventions, psychiatric comorbidities are prevalent, with lifetime estimates ranging from 60% to 70% for depression, binge-eating disorder, and anxiety disorders.[17] The correlation between obesity and mental health is hardly invisible.

The increasing recognition of obesity's connection to metabolic conditions, such as type 2 diabetes, hypertension, and cardiovascular diseases, has intensified pressure to treat obesity pharmacologically, notably with insulin and related drugs. Since the US Food and Drug Administration (FDA) approved GLP-1 receptor agonists for adolescents as young as 12, there has been a dramatic increase in the use of insulin to produce weight-loss prescription drugs.[18] From 2019 to 2023, the number of overweight patients receiving GLP-1 therapies in the United States increased by more than 700%, with women making up nearly 60% of users.[19] GLP-1 drugs underscore the complex interplay between obesity management, mental health, and metabolic health. For example, clinical data indicate a risk of retinal disease leading to blindness, which doubles among GLP-1 users after one year of treatment.[20] In the UK, increased reports of acute pancreatitis linked to taking weight-loss and diabetes injections have prompted health officials to carry out studies on GLP-1 side effects.[21] Receptor agonists of GLP-1 drugs for weight management have demonstrated antidepressant and anxiolytic effects.[22] According to a survey conducted in seven countries with high diabetes prevalence, three out of every four people with diabetes have experienced impacts on their mental well-being.[23] The risk of diabetes is likely to increase in patients exhibiting biochemical changes as a result of psychiatric disorders and those who receive treatment for mental health disorders.[24] There is a lower incidence of depression among patients treated with GLP-A receptor agonists compared to other insulin-based drugs, and a lower risk of both incident and recurrent suicidal ideation compared to other anti-obesity and anti-diabetes medications.[25] These links between obesity and mental health disorders suggest that patients with comorbidities, treated for mental health and weight loss with insulin-based medications, are thus exposed to a unique set of increased health risk factors.

Sidelining determinants of health through the pharmaceuticalization of obesity

Obesity is heavily shaped by mainstream psychiatry and public health narratives. Behaviors of bingeing, purging, and self-starvation are treated as psychological pathologies requiring individual psychological therapeutic intervention.[26] Public health initiatives for obesity prevention focus primarily on individual behavior modification. By framing obesity as an individual choice, public health policies are largely prevented from identifying and addressing the structural determinants of eating disorders. Food insecurity, discrimination, exposure to state violence, wealth inequality, and intergenerational trauma, affecting mostly disadvantaged populations, are some of the determinants of health that the medicalization of eating disorders ignores.[27]

The increasing reliance on pharmacological and surgical interventions to treat obesity has shifted the perception of eating disorders from a stigmatized, personal failure to a legitimate clinical condition deserving of medical attention. Both approaches—obesity as a social stigma and obesity as a clinically treatable disease—however, build on an individual-choice approach to eating disorders that may not always be convenient from human rights and public health law perspectives. While the shift can be empowering for patients, it can further reinforce health conditions as individual pathologies, unduly placing the onus on people rather than the enmeshing institutions themselves. From a public health perspective, the medicalization of eating disorders is a form of state intervention that, without addressing the broader social, economic, corporate, and environmental determinants shaping medical conditions, shifts the responsibility of the government in prioritizing population health to citizens. But eating disorders are symptoms of larger structural problems, many of which result from inadequate regulatory environments that allow corporations to value extraction, with implications for the population's mental health and comorbidities.

Treating obesity with GLP-1 drugs undercovers additional layers of unaddressed determinants of health. The medical establishment may weaponize weight loss as a solution to broader structural problems—and shift policy makers' attention away from those structural problems.[28] Obesity treatments are growing in popularity yet not accompanied by expanded health insurance coverage, improved health literacy about medical approaches to weight loss, or efforts to address junk food politics and food insecurity in marginalized communities.[29] On the other hand, the food industry profits from creating addiction to unhealthy, hyper-processed foods, while medical institutions are set to treat the consequences of the consumption patterns the food industry creates. Government subsidies favor the production of backbone ingredients for ultra-processed foods disproportionately consumed by low-income communities, whereas fresh produce and whole foods receive little financial support, becoming more expensive and less accessible options.[30] Calorie-counting policies as part of food labeling place the burden of responsibility on consumers rather than on food manufacturers, reinforcing the myth that poor health outcomes are caused by individual choice rather than the design and governance of the food system.[31] All of these policies foster a food environment in which the most affordable options are also the least nutritious and are obesity drivers.

Furthermore, an individual-responsibility approach to obesity may reinforce gender-, race-, and class-based stigmas around food consumption.[32] Eating disorders are ignored as adaptive and survival mechanisms developed in response to systemic oppression, deeply embedded in histories of trauma, racism, economic precarity, and cultural pressure.[33] Despite its apparent neutrality and universality, the mainstream narrative of obesity as an individual psychological problem positions eating disorders as conditions primarily affecting a specific population subgroup—namely, white, middle-class women who struggle with body image and the pursuit of thinness. A medicalized framing erases the experiences of other populations heavily affected by eating disorders, including people of color, LGBTQ+ individuals, poor and working-class communities, and immigrants, among others. For these groups, eating disorders are often shaped by structural historical, economic, and social contexts rather than merely aesthetic concerns. Constructions of fatness have historically been used to justify anti-Blackness, colonialism, and economic exploitation.[34] People of color face higher rates of medical fatphobia, yet health care providers prescribe weight-loss medication as a universal solution. Black and Latino communities systemically encounter structural barriers to health, such as food deserts, labor exploitation, and environmental racism. Empirical work consisting of interviews with working-class women of color suggests that women used food restriction, bingeing, purging, and other patterns that are unrecognized by medical professionals as mechanisms to navigate unsafe environments, cope with abuse, or assert control in precarious conditions.[35]

The clinical erasure of marginalized populations affected by eating disorders has profound, real consequences. For example, marginalized communities are significantly less likely to be diagnosed with eating disorders than their counterparts, even when they exhibit the same symptoms.[36] Sociological studies claim this moral discourse of clinical erasure reinforces fatphobia, racialized health narratives, and economic stigmas. For example, tracing the historical construction of fatphobia suggests that body size has long been used as a measure of moral worth, disproportionately harming Black women, who are often stereotyped as “naturally” overweight and “punished” as undeserving of medical intervention. The medicalization of obesity with insulin-based medications further entrenches these social inequalities. Recent studies show that among the US adults who are clinically eligible to receive GLP-1 drugs (semaglutides Ozempic and Wegovy, and tirzepatide Mounjaro), some population groups who bear the biggest burden of obesity encounter access-to-medicine challenges. For example, men are less likely than women to receive prescription drugs, while Black, Hispanic, and Asian individuals are less likely than white individuals to receive them.[37]

Pharmaceuticalization, health care financialization, and corrupted medical progress

Treating obesity with insulin-based GLP-1 weight-loss drugs has gained popularity in the United States as the FDA has expanded approvals for these drugs. Industry-sponsored scientific studies supporting the treatment of obesity with these medications have proliferated in recent years, spurring regulatory approval of these treatments for adolescents and adults. Ozempic, manufactured by Novo Nordisk, was approved by the FDA for children as young as 12, whereas Saxenda—a similar weight-loss drug from the same manufacturer but with a different active ingredient—has reported off-label clinical practices with patients as young as six years old.[38] In April 2025, WHO decided for the first time to officially back the use of weight-loss drugs to treat obesity in adults, marking an important shift in its approach to treating obesity with medicine.[39] Although it conducted a public consultation on a draft guideline, WHO had yet to release new guidelines on treating obesity with GLP-1 weight-loss drugs as of November 2025.

The pharmaceuticalization of obesity strips eating disorders of their political and economic context. The global insulin market is highly concentrated, with a few dominant pharmaceutical companies controlling the majority of production and commercialization: Novo Nordisk (Denmark), Eli Lilly (United States), and Sanofi (France). This structure reflects a broader trend of market concentration in the pharmaceutical industry, where a few corporations wield significant power over drug prices and access. Novo Nordisk, in particular, has established itself as a leader with an extensive portfolio of diabetes and obesity drugs globally, a powerful position that enables it to influence insulin pricing and availability.[40] The Danish pharmaceutical company holds about 50% to 60% of the insulin market worldwide and a leading share in obesity treatments, bringing significant implications for the political economy of obesity drugs and the development and marketing of GLP-1 receptor agonists.[41] Based on market capitalization and stock performance, Novo Nordisk is considered one of Europe's most valuable companies, with a share price that has quadrupled over the last five years (2019–2024). The company's profitability has also surged, with net income rising from US$4.3 billion in 2019 to more than US$16 billion in 2023.[42]

Novo Nordisk distances itself from the individual-responsibility approach and refrains from blaming individuals, food companies, or government policies for obesity. Instead, it characterizes obesity as a societal burden with economic implications. Although the company still uses a biomedical framing to call obesity an epidemic, it emphasizes the economic benefits that treatment can bring to governments, taxpayers, and the economy. In doing so, Novo Nordisk shifts the focus to unmet medical demand and paints itself as a scientific pioneer in responding to obesity with weight-loss medicine.[43] The company positions itself as a benevolent and responsible corporate actor that offers a pharmaceutical solution to the obesity epidemic.

Alongside this societal-economic-burden framing, Novo Nordisk constructs a narrative of victimhood regarding people with obesity. It portrays people with obesity as underprivileged victims of the epidemic who are stigmatized and feel ashamed to seek medical help, whose brains are "challenged," and who require medical intervention.[44] In this way, Novo Nordisk casts itself as a fighter of obesity stigma, a promoter of childhood obesity prevention, and a provider of pharmaceutical solutions. Importantly, the company presents people with obesity—particularly children—as a public health risk. The tension between benevolent messaging and a sales-driven agenda is apparent: the solution to obesity, Novo Nordisk says, is not exercise or lifestyle changes, but medical treatment—specifically, GLP-1 pharmaceuticals. The company has provided clinicians with scripted dialogues for talking with patients about obesity as a chronic disease and has advocated for insurance coverage for obesity treatment.

Novo Nordisk's approach to obesity must be situated within the larger phenomenon of the financialization of health care.[45] This trend is exemplified by financial actors' growing appetite as investor-owners in the pharmaceutical industry and by pharmaceutical companies' prioritization of financial returns and stability to satisfy investors over public health risks. Under this model, enhancing innovation or increasing access to resulting technologies is not prioritized; share value can be increased even without sales-based revenues—for example, through the accumulation of exclusionary rights (e.g., patents). Today, Novo Nordisk's expected share value benefits from both share-value creation and sales strategies. The company not only holds exclusivity rights and is a dominant player with half the share of the global insulin market but also profits from high insulin prices, particularly in the United States, where patients pay more than in other affluent economies.[46] The company also secures greater drug sales by closing deals with insurance companies. For example, in April 2025, the largest pharmacy benefit manager in the United States, CVS Caremark, announced that starting in July, Novo Nordisk's Wegovy would be the preferred GLP-1 medicine on its largest commercial formularies, making Novo Nordisk's weight-loss drug more accessible to patients than its Eli Lilly-produced rival, Zepbound.[47]

Share-value corporate strategies shape decision-making on profit allocation. Novo Nordisk's R&D expenditure ratios for insulin have been decreasing since 2009, but shareholder distributions have increased.[48] For example, in 2009, the company spent 94% of total shareholder distributions on R&D, while by 2018 this figure had dropped to 54%. The company also funds scientific research through the Novo Nordisk Foundation, though this represents only 7% of total shareholder distributions. Novo Nordisk also leverages other corporate practices to boost its share value. Share buybacks, for example, played a key role in increasing the company's stock price by 293% between 1999 and 2018. Share buybacks—although a legal tool to encourage private sector investment in the US economy—ultimately benefit company shareholders with surplus value that is extracted rather than reinvested in the economy.[49] The strategy of maximizing shareholder value also informs Novo Nordisk's innovation investment portfolio and commercial plans. Between 2009 and 2018, the company's focus on insulin sales grew, with these sales accounting for 81% of total revenues. The business strategy involved halting research on oral diabetes medication in 2011 and deliberately shifting the company's R&D investments toward insulin and injectable diabetes treatments, which promised higher returns—though this shift also created access problems in countries where storing injectables was challenging, as will be discussed later.

A critical view of drug makers' corporate practices suggests that a focus on financial returns through share repurchases or commercial strategies to increase insulin prices might be contributing to a tension between innovation and financialization.[50] While these corporate practices may help finance R&D (though not in a representative way), they also limit long-term scientific progress by restricting the research focus. The pharmaceuticalization of obesity and the focus on insulin-based GLP-1 drugs is a clear example. In November 2023, Novo Nordisk announced the discontinuation of Levemir— its prescription insulin detemir for patients with type 2 diabetes—for commercial reasons.[51] This decision was unexpected and resulted in insulin shortages for patients with diabetes. Under US regulations, drug makers must notify the FDA six months before they discontinue a product. However, even when companies follow this notification rule—as in the case of Novo Nordisk—these regulations alone cannot prevent shortages. Responding quickly to a supply gap is challenging, especially when alternative manufacturing capacities are unavailable.[52] Artificial insulin shortages resulting from unilaterally discontinuing a product have forced US patients to change their treatment regimens, exposing wider health system challenges, such as insufficient medical staff to apply the alternative treatments. Intellectual property rights relating to ingredients and devices raise another set of complexities difficult to overcome within the six-month period. For example, patents on insulin detemir expired only in 2019, delaying the market entry of biosimilar products. Meanwhile, patents on insulin delivery devices are in force until 2032 (and yet subject to litigation against another dominant insulin manufacturer, Sanofi), limiting the entrance of generics and less expensive alternatives. In response to shortages of diabetes drugs and blockbuster obesity medication, the FDA authorized compounding pharmacies to produce copies of brand-name GLP-1 drugs for users to access at a reduced price.[53] Pharmaceutical companies, which saw compounders as a threat to their obesity drug sales, responded with legal actions against these pharmacies, arguing that their copies were not safe. Their allegations were supported by hundreds of adverse-event reports submitted to the FDA, although a causal link between users' harms and compounded drugs remained unclear.[54] In parallel, more financialized actors have become interested in the medicalization of obesity, with similar expectations of financial returns. For example, private equity firms have demonstrated a growing interest in acquiring weight-loss clinics offering medications and wellness therapies, as well as research organizations conducting R&D on obesity.[55]

Drug makers' plans to discontinue the manufacturing of lucrative treatments in favor of more profitable revenue streams can be anticipated—for example, by looking into the relative profitability of products within a company's product portfolio.[56] However, it remains difficult to estimate with certainty when production capacity will become constrained since product-level manufacturing information is rarely publicly available. When Novo Nordisk repurposed its existing insulin production lines to produce blockbuster GLP-1 drugs for diabetes and obesity, there was speculation about the company's manufacturing capacity and production plans.[57] Proscribing the repurposing of a company's existing production capacity when alternative means of manufacturing are nonexistent—or requiring a company to reinvest a percentage of profits, once a certain threshold is met, to increase manufacturing capacity—could be ways to counteract socially harmful shareholder-value-maximization practices. Additional actions could include transparency commitments to public investors to disclose data on staff, infrastructure, and resources available by product and location to allow for better estimations of production capacity constraints.[58] These are all responses that governments can take to guarantee people's health rights and curb the effects of financialization. It is the government‘s role to foster a well-functioning market in which the voluntary departure of a manufacturer does not harm patients or the health system's functioning. Legislators and policy makers should ensure that alternative suppliers, domestically or globally, are ready to address people's medical demands without exacerbating existing health disparities.

The effects of pharmaceuticalization in low- and middle-income countries

The rapid adoption and high costs of insulin and GLP-1 drugs have influenced perceptions of obesity treatment in LMICs, too. Local approaches to obesity and mental health are often influenced by the dominant medical models from the northern hemisphere, which emphasize pharmacological solutions and are supported by aggressive marketing campaigns and corporate influence over policymaking and clinical research to establish and sustain blockbuster drugs' market dominance.[59] Pharmaceutical giants thus influence medical knowledge and treatment practices, framing obesity as a primarily medical issue needing medication.[60] However, due to high costs, limited health care infrastructure, and deregulatory state policies—or the supranational regulatory power of agencies such as the FDA—many countries in Latin America and Africa face restricted access to these medications.[61] Moreover, pharmaceuticalization influences resource allocation: countries may prioritize expensive medications over comprehensive public health strategies that address the broader determinants of health, affecting overall health outcomes and mental health strategies in these regions.

The repurposing of manufacturing capacities and the resulting limited accessibility of insulin treatments have had terrible consequences for people with chronic diseases in Africa. For one, Novo Nordisk is the primary supplier of insulin to the South African public health system, which serves the population with the highest prevalence of diabetes in the region. The company's decision to phase out the production of insulin pens, which are easier to use than injectables and allow more accurate dosing, significantly harmed patients.[62] This decision left the South African public health system with the strenuous task of shifting its patients onto new formulations within a four-month span. Among other measures, the National Department of Health directed health care workers to ration the scarce supply of insulin pens, prioritizing elderly patients, young children, and patients with visual impairments or arthritis. Other wider health system effects included the diversion of health care workers and resources to support the transition, resulting in treatment delays for other medical conditions. Even in a well-resourced health system, the time and resources required to transition patients would have been considerable. Health care workers in the United States, for example, are not spread evenly to reliably facilitate a change in regimens, resulting in expensive care or limited long-acting treatment options for many patients.[63]

Similar supply constraints have been reported in Latin America because of manufacturing repurposing. In Colombia, for example, officials have reported nationwide shortages of both long- and short-acting insulin, including Novo Nordisk's product Tresiba, blaming "market factors."[64] In a highly concentrated insulin market, problems affecting any one of the three main drug makers can have significant consequences for the availability of products, without the possibility of other suppliers being able to respond in a timely manner.

Beyond the issue of shortages, manufacturers have not lowered global prices for GLP-1 drugs or insulin, while generic medicines are unavailable due to patent protections. This has had the effect of limiting access for lower-income populations at the same time that affluent patients are accessing these medicines through private health care, creating a new set of distortions in access to health, most visible in settings with greater social and economic inequalities.[65] In countries such as Argentina and Chile, government programs have attempted to curb this limited access by including newer diabetes medications and making these drugs available through certain public health care programs, especially for managing diabetes and obesity.[66]

One way to address GLP-1 drugs' high costs is by increasing supply through local manufacturing. In April 2025, Novo Nordisk announced plans to expand its manufacturing plant in Brazil.[67] Brazil is an important market for Novo Nordisk's obesity drugs. It represents the pharmaceutical's fifth biggest market worldwide and the Latin American country with the most significant adoption and usage of GLP-1 drugs, particularly in urban and private health care settings.[68] With the expanded manufacturing facility in Brazil, Novo Nordisk plans to serve local demands but also to strengthen the company's global production capacity by producing injectables, including anti-obesity drugs Ozempic and Wegovy, in 2028 and producing a generic drug based on semaglutide—Ozempic and Wegovi's active ingredient that is set to lose patent protection in Brazil in 2026.[69] Novo Nordisk's manufacturing expansion plans could address the high increase in diabetes in the Latin American region, which has been significantly associated with high rates of obesity.[70] However, the fact that only 13% of Latin America's locally manufactured drugs serve domestic needs raises concerns that expanded local manufacturing capacity may be directed primarily toward higher-paying markets outside of the region.

Conclusion

When policy and practice emphasize medication and surgical interventions as primary solutions, they sideline the social and structural determinants of health. This narrow biomedical framing also reinforces corporate control over health care systems and the adjacent food industry. When obesity is cast as a clinical problem to be managed through pharmaceuticals, policy makers inadvertently legitimize the commercial interests of pharmaceutical companies.

Legislators and policy makers must interrogate the deeper structural forces that shape eating and mental health disorders. A moral political economy framework, informed by human rights, provides a productive lens for this task. The moral dimension underscores the ethical failures of medicalization—how gender, race, and class influence social understandings of eating and body disorders—while pharmaceutical firms define treatments according to their own commercial imperatives. The political economy dimension reveals how the medicalization of obesity transfers governing power to dominant pharmaceutical companies operating in highly concentrated markets, raising questions about the accountability of corporate power. A human rights perspective recenters the right to health and health care as a guiding principle for scientific progress in medicine. Such an approach may help anticipate future long-term effects of widespread GLP-1 use and internalize damages when governments negotiate further availability and affordability with drug makers (for example, drug negotiation processes mandated by the US Inflation Reduction Act, or price controls directly discussed with Novo Nordisk). Similarly, the approach may help assess the antitrust risk of corporate practices in the consolidated market of obesity blockbuster prescription drugs (for example, in the context of Pfizer and Novo Nordisk's acquisition battle for weight-loss startup Metsera).

Acknowledgment

I am grateful to Lucy Gilchrist for her research assistance.

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Reflections on Institutional Corruption in Mental Health Policy Implementation: Global Insights and the Eastern European Experience

DAINIUS PŪRAS AND JULIE HANNAH

Abstract

Existing evidence shows that mental health policies and services are especially vulnerable to ineffective and corrupt practices. Systemic obstacles, such as the overuse of the biomedical model, power asymmetries, and selective evidence, undermine both the realization of the right to health and the rights-based implementation of policies in practice. This paper draws on the personal experience of the authors alongside global insights to examine the relationship between institutional corruption and the right to mental health, with a focus on Central and Eastern Europe as a bellwether. Following the societal transitions of the 1990s and beyond, prolonged psychosocial stress contributed to widespread self-destructive behavior and high mortality rates, particularly among rural, middle-aged men. In response, foreign consultants frequently advised governments to prioritize diagnosing clinical depression and prescribing new-generation psychiatric medications as the principal strategy. We argue that this narrow biomedical focus, reinforced by biased evidence, represents a form of institutional corruption: it distorts problem framing, entrenches biomedical dominance, sidelines community and social responses, and ultimately compromises the right to health. Recognizing and addressing these dynamics is essential to align mental health policy with rights-based, context-responsive care.

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Competing interests: None declared.

Introduction

This paper explores global failures and missed opportunities to reform mental health systems in line with modern, rights-based approaches. These global obstacles are reflected in the experience of Central and Eastern Europe (CEE), where authoritarian legacies left deep imprints on mental health systems. Even after the collapse of the Soviet Union, the region struggled to dismantle outdated practices. As a result, it failed to seize the opportunity to implement transformative, rights-based reforms during the post-Soviet transition.

The paper draws on the personal experiences of its authors, Dainius Pūras and Julie Hannah. Pūras served as the United Nations (UN) Special Rapporteur on the right to physical and mental health from 2014 to 2020. During this period, he was supported by Hannah, a human rights expert and advocate from the University of Essex, who played a key role in shaping the mandate's work on the right to mental health. The paper draws from the tradition of participant observation as a methodological foundation, reflecting on insights gained through the authors' active involvement in policy processes, advocacy, and institutional reform at both regional and global levels.[1] In this way, the authors offer an experiential account that bridges personal engagement with a broader analysis of systemic challenges.

The first half of the paper focuses on Pūras's earlier experiences in CEE—before, during, and after the profound political and social transformations of the late 20th century. In particular, it highlights how mental health systems were shaped by Cold War dynamics on both sides of the Berlin Wall and examines the missed opportunities to invest in a human rights-based approach following its fall. This regional account informs the paper's second part, which presents reflections on global challenges in the field of mental health and human rights, grounded in the experience of the Special Rapporteur and the positions advanced by the UN right to health mandate during his tenure.

Underpinning these reflections is the regional case of CEE, which illustrates the varied roots of institutional corruption in mental health care, with lessons that are globally relevant.

Existing evidence indicates that mental health policies and services are especially susceptible to ineffective and corrupt practices.[2] This is a concern echoed by Robert Whitaker and Lisa Cosgrove, who describe the institutional corruption of psychiatry as rooted in systemic distortions that prioritize commercial and professional interests over patient well-being.[3] When viewed through Lawrence Lessig's lens on institutional corruption, where legal but ethically compromising influences distort an institution's core purpose, mental health systems can be seen as structurally vulnerable to such corruption.[4] In this context, policy implementation is often shaped less by public health priorities and human rights obligations than by entrenched financial, professional, and political dependencies, which systematically undermine efforts to scale equitable, community-based mental health services. The roots of such institutional corruption lie in embedded systemic obstacles, including an overreliance on the biomedical model and pharmacological interventions, entrenched power asymmetries, and the production and use of biased evidence.[5] These factors remain pervasive across all levels of mental health governance, distorting priorities away from people's actual needs and undermining a delivery of care that is equitable, evidence-based, and responsive to context. As a result, even when mental health policies appear to reflect modern human rights and public health frameworks, their implementation often fails to uphold the core principles of the right to health.[6]

In CEE, despite clear evidence that high rates of suicide and common mental health conditions in the late 20th century were linked to the stresses of profound societal transition and widespread patterns of destructive and self-destructive behavior, mental health policy and service development followed a largely medicalized path. Depression and other mental health conditions were treated mainly as biomedical issues, attributed to chemical imbalances in the brain rather than as outcomes of social and structural distress. Framing this situation as a case of institutional corruption, where systems are designed to serve entrenched professional and political interests instead of well-being, the discussion turns to global developments in mental health policy, with particular attention to these structural obstacles that continue to undermine the full realization of the right to mental health for all.

Reflections on the Central and Eastern European experience

This section outlines the state of mental health policies and services in CEE before and after the fall of the Soviet Union, during a time of profound societal transition. It explores the interaction between distinct mental health systems shaped by differing political, economic, and ideological contexts during the Cold War. With the collapse of the Soviet Union in the 1990s, these once-separated systems began to converge, bringing both new opportunities and complex challenges for developing effective, transparent, and rights-based mental health care. To understand the transformations of the 1990s, we first examine the state of mental health policy and services in the region before that period.

The Soviet era of psychiatry in Central and Eastern Europe

CEE is a unique region shaped by 50–70 years under a Soviet-style totalitarian legacy. Following the collapse of the Soviet Union in the early 1990s, many CEE countries became known for their peaceful revolutions and transitions toward national independence and democracy. This historical turning point raised important questions: What were the opportunities and obstacles to introducing and adapting evidence and human rights-based mental health care practices in the region? How does the CEE experience differ from that of other regions?

All regions today face significant challenges in addressing global mental health issues, especially amid a shifting paradigm in mental health thinking. In this regard, it is often said that all countries may be considered "developing." Yet regional context matters, particularly when it concerns the institutional legacies from which such regions are building their reform trajectories. They shape not only existing structures and professional cultures but also public trust, governance capacities, and openness to reform. For this reason, the historical, political, and social specificities of regional context must be carefully considered when formulating and implementing national mental health policies, as they can profoundly influence both the process and the outcomes of reform.

It is important to highlight that the Soviet school of psychiatry was deeply influenced by the postwar and Cold War context. High-level political decisions made in Moscow positioned psychiatry and mental health care as strategic tools of ideological confrontation with the West. Several psychiatric research institutes, based primarily in Moscow, were tasked with constructing the theoretical foundations of Soviet psychiatry as both a science and a practice.[7]

A central message promoted by the political leadership was that, with the defeat of capitalism and the progression toward a society of "mature socialism," all social and psychosocial causes of mental health issues had supposedly been eradicated within the Soviet Union. This message, rooted in ideological propaganda and wishful thinking, became a dominant narrative. The role of scientific institutions and academia was, in effect, to generate so-called evidence in support of this politically driven claim. An example of this was the development of the concept of "sluggish schizophrenia"[8] by Soviet psychiatric authorities, which served to justify and reinforce the regime's political narrative. Such a diagnosis was used to pathologize dissent and frame political nonconformity as a type of "mental illness," aligning psychiatric practice with the objectives of the totalitarian state.

The narrative developed by the Soviet school of psychiatry emphasized that in the Western world—particularly in the United States and Western Europe—violations of economic and social rights under capitalism were the primary causes of widespread mental health conditions. By contrast, according to the Moscow school of psychiatry, such issues existed in the Soviet Union and its satellite states only to a much lesser extent.

At the highest political levels, it was decided that in the Soviet Union, incidents such as suicide, violence, heavy drinking, and other forms of behavior deemed inappropriate could be explained only as manifestations of a mental health condition rooted in brain pathology. Leading psychiatric research institutes in Moscow determined that these cases were most often to be classified as forms of schizophrenia. To support this position, diagnostic criteria for schizophrenia were significantly broadened.

Meanwhile, Soviet psychiatric authorities maintained that if similar behaviors or psychological conditions emerged in the United States or other capitalist countries, they were to be interpreted as the inevitable outcomes of exploitation and alienation caused by the oppressive capitalist system. This double standard served to align psychiatric theory and diagnosis with ideological propaganda, reinforcing the notion of the superiority of Soviet socialism and the pathology of dissent under capitalism.

For those without lived experience of the Soviet system, this way of thinking may appear logical. After all, there is substantial evidence that inequality, particularly under capitalism and neoliberal policies, can have harmful effects on mental health and societal well-being.[9] This understanding may explain why many experts familiar only with the shortcomings of capitalism are not sufficiently critical of the effects of Soviet-style socialism.

In practice, however, the Soviet system evolved into an Orwellian society, marked by widespread institutional corruption, including within the health care sector. Psychiatry was no exception.[10] Mental health care and decision-making was deeply affected by a disconnect between two co-existing realities: the official narrative presented in documents and propaganda, and the lived reality of everyday practice. As in Orwell's novel, while the system claimed equality, in reality, "some [were] more equal than others."[11]

This legacy, rooted in a totalitarian system that left no room for democratic oversight or civil society, produced deeply harmful effects on mental health care and outcomes.[12] Psychiatric training emphasized a strictly biological model, reinforced by a strongly paternalistic approach. For example, a disturbing marker of professional competence was the ability to persuade the parents of children with intellectual disabilities or autism to relinquish custody, or to convince the spouse of a person diagnosed with a mental health condition to seek divorce. Treatment practices relied heavily on high doses of psychotropic medications, prolonged inpatient care in large psychiatric hospitals, and the widespread use of institutionalization for individuals deemed "treatment resistant." Receiving a psychiatric diagnosis often resulted in the loss of fundamental rights, with little to no legal protection or recourse.

The post-collapse period

In the late 1980s and early 1990s, the entire CEE region underwent a dramatic transformation. Countries that had been occupied or dominated by the Soviet Union regained their independence and began transitioning toward democracy and a market-based economy.

There was widespread enthusiasm to reform areas that had been suppressed under the former system, and mental health care was among them. Efforts were made to introduce previously marginalized elements such as psychotherapy, psychosocial interventions, modern public health approaches, and human rights principles.[13] These reforms aimed to restore balance within the bio-psycho-social model, countering the narrow biomedical focus imposed during the Soviet era.

Although there was optimism across CEE countries in the early 1990s, the societal transition also brought serious negative consequences. One of the most significant was a surge in premature deaths across the region during the last decade of the 20th century. According to Giovanni Cornia and Renato Paniccià, the abrupt and intense psychosocial stress caused by the transition from a centrally planned system to a radically different political and economic model led to a sharp rise in morbidity and mortality among large swaths of the population.[14] It is estimated that approximately four million more people died than should have been expected in a region of around 400 million inhabitants.

Government responses to the region's stress-induced crisis of mortality

The last decade of the 20th century marked a pivotal moment for the global community. With the end of the Cold War, there was widespread hope that countries and regions, including Europe, would fully embrace a human rights-based approach, particularly in the field of mental health. As history has shown, the right to mental health can be meaningfully realized only when all human rights are upheld equally and without exception. However, during the Cold War, both ideological blocs misused the concept of human rights, applying it selectively to serve political aims. In the "capitalist West," economic and social rights were often neglected, while in the "socialist East," civil and political rights were suppressed. In both cases, this selective application of human rights had a detrimental impact on societal mental health.

In the 1990s and into the early 2000s, there were strong expectations that the CEE region would become a fertile ground for the implementation of modern, rights-based approaches across sectors such as health, mental health, social welfare, and education. In the field of mental health specifically, it was hoped that Western consultants would encourage the new democracies to adopt public health strategies, human rights-based frameworks, and modern psychosocial interventions—tools seen as essential for addressing the region's high suicide rates and widespread challenges to societal mental well-being.

To the surprise of many local mental health professionals, consultants from academic centers in the Global North who arrived in the CEE region after the collapse of the Soviet Union did not prioritize psychosocial, community-based interventions, public health strategies, or human rights-based approaches.[15] Instead, their main recommendation was to invest in the biomedical model—specifically, to ensure coverage for the widespread use of new-generation psychotropic medications. Prominent psychiatrists from Europe and North America visited Lithuania and other newly independent states to advise governments that these medications should be the first-line treatment for conditions such as depression and schizophrenia, and were essential to reducing high suicide rates.[16]

Unfortunately, many of these consultants overlooked the broader social determinants of mental health and failed to recognize that, unlike in the West, the CEE region had not been shaped by psychodynamic or other psychological traditions. On the contrary, the region had long been heavily reliant on the biomedical model—an approach that had already contributed to a narrow, medicalized view of mental health care.

The trajectory of psychiatry and mental health care in Lithuania over the past few decades offers a complex snapshot. While the country has made significant progress in areas such as democratic governance, the rule of law, and the development of a vibrant civil society—especially since joining the European Union in 2004—these positive changes have had a limited impact on the mental health sector.

Following the advice of foreign consultants, Lithuania generally chose not to radically reform its mental health system but instead to invest in improving the existing model. As a result, after more than three decades, the system still relies on the same outdated infrastructure.[17] Despite considerable investment, only the facade of the mental health system has been redecorated, while its institutional culture continues to be marked by social exclusion, institutionalization, overmedicalization, and discriminatory practices.[18] Independent human rights monitoring in psychiatric facilities faces ongoing resistance. Institutional care remains in high demand, and large residential institutions remain full due to the lack of a diverse and adequately resourced network of community-based services.

Officially, Lithuania has more than 100 outpatient mental health centers serving a population of 2.7 million—an impressive ratio on paper. However, there is insufficient recognition among key stakeholders that these centers often fail to address core issues, such as the need to prevent institutionalization and to reduce the excessive use of psychotropic medications. Thus, these services are not functioning as truly comprehensive, community-based alternatives. Resistance to meaningful change comes not only from government authorities but also from influential figures within the psychiatric profession.

In response, Mental Health 2030, a nongovernmental and expert coalition, has repeatedly called on national authorities to critically examine the current, ineffective infrastructure and begin implementing World Health Organization recommendations and human rights obligations, particularly those related to the development of quality, rights-based outpatient services.[19]

What preliminary conclusions can we draw from the development of mental health policies and services in the CEE region? An opportunity for reform was missed. Ironically and paradoxically, it was Western experts who advised investment in the existing, harmful status quo—reinforcing over-reliance on the biomedical model by medicalizing issues rooted in the profound societal stress of the transition period, such as high suicide rates.

This outcome may be explained in part by the timing of two overlapping processes in different parts of the world. Just as CEE countries were emerging from decades of repressive, biologically driven psychiatry, the West was experiencing the "Prozac era," marked by disillusionment with psychotherapy and a renewed emphasis on pharmacological treatment. As a result, the CEE region, instead of moving toward a more balanced approach, entered a new phase of overmedicalization.

The effects of this trend remain visible today. The institutional corruption of the Soviet era did not disappear—it adapted and intertwined with new forms of influence.[20] The old Orwellian-style control evolved into a different kind of corruption, generously fed by the influence of the pharmaceutical industry and its close ties to the psychiatric establishment within the new environment of neoliberalism.

These historical and regional insights are essential when considering global mental health developments, including the harmful effects of totalitarianism, neoliberalism, and deepening social inequalities.

Bridging perspectives: From Central and Eastern Europe to global recognition of reform imperatives

We now turn to examine the broader global landscape of mental health over the past several decades. The first quarter of the 21st century has been marked by growing efforts to identify and dismantle systemic obstacles that have hindered meaningful reform in mental health care. Much has taken place in the field of mental health policy and services during these first 25 years, revealing both progress and challenges.

To understand this period, it is essential to recognize the dominant narrative that prevailed at the end of the 20th century: a widespread belief in the triumph of the biomedical model. The promise appeared bold and compelling—that advances in neuroscience and neuroimaging would soon identify biomarkers for major mental health conditions, enabling more precise diagnoses and the development of effective, evidence-based biomedical interventions that would significantly improve outcomes.

This scientific optimism was reflected by Edward Shorter, a renowned historian of psychiatry, who wrote at the turn of the century:

> *If there is one central intellectual reality at the end of the twentieth century, it is that the biological approach to psychiatry … has been a smashing success.*[21]

Shorter's observation also reflected the prevailing consensus of the time and shaped the direction and priorities of mental health systems moving into the 21st century. This optimism and consensus aligned with powerful professional, commercial, and bureaucratic incentives, channeling resources toward a narrow basket of biomedical solutions in service of these vested interests rather than the public good.

However, it did not take long for skepticism to darken the promise of the biomedical paradigm. Breakthroughs failed to materialize: biomarkers for mental health conditions remained elusive, and the effectiveness of new psychotropic medications fell short of expectations. Despite initial enthusiasm, many of these medications did not deliver the transformative impact claimed by pharmaceutical companies and endorsed by leading figures in academic psychiatry. Meanwhile, other essential components of modern mental health care were underfunded, including psychosocial support, prevention and promotion strategies, and rights-based approaches.[22]

Importantly, this biomedical optimism undermined the full and effective realization of a human rights-based approach to mental health. The dominant logic held that if effective medications were now available, they should be accessible to everyone. When individuals diagnosed with conditions such as depression or schizophrenia refused treatment, coercive or involuntary measures were often framed as justifiable. In practice, the rise of the biomedical model did not lead to improved human rights protections. On the contrary, it became clear (globally) that this paradigm carried serious side effects, both in terms of clinical outcomes and in its implications for autonomy, dignity, and systemic equity.[23]

The adoption of the *Convention on the Rights of Persons with Disabilities* (CRPD) in 2006 marked a transformative moment in global mental health discourse.[24] It introduced clear principles for the protection of the rights of persons with disabilities, including those with psychosocial and intellectual disabilities, and sent an unequivocal message: realizing these rights requires moving away from a purely medical model and embracing a human rights-based, social model of care and support.[25]

This shift in the normative framework and a growing international consensus on the need to move beyond the status quo is reflected in key international documents. These include multiple UN Human Rights Council resolutions, as well as reports by the UN Special Rapporteur on the rights of persons with disabilities, the UN High Commissioner for Human Rights, and the UN Special Rapporteur on the right to health.[26]

The UN Special Rapporteur on the right to health identified three major systemic obstacles to the realization of the right to mental health, including an overreliance on the biomedical model and biomedical interventions; persistent power asymmetries; and the biased use of evidence and knowledge. The combined weight of these barriers continues to exert a powerful influence on decision-making processes at all levels of mental health systems. Together, they impede transformative change and contribute to what can be described as institutional corruption within mental health care.

These normative positions are complemented by three recent documents from the World Health Organization.[27] Together, they reflect an evidence-based call to action to invest in services that uphold human rights, eliminate coercion, and empower those who use mental health services.[28]

Is there sufficient evidence to support the claim that the status quo in mental health care is no longer working and increasingly doing more harm than good? We believe that the answer is yes. This growing body of evidence and international consensus points to the urgent need to move away from traditional models of mental health care and psychiatry that rely heavily on coercion, discrimination, and overmedicalization.

Since the adoption of the CRPD, advocates have called on UN member states and other stakeholders to abandon the entrenched status quo in psychiatry. The central debate among experts is no longer whether coercive measures are effective, but whether they should be substantially reduced or banned outright, with a view toward their full elimination.[29]

A robust and growing evidence base further undermines the legitimacy of the status quo. Research increasingly shows that systems overly focused on biomedical interventions, particularly psychotropic medications and nonconsensual measures, are not achieving improved mental health outcomes.[30] Just as important, civil society movements led by users and former users of mental health services, as well as organizations of persons with disabilities, have played a central role in exposing systemic failures.[31] Many of these advocacy efforts originated in CEE.[32] These movements have challenged the underlying causes of human rights violations, proposed alternative approaches, and helped shift the global narrative on mental health toward one centered on dignity, autonomy, and social inclusion.

The failures of the status quo manifest differently across global contexts. In the Global South, the primary challenge remains the lack of access to acceptable, community mental health services. In contrast, the Global North faces a different kind of crisis. Here, the biomedical model has dominated for decades and coercive measures have not only persisted but are on the rise in many countries.[33] Ironically, this entrenched infrastructure often presents a greater barrier to reform than in lower-resource settings, leading some experts to suggest that transformative change may be more feasible in the Global South.[34]

Proponents of the biomedical (neurobiological) model have long claimed that effective treatment with psychotropic medications would help reduce stigma. However, this promise has not been fulfilled. On the contrary, the dominance of the biomedical paradigm has reinforced the use of involuntary treatment, often linked to higher doses of medication and the widespread practice of polypharmacy.[35] In many settings, refusal to take medication remains one of the most common justifications for coercive interventions. As a result, overreliance on medication-based treatment has likely contributed to the continued rise of involuntary practices, even in economically advanced countries. Instead of diminishing stigma and discrimination, these outcomes have created conditions in which they continue to thrive.

In many countries, coercion remains widespread in mental health care services. Evidence indicates that the use of coercive measures is not only persistent but increasing, despite substantial investments in mental health systems and stated commitments to use involuntary interventions only as a last resort.[36] For example, in the United Kingdom, the use of coercion under the Mental Health Act rose by 43% between 2006 and 2017.[37] Similar upward trends have been reported in other European countries, such as Scotland, Ireland, Belgium, and France.[38] Moreover, a consistent pattern of human rights violations in psychiatric institutions across Europe has been documented.[39]

To a large extent, this systemic global failure in mental health services is rooted in the routine use of nonconsensual measures, which providers are legally permitted to apply. At the clinical level, coercion corrupts the therapeutic alliance and undermines a core ethical principle of "do no harm." Although mental health laws in many countries are intended to safeguard the rights of persons with psychosocial disabilities, in practice these laws are frequently used to override those rights. What is legally framed as an exception is, in reality, too often treated as the rule.

To conclude this analysis, we return to the work of esteemed historian Edward Shorter. While in 1997, he confidently declared the triumph of biological psychiatry, by 2021 his assessment had shifted dramatically. In *The Rise and Fall of the Age of Psychopharmacology*, Shorter offers a sobering historical account, ultimately concluding that the story of psychopharmacology is one of public health failure.[40] He argues that psychiatry's diagnostic systems and therapeutic interventions have largely failed and that the field has retreated significantly from its earlier aspirations.

This stark reassessment reflects a broader reality: psychiatry, under the dominance of the biomedical paradigm, has not only lost its scientific footing but now appears to find itself in a profound crisis of both evidence and of values.

Moving beyond the impasse: Structural changes for sustainable mental health reform

A growing body of evidence supports the conclusion that the continued dominance of the biomedical model does more harm than good. Despite these calls and the accumulation of data, signs of meaningful change remain limited. In many regions and countries, the status quo in psychiatry, when actual practices are examined, continues to be firmly grounded in the biomedical paradigm.[41]

Nearly three decades after the ambitious *World Health Report 2001*, progress has been slow, if not stagnant. Throughout the 2010s and into the

2020s, effective, rights-based, and scalable alternatives have remained on the margins of mental health systems. In many countries, these noncoercive, community-based services are still absent from national plans, while in others, existing alternative models face growing pressure to shut down in favor of a return to the monopoly of mainstream psychiatry.

In several regions, including parts of Europe, substantial human and financial resources continue to be funneled into large residential institutions for the long-term care of persons with psychosocial disabilities. Medical education, particularly in psychiatry, continues to emphasize biomedical interventions as the first-line response, reinforcing the existing paradigm. Despite long-standing recommendations by the World Health Organization to move away from institutional psychiatric hospitals, these facilities still receive priority investments in many countries and often remain closely tied to academic psychiatry.

Mental health laws, while often framed in humanistic language invoking dignity and rights, frequently serve to legitimize the opposite. They continue to undermine the legal capacity and equal protection of persons with psychosocial and intellectual disabilities by permitting involuntary placement and treatment. Even when international funding is available, it often goes toward renovating psychiatric hospitals or large institutions, effectively reinforcing outdated systems and undermining the potential for structural reform.[42]

To enhance the quality of the global discourse on the present and future of mental health care, it is essential to include a diversity of voices and perspectives. However, a recent study found that the global mental health field continues to be shaped predominantly by elite, Western, and medicalized viewpoints.[43]

The psychiatric profession remains a central actor in shaping both global discourse and national mental health policies and services. Yet many influential psychiatric associations have so far resisted emerging reforms and continue to support the status quo. In this context, a study analyzing responses from major psychiatric organizations to the 2017 report of the UN Special Rapporteur on the right to health is particularly revealing.[44] Many prominent psychiatrists maintained that psychiatric expertise should remain the guiding force in mental health care, regardless of a person's consent, and that the protection of the right to health and restoration of dignity through clinical intervention must precede the exercise of other human rights.

This position reflects a hierarchical understanding of human rights that stands in direct opposition to the principles of the CRPD and the interpretation offered by the UN Committee on the Rights of Persons with Disabilities and many other international bodies and experts. Nearly two decades after the CRPD's adoption, there remains a significant divide between the psychiatric establishment and those advocating for a human rights-based approach to mental health. This enduring divide has been characterized as an "impasse," highlighting deep disagreements over coercion, legal capacity, and systemic discrimination.[45]

Academic psychiatry plays a particularly influential role, given its control over medical education and research agendas. Calls for reform have come not only from external critics but also from within academic psychiatry itself, where some members have acknowledged the urgent need to rebalance priorities in training, service delivery, and evidence production.[46] Nevertheless, with some exceptions, academic psychiatry continues to largely uphold the status quo.

The medicalization of public mental health has been driven in part by a lack of transparency and accountability in medical education and research, leading to biased evidence being embedded into clinical practice on a global scale. This trend has affected all regions, including CEE, as previously discussed. It must be met with strong corrective action by states and international organizations to ensure that mental health policies are grounded in non-biased evidence and a human rights-based approach. This obvious crisis in academic psychiatry, compounded by questionable ties with the pharmaceutical industry, has contributed to a "corruption of knowledge" in the mental health field. This crisis should be seen as a warning for psychiatry and mental health care, as well as for the broader health sector.[47]

Overall, a significant portion of the psychiatric profession, including many leaders within academic psychiatry, continues to oppose the CRPD framework and the positions articulated by the Committee on the Rights of Persons with Disabilities, particularly in General Comment 1 on legal capacity.[48] However, there are encouraging signs of change. Influential figures within academic psychiatry and the leadership of the World Psychiatric Association have recently begun to adopt more progressive stances. Notably, respected psychiatrists have co-authored publications advocating for a rights-based approach that centers people with lived experience and promotes alternatives to coercion and violence in care settings.[49] Furthermore, the World Psychiatric Association has launched a campaign and issued a position statement on the reduction of coercion in mental health services.[50] This is a clear signal that the psychiatric community, albeit cautiously, is beginning to align with broader efforts to reform mental health care.

The strengthening of social psychiatry may offer a promising pathway forward, helping the psychiatric profession address its crisis of evidence and values while building common ground with a global coalition of stakeholders committed to advancing rights-based mental health systems.[51]

Conclusion

Mental health services worldwide remain anchored in laws, practices, and institutional cultures that obstruct the full realization of the right to mental health and the foundational principles of the CRPD. Even in light of authoritative calls for reform, including from the World Health Organization, systemic transformation remains elusive across both high- and low-income settings. For such changes to happen, there is need for a unified coalition of powerful stakeholders committed and willing to be active participants.

The reflections presented in this paper, drawn from both regional and global perspectives, highlight the systemic obstacles that continue to impede the implementation of modern, rights-based mental health policies and services. The most critical elements—overreliance on the biomedical model and interventions, entrenched power asymmetries, and the biased use of evidence—interact to sustain a vicious cycle of discrimination, coercion, disempowerment, and helplessness. Likewise, these factors together contribute to the sustained presence of institutional corruption, where legal, policy, professional, and health systems consistently serve entrenched interests.

These factors do not exist in isolation. They reinforce one another and together perpetuate a crisis of both evidence and values in mental health care. Left unchallenged, they present a universal barrier to realizing the right to mental health and are relevant across all regions, irrespective of economic status. The experience of CEE serves as a cautionary tale, where post-transition opportunities for reform were lost to ineffective investments and the reinforcement of outdated and harmful systems.

Going forward, the international mental health movement must prioritize dismantling these systemic barriers. The primary goal should no longer be only the reduction of a "treatment gap" but rather the transformation of the system itself, ensuring that care is accessible, noncoercive, and rights based. Addressing institutional corruption—as both a cause and a consequence of systemic failure—is central to this effort.

Acknowledgments

We dedicate this paper to the late Bhargavi Davar, Gábor Gombos, Saulius Pečiulis, and Jolijn Santegoeds—scholars, organizers, and truth-tellers. Any light in these pages is theirs; any errors are ours.

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Regression of Hard-Won Advances in Socialized Medicine: The Emergence of the Private Sector in Health Care in Serbia

MILUTIN KOSTIĆ AND DANILO VUKOVIĆ

Abstract

Dual practice physicians are those who work in both the public and private sectors: for example, in the morning seeing patients in a state-run hospital, and in the afternoon seeing paying customers in a private facility. Dual practice is a legal but morally problematic practice that can lead to dual loyalty. In Serbia, dual practice has contributed to institutional corruption because physicians who work in both sectors siphon patients from public facilities into private ones and have little incentive to protect the public system. This problem is especially acute in the areas of psychiatry and the public mental health care sector. Private health care is unregulated, with no legal framework for psychotherapy, and there is widespread reliance on cheap anti-anxiety drugs in the population. All of this contributes to rising health care costs, poorer care in both the private and public sectors, overworked physicians, and the shortsighted complicity of the guilds. This is an attack on the right to health: the poor will often get insufficient care, while the patients who are financially better off are at risk of overtreatment and overdiagnosis.

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Competing interests: None declared.

Introduction

This paper argues that dual practice among health care workers constitutes a form of institutional corruption. Dual practice—that is, the practice of working simultaneously at both private and public health facilities—differs from petty corruption and gifts because it is a legal and institutional opportunity for practitioners to steer their patients toward private practice due to real or perceived obstacles, shortages, long waiting lists, and poorer conditions in the public sector, thereby securing additional income. It also gives rise to a dual loyalty that may compromise physicians' commitment to the public sector, contributing to complacency toward its deterioration. Institutional corruption in health care is a human rights violation because it breaches equality and access to rights and services.

In Serbian public discourse, dual practice is justified as an antidiscriminatory measure (because it allows doctors to work after hours like any other profession) and as a demographic and human resources management strategy (because it increases doctors' income and reduces their motivation to migrate).[1] However, this topic is rarely framed in terms of equal access to rights, particularly how this arrangement deteriorates "the right to a system of health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health."[2]

Duality in health care has normalized the migration of patients between public and private practices. It enables patients to navigate between inefficient public health care, on the one hand, and supplementary private care, on the other, to achieve better health outcomes. However, it also means that they often end up paying for services that are covered by their insurance, resulting in significant out-of-pocket expenses. Consequently, dual practice leads to high health care costs and health inequalities. In the most extreme cases, it could lead desperate people to experience economic hardship, pushing them into poverty and undermining their ability to exercise basic human rights such as access to adequate living conditions, food, and health care.

Serbia's path: From universal public to universal public plus supplementary private health care

The spring of 1945 saw the communist party firmly in control of Serbia and, by the end of the war, the whole of Yugoslavia. In 1946, laws inspired by the idea of socialized medicine were introduced, establishing state medical coverage for certain professions, encompassing 12% of the population. Over the years, other professional groups were gradually included, and in 1959, farmers marked the last group to be added to the public health care scheme. A year earlier, private practice in medicine was banned (with rare exceptions), and for nearly five decades thereafter, state institutions were the only providers of health care services. With the fall of communism and the onset of the transition period, one of the first changes was the reinstatement of private practice. Legislative reforms in 1986 and 1989 allowed private practice, including both dental and medical practice. However, several factors contributed to its slow initial acceptance.

First, the war and sanctions of the 1990s led to an economic decline and to the impoverishment of large segments of the population. This happened while Serbia was already entering the transition process with relatively unfavorable indicators. For example, by the 1980s nearly one in four Serbian citizens lived in poverty, compared to 15% just a decade earlier.[3]

Second, the health care system established by the communists—especially in the area of specialty services—was still functioning relatively well and enjoyed high levels of public trust owing to its fairly effective operation over the preceding decades. Finally, the idea of private practice as a respectable alternative to publicly provided care was still unfamiliar to many people, particularly with regard to a profession such as medicine that is driven by altruism. Due to these factors, private practice played only a minor role until the start of the genuine capitalist transition in 2000.

The decades-long dominance of public health care shaped a network of prestigious public institutions that came to occupy a central place in the field and in society. This prestige remains strong today, as all medical students and residents in Serbia continue to be educated within these institutions. There are no private medical schools due to, above all, the fact that medical education requires practical instruction that can be conducted only in large clinical centers offering all specialty services—centers that have existed solely within the public health sector since the communist era. The medical schools within these centers date back to pre-World War II; they are publicly run and technically state-owned, but with significant autonomy. Consequently, all professors who hold prestigious academic titles are necessarily employed in the public sector. This arrangement has helped preserve trust in the public system, even among wealthier members of society. The most complex procedures and conditions are still almost exclusively treated within the public sector.

In this regard, psychiatry remains even more closely rooted in the public system compared to most other specialties. Currently, there are no psychiatric wards in private medical centers, outside of addiction treatment. For all other types of psychiatric symptomatology, such as psychosis, bipolar disorder, suicidality, or depression, only outpatient care is available outside the public sector. Therefore, any patient who needs day-hospital or inpatient care must go to a government-run facility, even if they are financially well-off or their outpatient doctor is in the private sector. This has led to situations that are unimaginable in most Western countries: a famous movie star or a prominent politician in such a crisis could find themselves being treated in the same ward—or waiting in the same line for medication—as a factory worker, a farmer, or even a homeless person.

Currently, the Serbian health system's funding comes from multiple sources, including compulsory health insurance contributions, taxes, out-of-pocket expenditures, and supplemental health insurance. Of these, the main source is contributions to compulsory health insurance, which are collected from employees' salaries and employers' profits. Serbia's 2022 Law on Contributions for Compulsory Social Insurance specifies contribution from salaried incomes: 26% for pension and disability insurance, 10.3% for health insurance, and 0.75% for unemployment insurance.

Public financing in the health system has been steadily declining, accounting for only 59.4% of total health expenditures in 2018. Private expenditures—consisting mainly of out-of-pocket payments (96%)—made up the remaining 39.6%.[4] This share of out-of-pocket spending in Serbia is considerably higher than in most European Union countries (e.g., 24.5% in Hungary, 16.1% in Austria, and 12.9% in Slovenia).[5]

Theory: Transition, siphoning out, and the neoliberal push

Transition and corruption

Corruption is the misuse of entrusted power for personal gain, and it can manifest as both petty and grand corruption. Petty corruption involves small gifts, services, or modest financial contributions to low- to mid-level officials.[6] These acts are illegal but can be considered acceptable for some patients when there are no other ways to assert rights or access services. In this sense, petty corruption can help individuals cope with a failing public sector that regularly does not provide services. In contrast, grand corruption involves only a small group of high-level officials and is characterized by enabling a select group to amass wealth. Grand corruption is significant because it exacerbates and highlights perceived societal inequalities, making it widely regarded as unacceptable. People are less tolerant of it, and its existence often sparks moral condemnation and public outrage.[7]

Corruption, at its core, embodies the idea that officials and politicians prioritize personal interests over the common good and make decisions based on individual preferences rather than objective standards. This fundamentally violates the principle of equality before the law by giving certain citizens preferential treatment in their dealing with institutions and legal systems.[8] As a result, corruption prevents equal access to rights, services, and resources such as education, health care, employment, and administrative facilities.

Expanding on this idea, Balakrishna Rajagopal argues that corruption can sometimes be the root cause of human rights violations, either by acting as a structural cause that allows such violations or by directly constituting human rights breaches.[9] As a structural enabler, corruption weakens the rule of law, which is essential for protecting human rights. This happens as bureaucracy disrupts the fair and efficient delivery of public goods vital for realizing human rights. Corruption also adds subjective elements and arbitrary practices to administrative decisions and law enforcement, leading to human rights violations. Additionally, it undermines the independence and impartiality of the judiciary—key factors in safeguarding human rights—and weakens representative institutions by injecting individual interests into democratic decision-making processes meant for collective well-being.

On the other hand, corruption can directly constitute violations of human rights. For example, the right to political participation is undermined by the unfair distribution of public goods that sideline citizens' interests; the right to freedom of speech is infringed when journalists are bribed to write or not write about specific topics or when bribes prevent access to information about government transactions with the private sector; and the right to equality before the law, including the right not to face discrimination, is violated when certain individuals or groups are given privileges because they paid a bribe.[10]

In all countries that underwent a post-socialist transition, privatization was a massive administrative, economic, and political effort that paved the way for the emergence of new economic and political elites.[11] Unfortunately, privatization also created opportunities for corruption.[12] As in many other countries of the Eastern bloc and the Balkans, such a transition and the rise in corruption have led many to believe that corruption is among the most pressing social and political issues in Serbia.[13]

Furthermore, the development of private firms across various sectors, including public services such as health care and education, began with limited financial resources. After the collapse of socialism, the new Serbian economic elite emerged mostly from the ranks of the former nomenklatura. During the 1990s, two-thirds—and by 2003, half—of those belonging to the economic elite were former members of the socialist political and economic elite or their descendants.[14] Since then, they have been siphoning off public resources to establish their private businesses, whether factories or hospitals. The first private medical facilities, as well as the first private medical schools, were established by professionals from the public sector who lacked the financial means for initial investments and therefore relied on their positional and social capital to start and sustain their businesses.

Corruption in health care

Small-scale corruption, in the form of bribes to public health workers, is widespread in Serbia. Although it is generally frowned on in private conversations, in real-world situations, people often perceive it as necessary. When health is at risk, morals tend to be lower on the list of priorities. Because of this, more than half the patients visiting public hospitals give small gifts or even money to physicians or nurses, and half of them expect to receive better treatment because of it.[15] In a survey, over two-fifths of people (41%) said that they believe it is necessary to give a bribe at a public health hospital if they need an operation, while just half as many (20%) believe that it is not necessary, and the rest are undecided.[16]

This is a direct and easily recognized form of corruption. However, other types also exist. One well-known example in the public sector is the siphoning of patients from public to private health care. This often results from the mixed work hours of many health care workers. Physicians who work in both the private and public sectors may encourage the patients they see in the public system to schedule their next appointment in the private sector, convincing them that they will receive more time and better conditions there—albeit for a fee. Anecdotally, the first author, a psychiatrist in a public hospital (who does not work part time in the private sector), finds that many patients expect the physician to suggest such a referral or even ask for it themselves, believing it to be customary practice or a way to receive better care.

The neoliberal push

The opening of the first private practices, followed by small hospitals, and ultimately large private medical centers, was in line with "medical neoliberalism," an ideology that promotes treating health as a commodity and the patient as a consumer.[17] This reflects freedom of choice, one of the hallmarks of capitalism—for example, the right to choose the school we attend, the career we pursue, the products we use, and the services we receive, along with the responsibility for the choices made. The idea is that this freedom of choice will, in all areas where the free market is allowed to function, lead to greater autonomy for consumers (in medicine: patients), resulting in competition, which will in turn lead to better and more effective services.[18]

However, it is questionable whether the same concepts that work in other areas are equally applicable in medicine—specifically, because patients lack the knowledge to make informed decisions and there is an asymmetry of power, with patients depending on the physician.[19] Of course, the problem lies in the fact that in an economically unequal society, the question of choice is heavily influenced by a person's financial status. For example, a study from Vietnam on behavioral economics shows that consumer sensitivity to health care costs of screening varies depending on the socioeconomic capabilities of the individual.[20]

As a result, the ones choosing will be the ones with the means to choose, while the poor will be left with what is available. Compounding this, studies show that there is no solid proof that the neoliberal free-market approach in medicine improves the quality or effectiveness of health care services.[21] Studies also show that private medical institutions do not necessarily provide better medical care than public ones and that, in some cases, they might even deliver worse care.[22]

Dual practice

Issues arising from dual practice

Physicians have the right to work, and it would raise ethical concerns if the state were to determine what a person must do in their free time. Thus, if wanting to work is what a physician wants to do, that is their right. However, it is important to recognize that beyond a certain number of working hours, the focus and quality of one's work tend to decline.[23] This means that if a physician from a public hospital, after completing an eight-hour shift, proceeds to work in a private facility, their focus and quality of service are likely to be significantly diminished. Yet patients often feel that they receive better and more attentive care in the private sector, so much so that they are willing to switch from one setting to the other for the same doctor.[24] This is largely because physicians in the public sector tend to conserve energy in a stable job that does not closely measure their effectiveness, and where the number of consultations and the level of patient satisfaction have no impact on their salary.[25] Thus, the biological limitations of the human body and the financial incentives that exist create a fertile ground for institutional corruption. Three issues arise from this corruption.

Issue 1: Degradation of the quality of public services. The first is the *degradation of public health care quality* and the *passive siphoning of resources* from the public to the private sector. Even when a patient remains in the public sector, as mentioned above, they believe that additional payments or gifts to medical personnel or additional checkups in a private clinic are necessary to receive quality service.

A key part of work in the public sector should include not only routine tasks but also advocating for better working conditions for health workers and better care for patients. Health care expenditures per person in Serbia are near the bottom in Europe, lower only in Moldova.[26] In this light, it is reasonable to hypothesize that many workers who operate in both the private and public sector feel conflicted about the state's lack of support for public health care. If the quality of work in the public system were to improve significantly, the private sector might receive fewer patients, thereby leading to less private work for which doctors are paid by the consultation. On the other hand, the public sector could experience a higher patient load, yet for the same salary. Although most physicians probably do not consciously think in these terms, it is evident that the current system has created a double loyalty and a clear financial incentive to (at least subconsciously) prioritize private work at the expense of public because the direct personal gains for the physician are greater when such a priority is made. This can lead to institutional corruption. In other words, a legal and publicly morally acceptable system exists in which the institution and individuals have a clear personal incentive that overrides the incentive the institution and individuals in it are meant to put in first place: the patient's well-being.

Issue 2: Overtreatment and overdiagnosis (as a human rights violation). Receiving direct payments for medical consultations in the private sector encourages physicians to communicate more carefully, leading to higher satisfaction among service users. However, it also creates financial incentives that are not always in the patient's best interest. Tests that otherwise would not be performed and could even cause harm are more readily ordered when the patient is paying. This is often understood by lay people to mean that private health care patients receive better care because they receive more tests and treatments, whereas the concepts of overtreatment and overdiagnosis are less prevalent in the public sphere. Considering that "the potential consequences of overdiagnosis and overtreatment may be significant and include such harms as the psychological and behavioral effects of disease labelling, physical harms and side effects of unnecessary tests or treatments, unnecessary treatment negatively affecting quality of life, increased financial costs to individuals and wasted resources and opportunity costs to the health system," a case can be made that it is just the opposite side of the same coin as undertreatment.[27] Further, as as Kanny Ooi points out:

> *doctors in private practice usually operate a fee-for-service model where they charge for each consultation conducted, and for each test and procedure performed. Although most doctors do not intentionally abuse or defraud the health system, operating a fee-for-service model essentially means earning more for doing more irrespective of what the outcome may be for the patient.*[28]

This means that overtreatment and overdiagnosis in the private sector are shaped, at least in part, by institutional corruption. In this sense, the overtreatment and overdiagnosis that stem from a private health care system that incentivizes the physician to almost always choose intervention whenever there is doubt could be viewed as a form of institutional corruption, which in turn may amount to a human rights violation. As noted by the Office of the United Nations High Commissioner for Human Rights and the World Health Organization in a fact sheet on the right to health, "All services, goods and facilities must be available, accessible, acceptable and of good quality … Finally, they must be scientifically and medically appropriate and of good quality."[29] In terms of health, it is recognized that "good quality" is absent not just when patients do not receive necessary care but also when they receive care that is unnecessary.[30] While this is not caused solely by financial interests in the private sector, these interests often exacerbate the problem.

Issue 3: Subjective satisfaction vs. quality of services. In line with the previous two issues, another factor related to dual practice is the massive influence of subjective feelings in valuing a service. Thus, even if a given service is measurably worse in one place compared to another, a patient might still prefer the worse option because of the simplicity of the process, the aesthetics of the room, or the decorum of the workers. A study from 2020 found that one of the three main problems in public health care in Serbia, as seen by citizens, is "insufficient motivation and dedication of the staff."[31] Another study, which examined how patients navigate between the private and public health care systems, quoted a patient as saying:

> *"What we are paying for is the human relationship. It is not like a hotel here, but they at least look you in the eyes and have patience with you, I know it is*

> *not easy for them, but they can at least introduce themselves. They can ask how we are feeling. Sometimes a single word means a lot, a single smile. We are paying for kindness.*"[32]

Of course, psychiatric patients are not spared from this need, and they are possibly the category of patients mostly influenced by the relationship with their psychiatrist.[33] Studies show that satisfaction with private health care in psychiatry is often greater precisely because of the difference in approach.[34]

It is similar to buying a coffee at a nice-looking café versus a café that is dirtier or has a rude cashier, even if the first place serves worse coffee. This effect might be even more pronounced in medicine, where the placebo effect has a major influence on the measurable metrics. Choosing a clinic is also influenced by aesthetic details that affect cost and subjective satisfaction, but not necessarily by the health outcomes experienced by its patients. However, satisfaction is an important factor for any consumer, and objective measures are nearly impossible to recognize on an individual basis in health care. As a result, people with means are increasingly opting for private practice over public health care. This shift affects not only their individual health care costs but also their attitude toward public health care and the perceived obligation to pay for it.[35] The sentiment of "if I don't use it, why should I pay for it" undermines solidarity and the sense of duty toward all members of society.[36] Thus, on a population level, these individual decisions affect the whole of society. They can even affect the public sector directly. The psychological effect of receiving direct payments from patients for work in the private sector could lead physicians to view their work in the public sector, and the patients they see there, as less important or less worthy of maximum attention—unless a gift or payment (i.e., a bribe) is given, which might explain at least part of the petty corruption in the public sector. This further diminishes trust and perpetuates a vicious cycle that is directly influenced by the institutional corruption of dual practice, which enables petty corruption and degrades the quality of care, which is a human rights violation.

Dual practice in Serbia

In Serbia, physicians working in the public sector have the right to also work in the private sector, and many do so to supplement their monthly income. Such physicians usually work in a public hospital in the morning and early afternoon (typically from 7 a.m. to 3 p.m.) and then move to a private clinic in the late afternoon. Some have their own small private practices, while others work for private medical centers that are eager to hire these physicians as part-time employees—both because of the prestige they carry from the public sector (especially if they also hold academic titles) and because of the expectation that they will attract patients from the public sector, thereby bringing business with them.

A 2020 study found that 27% of public sector physicians plan to work in both sectors simultaneously. This trend is even more common among physicians in their twenties, with 36% intending to do so. Only 7% plan to work full time in the private sector, while 45% intend to work exclusively in the public sector.[37]

Dual work has normalized the migration of patients between public and private practices. It allows patients to navigate inefficient public and supplementary private health care more effectively to achieve better outcomes. However, as a result, patients often end up paying for services that are covered by their public health insurance, which can lead to significant health expenses.[38] A quarter of physicians working in dual practice worldwide report that their motivation for working in the public sector is because it allows them to recruit patients to their private practice.[39] In Serbia, a 2020 study found that citizens perceive poor organization and long waiting lists as the primary problems with the country's public health system—problems that, in theory, could be addressed with relatively low financial investment, provided that a motivated workforce is in place.[40] In 2024, Serbia's then minister of health (a physician herself) claimed that the long waiting lists for surgeries were being intentionally created to steer patients toward private practice, where they would have to pay the same surgeons who also work in the public sector.[41]

Moving to the private sector is often viewed as more practical, especially if it allows one to bypass the primary care setting. In today's world, where patients can check symptoms online, they often know upfront what type of specialist they need.[42] This further renders the primary care doctor even more redundant, turning them into an administrative obstacle, since in the current public health care model, the primary care doctor is meant to perform triage and give patients referrals to see specialists. In private health care, patients call directly and go straight to the specialist they believe they need, making the process simpler and more practical.

All of this leads to more health inequalities. Citizens with higher socioeconomic status are more likely to see specialized physicians, gynecologists, stomatologists, psychiatrists, and others.[43] Again, higher socioeconomic status is the main factor influencing the likelihood of using private health care options.[44] Because of this, although 27.7% of people nationwide use private health care, this figure rises to 42.8% among those with higher socioeconomic status. There has been a sharp rise in the use of private health care services in recent years: while 15.2% of citizens used private practice in 2013, this figure rose to 27.7% in 2019.[45] The public health care system's inability to provide necessary and effective care for everyone has resulted in the growth of the private sector.

The rise of the private sector and the marginalization of the public sector has not brought observable benefits for public health. While direct data on causality are hard to obtain, some indirect data may be interpreted to show that this phenomenon is negatively influencing health outcomes and health inequities. According to a World Bank and UNICEF report from 2023 on health care in Serbia:

> *Despite improvements over the last decades, Serbia does not compare well with peers and aspirational peers in health outcomes. Life expectancy at birth is lower than in several Western Balkan countries. At 12 per 100,000 live births, maternal mortality in 2017 was more than double the EU average. Serbia ranks second highest on mortality per 100,000 population among comparator countries, performing better than only Bulgaria.*[46]

The same report recognizes that Serbia is continually lowering the amount spent on public health care, eager to give ground to the private sector so that the money in the budget can be allocated elsewhere. At the same time, the state is reluctant to introduce stricter regulations on the private sector and dual work, which leads to an inefficient and expensive health care system that is especially damaging to those who are lower on the socioeconomic ladder. As the report finds:

> *Long-term trend shows a decline in the government's health spending, from 6.2 percent GDP during 2008–2010 to 5.1 percent in 2018. At the same time, private expenditure stayed at 3.7–4.1 percent of GDP. The health system relies heavily on OOP (out-of-pocket), which makes Serbia an outlier when compared with peers and aspirational peers … The system performs poorly on financial protection, relying on OOP payment for 42 percent of total health expenditure. Roughly 86 percent of OOP is spent in the private sector … Some 4–5 percent of the population suffers from "catastrophic" health expenditure each year (health expenditure that exceeds 25 percent of total household nonfood expenditure), a level that is higher than in all comparator countries except Albania … Private providers are a popular choice among the population due to their convenience and seemingly better facilities. However, except for a small number of selected services, private services are not contracted by the National Health Insurance Fund (NHIF) for the public benefit package, limiting the government's ability to regulate the private sector or helping to reduce OOP spending on private services.*[47]

This is a major problem for private mental health services, too, given that Serbian law currently recognizes only psychiatrists and psychologists—but not psychotherapists—as legal entities. This creates a substantial gray zone, allows the profession to self-regulate, and places the entire private psychotherapy sector—which has been rising quickly in the last decade—outside of any legal framework.[48] As a result, the official figures for out-of-pocket spending are probably underestimates, particularly as patient spending on psychotherapy has not been taken into account.

Just as the entire public health sector is being deprioritized, so is mental health. In 2019, the state published an action plan highlighting the need for more community mental health centers, which are more accessible than hospitals and offer support to a broader array of people. At the time of the action plan's publication, there were five such centers in Serbia, and the aspiration was to have 20 by 2022. But as of today—the end of 2025—the total number is just six.[49]

Such neglect and lack of investment in the public health care sector have not produced any backlash among professionals working in this sector, likely due in part to general political apathy, but possibly also due to dual loyalty. This lack of support for mental health in the public sector—as well as the unregulated, non-insured, and expensive private mental health sector—has contributed to the widespread use of cheap anti-anxiety drugs. These drugs are being overprescribed by physicians, but also sold illegally by private pharmacies to patients without a doctor's prescription.[50] A recent comparative study that analyzed the use of psychiatric drugs across countries found that Serbia ranks first in tranquilizer use in the world.[51]

The unregulated landscape of dual practice in Serbia

Public framing of the problems: From patients' to doctors' rights

Although the public has long been aware of the direct ways in which corruption exists in the public health sector, the government has only recently taken steps to address the issue. In 2022, the newly appointed minister of health, Danica Grujičić, who is a physician herself, publicly stated that "physicians shouldn't be able to work in both the private and public sectors because it is a generator of corruption."[52] This triggered an immediate backlash from physicians, who defended their "right to work" and labeled her statement hypocritical, since she had worked in both the private and public sectors before taking office. In one response, an opposition member and physician engaged in dual practice argued that any alleged siphoning of patients should be proven; he also stated that he does most of his laboratory and imaging analyses in the private sector because these services are either unavailable or have long waiting lists in the public sector. Interestingly, he also claimed that patients in the private sector have "90% unnecessary tests done to them."[53]

This interaction highlights the ambivalence and institutional corruption at the core of the Serbian health care system and the physicians who are a part of it. On one hand, the minister of health correctly recognizes the corruption arising from the current model—but only after assuming a political role and ceasing to work as a physician. On the other, the physician defending his right to work in both the public and private health care systems correctly acknowledges that this duality results in unnecessary tests and that he himself experiences poorer service in the public sector partly because of this. He also calls for legal proof of corruption in cases of siphoning, probably aware that such proof is nearly impossible to obtain.

Under the current system, decision-makers are arguably the primary beneficiaries because they can keep medical professionals politically passive. Although public sector physicians in Serbia earn the lowest salaries in the profession across Southeast Europe, they manage to supplement their income through additional work in the private sector.[54] As the above interaction demonstrates, everyone is aware of these systemic problems, yet there is little motivation to remedy them. Consequently, while no one is genuinely satisfied, short-term incentives encourage the preservation of the status quo. But this dynamic results in fatigue among physicians: according to a 2020 study, feeling overworked was physicians' top complaint, cited by 50% of respondents.[55] Meanwhile, decision-makers can divert increasing funds from the public sector, confident that there will be little to no backlash from workers or patients.

Defining policies and framing the public discourse

Medical doctors have led Serbia's public health care system for decades. Typically, health ministers, state secretaries, and other high-level public officials are selected from the ranks of doctors and university professors. Medical doctors have served as ministers of health for 23 of the last 25 years. This is part of the explanation for the pervasiveness of dual practice, along with all its negative consequences: the governance structures in the public health care system have been dominated by medical doctors who have no interest in restricting dual practice. Resistance to the status quo is rare, as illustrated by the cases of the association Doctors Against Corruption and former minister of health Grujičić; although both were highly critical of corruption in health care, their voices remained marginal.[56]

Serbia's legislation is also conducive to dual practice and its potential for corruption. The accreditation of health institutions is conducted in accordance with established quality standards. The quality standards for primary, secondary, and tertiary health care institutions do not specify the structure or legal status of employees; in particular, they do not establish specific requirements regarding the number of full-time employees that an institution must have.[57] This leaves an open door for dual practice in the public and private sectors.

The first and only serious attempt to regulate this problem happened in 2005, when dual practice was effectively banned by the Law on Health Care. The ban was supposed to take effect after a three-year period. However, in 2008, when the prohibition was due to be enforced, the Medical Chamber filed a case before the Constitutional Court, and in 2010, the court effectively annulled the restriction. Interestingly, the public discussion was framed around antidiscrimination issues, while the issue of access to rights and health care services played a marginal role.[58]

Over time, the private sector became stronger, but it was not until 2013 that a major investment in private health care occurred, marked by the acquisition and merger of several private practices. This process has gradually established the first large private medical network comprising primary and secondary health care facilities. Despite its size and foreign investments that followed, it still relies on the part-time or full-time work of doctors from the public sector. In essence, dual practice has become a part of the business model of both private and public health care institutions, which partly explains its persistence.

The other part of the explanation lies in the health care system's governance structures. To shed additional light on the issue, we will make a parallel between health care and education. Governance structures in both fields are controlled by professional elites who are able to influence public policies. In both cases, these policies primarily protect the interests of doctors and teachers, rather than the broader public. Thus, the primary beneficiaries of the two systems are university professors (in higher education) and specialist doctors who are also university teachers (in health care).[59]

However, there are significant differences between the two systems. Unlike in the health care system, dual practice in higher education has been regulated. The accreditation system for higher education institutions clearly prescribes the number and structure of employees, as well as the ratio of permanent and temporary employees.[60] This makes it practically impossible for a private educational institution to rely on the work of teachers from state universities whom it hires on a part-time basis.

Moreover, the education system is shaped by external pressures and incentives—mechanisms that are largely absent in health care. The European Union maintains a relatively unified policy in the field of higher education. The Bologna Process, which seeks to ensure compatibility in higher education systems across Europe, has helped regulate Serbia's previously deregulated higher education system. By contrast, the health care system lacks a similar external incentive to limit dual practice or protect patients' rights and interests.

Conclusion

Patients in Serbia's public health care sector are receiving constantly deteriorating care. Those who have money are switching to the private sector. Moreover, patients in the private sector are receiving care that is often detrimental because it uses unnecessary resources and includes unnecessary tests. Nonetheless, the guild and physicians within it are seemingly satisfied with the status quo because they believe that it provides the best of both worlds: stability, prestige, and low expectations in public health care, combined with higher financial returns in the private sector.

If the state were to abolish or more closely control dual practice while also increasing investment in public health care, it would reduce profits in the private sector—and with key actors "sitting in both camps," their incentive to pursue such reforms is limited. In our view, this inertia is likely to be detrimental to physicians in the long term: fighting for a better public health sector—with better conditions for patients and better salaries for workers—would increase the quality of life of physicians and nurses by allowing them more free time, giving them more respect, and reducing the likelihood of being overworked by long work days.

Serbia's current health care system is a product of historical conditions and compromises made to appease everyone. Unfortunately, it has predictably failed to do so, and in a way that harms all sides. Public health is receiving less funding and patients seem to experience poor-quality care. Private health care users are getting more care, which often is not better and can lead to overtreatment and overdiagnosis. Physicians are often pulled by both the security of a public sector job and the additional income from private practice. This mix causes them to be overworked and further damages the public health care system, ultimately compromising the right to health for Serbian residents. Addressing this issue is hindered by institutional corruption embedded in the way the system is built.

Funding

This paper is the result of research conducted within the strategic project of the University of Belgrade Faculty of Law for the year 2025 titled "Problems of Creation, Interpretation and Application of Law."

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A Hard Pill to Swallow: Pharmacy Chain Dominance and the Commodification of Mental Health in Peru

ALBERTO VÁSQUEZ ENCALADA

Abstract

Peru's mental health system remains marked by chronic underinvestment, fragmentation, and weak regulation, leaving many without adequate access to care. In this context, private pharmacy chains have become central actors in the provision of mental health services, functioning as de facto points of access for psychotropic medications. Drawing on the concept of institutional corruption and a rights-based analysis, this paper examines how their dominance has transformed access to psychotropic medication into a market-controlled process in which commercial interests shape treatment pathways, reinforcing inequality and overmedicalization and undermining the right to health.

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Competing interests: None declared.

Introduction

Peru's public health system has long struggled with underinvestment, fragmentation, and structural inefficiencies, leaving vast segments of the population without adequate care.[1] These challenges are particularly acute in the field of mental health, where services remain scarce, geographically uneven, and under-resourced.[2] The implementation of community-based mental health reforms in recent years, although significant at the policy level, has yet to shift the system away from biomedical approaches or meet the minimum standards of availability, accessibility, acceptability, and quality outlined in the international right to health framework.[3]

In this landscape, private pharmacy chains have emerged as central actors in the provision of mental health care. For many Peruvians, especially in underserved areas, pharmacies and *boticas* (drugstores) serve not only as dispensaries but also as the first and often only point of contact with the health care system.[4] People frequently bypass formal consultations, relying instead on over-the-counter medications and informal advice from pharmacy staff.[5] These private pharmacies operate in a market dominated by two conglomerates that control most of the retail sector. They influence pricing, promote branded and private-label medications over affordable generics, and benefit from regulatory gaps that allow for commercial practices with limited oversight. In the absence of strong public provision or regulatory enforcement, pharmacies have accrued significant power over what medicines are available, how they are dispensed, and at what price.

This paper argues that the growing dominance of pharmacy chains in Peru reflects a broader process of regulatory capture and structural conflicts of interest, analyzed through the lens of institutional corruption. In this context, both illegal and legally permitted but ethically problematic practices can distort public health goals and prioritize commercial interests over equitable mental health care. The paper examines how these actors shape access to medication, reinforce inequalities, and operate within a context of weak state oversight. In Peru, pharmacies and boticas function similarly as retail outlets for medications—the key difference being that pharmacies must be owned by a professional pharmacist, although both are legally required to operate under the technical direction of one. For simplicity, the term "pharmacies" is used throughout the paper to refer to both. The analysis draws on the international right to health framework and the Convention on the Rights of Persons with Disabilities (CRPD) to assess state obligations and the impact of market-driven practices on equitable access to mental health care.

This paper is based on a critical synthesis of secondary sources rather than primary empirical research. It draws on academic literature, legal and policy documents, regulatory decisions, and investigative journalism published between 2010 and 2025, identified through targeted searches in PubMed, SciELO, Google Scholar, and official Peruvian databases. While not a comprehensive empirical study, the paper builds a rights-based analysis through the critical synthesis of existing evidence and case examples to illuminate structural dynamics and contribute to discussions on institutional corruption in health governance. Findings depend on the availability and quality of existing data, and information gaps—especially on private pharmacy operations—remain significant.

Mental health care in Peru: Context and challenges

Mental health care in Peru has historically faced significant barriers, characterized by inadequate infrastructure, insufficient resources, and fragmented service delivery.[6] Over the past decade, however, there has been a marked shift in policy and investment, with the adoption of a community-based mental health model centered on human rights, universal health coverage, and decentralized care.[7] Aimed at serving the entire population—particularly those with moderate to severe conditions—this reform has led to the creation of 291 community mental health centers, 94 protected housing facilities, 54 specialized hospital units, and the nationwide deployment of multidisciplinary teams.[8]

Despite these advances, implementation remains uneven, and gaps in coverage and quality persist. Public mental health facilities are still concentrated mainly in Lima and other urban centers, leaving rural and remote regions severely underserved. The national treatment gap remains high, with an estimated 72.4% of people needing mental health care not receiving it.[9] While public investment in mental health increased by 223.7% between 2015 and 2022—an average annual growth of 16%—mental health still represented only 2.6% of the total health budget in 2023, well below the 10% benchmark recommended by the World Health Organization.[10]

A persistent shortage of trained personnel further compromises the quality of services. The number of psychologists in primary care has considerably increased, but the availability of mental health specialists remains inadequate, especially in non-urban areas.[11] In many regions, the existing infrastructure and human resources are still insufficient to meet growing demand. Furthermore, the continued dominance of a biomedical and custodial approach in professional education and clinical practice undermines efforts to shift toward more community-based, rights-oriented care models.[12]

In addition, public mental health facilities face persistent shortages of psychotropic medications. Both community mental health centers and psychiatric hospitals report recurring difficulties in maintaining a stable supply of drugs such as antidepressants, antipsychotics, and mood stabilizers.[13] These shortages stem from chronic delays in procurement, coordinated by the Ministry of Health. When procurement processes break down, hospitals often resort to direct purchases, typically at higher prices.[14] The Ministry of Health has identified these delays as a significant bottleneck in scaling up mental health services.[15] These stock ruptures disrupt treatment continuity and disproportionately affect low-income users who depend on public services.

These systemic barriers have had a direct impact on access to mental health care, particularly for individuals who rely on medication as their primary form of treatment. In the absence of consistent availability of psychotropic drugs in public facilities, many are forced to purchase them out of pocket from private pharmacies, where generic options are often unavailable.[16] The financial burden this imposes on households is significant. For example, a monthly treatment with brand-name antidepressants such as fluoxetine or sertraline can cost the equivalent of 8.5 to 19.2 days of work, while even generic options may require more than five days of wages.[17] These expenditures far exceed national averages.[18] As will be explored further in this paper, in some cases, the price difference between generics and branded drugs is negligible, further undermining affordability.

Recent data from the Ministry of Health show that although out-of-pocket spending is concentrated largely on medications not listed as essential by the Ministry of Health, more than half of all units consumed correspond to essential medicines that, in principle, should have been provided under the Essential Health Insurance Plan.[19] Psychotropic medications accounted for 10.3% of total out-of-pocket pharmaceutical spending in Peru's private retail sector between 2018 and 2023, making them the fourth-largest therapeutic category after anti-infectives, pain and palliative care, and cardiovascular treatments.[20] The most commonly consumed psychotropic medications included clonazepam, sertraline, and fluoxetine. These figures illustrate both a high demand for such drugs and a systemic failure to ensure their availability and affordability through guaranteed public mechanisms.

These systemic deficits have also fueled the widespread practice of self-medication. Self-medication is common throughout Peru, crossing regions and socioeconomic groups. National data show that nearly 76% of people report purchasing medication without a prescription, and a 2019 market survey found that only 6% of Peruvians claimed not to self-medicate at all.[21] The prevalence is especially high in low-income populations and in the Andes and Amazon regions, where barriers to accessing public health services are greatest. In Lima, studies reveal that self-medication is more frequent in low-income districts (66.7%) compared to wealthier areas (40.6%). During the COVID-19 pandemic, this trend became even more pronounced.[22]

Several factors explain the persistence of self-medication in Peru, including limited access to affordable public health, weak pharmaceutical regulation enforcement, and cultural reliance on family advice for minor illnesses. Pharmacies often sell restricted medications without prescriptions, with pharmacists recommending drugs based on informal consultations. Although Peruvian law criminalizes the sale of psychotropic drugs without a prescription (Law No. 30681), enforcement is weak.[23] A study found that not requesting a prescription is the strongest predictor of unsafe self-medication.[24] These issues, driven by poor access to public care and commercial interests, disproportionately affect low-income users and may lead to unsafe medication practices.

Taken together, these dynamics reveal a fragmented and inequitable mental health system in which pharmacies have become default providers—particularly for those facing economic and geographic barriers to formal care—reflecting a mismatch between supply and need that drives reliance on market-based pathways to care.

Pharmacy chains and market dominance

Pharmacies play a critical role as frontline health care providers in low- and middle-income countries, where formal health systems face chronic underfunding, workforce shortages, and limited infrastructure. However, this prominent role has raised concerns regarding the consistency and quality of the service they provide. Studies have documented problematic issues, including inadequate training among their staff, weak or uneven regulatory enforcement, and the routine sale of prescription-only medications without authorization.[25]

Private pharmacies have a broad presence across Peru. As of 2024, there were 23,280 registered establishments, with the majority located in urban areas.[26] Due to their widespread availability, relatively low cost, and perceived convenience, they often serve as initial contact points for health care advice and medications, particularly where formal health services are scarce or difficult to access.[27]

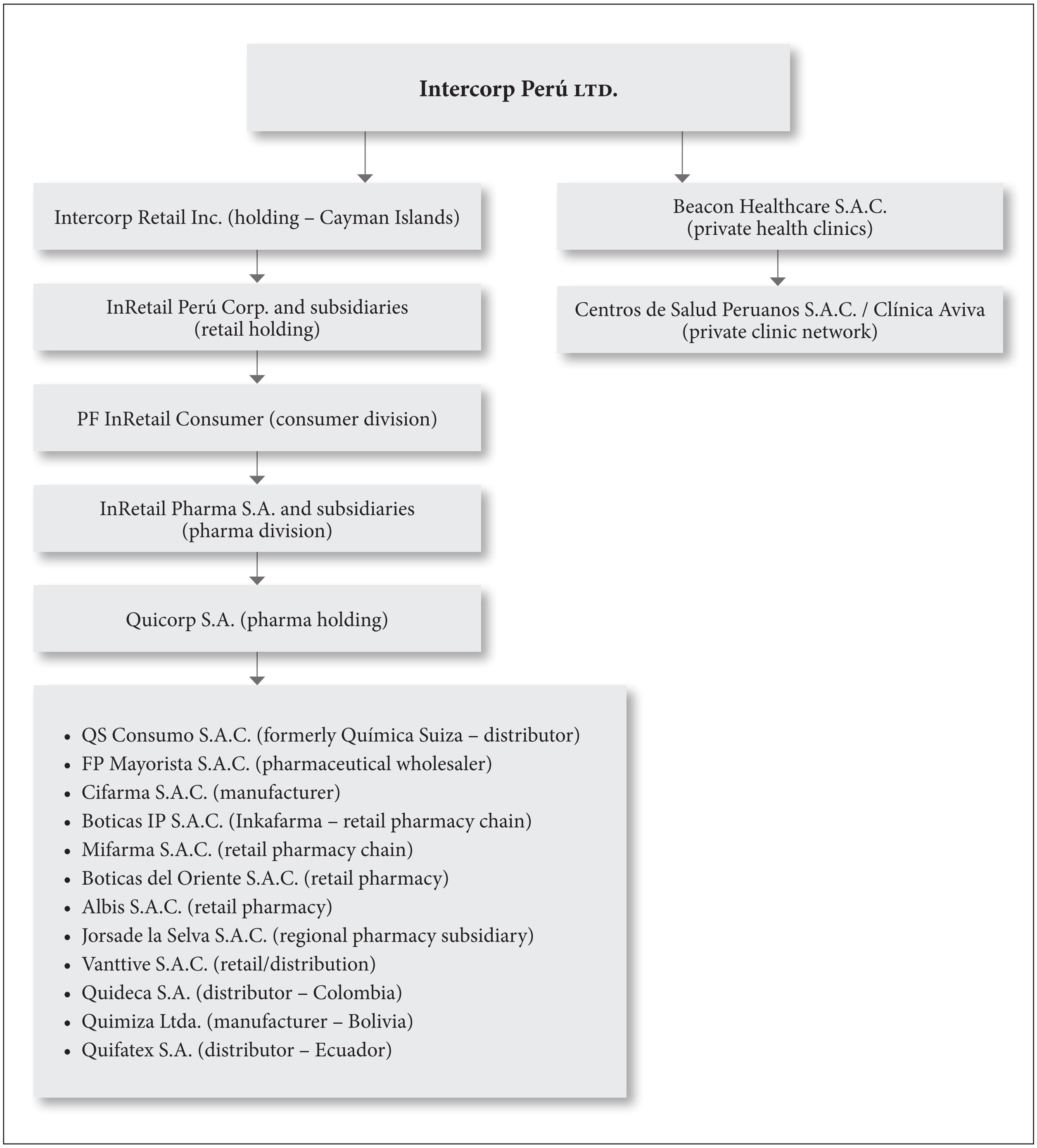
The Peruvian retail pharmacy market is notably concentrated, dominated by two major chains—InkaFarma and Mifarma—both owned by InRetail Pharma since 2018. Although independent establishments constitute 85.8% of all private pharmacies, chain pharmacies control approximately 79.2% of total pharmaceutical retail sales, with InkaFarma and Mifarma alone making up 57.3% of chain-affiliated establishments.[28] This level of market consolidation grants these chains considerable influence over medication pricing, availability, and retail practices. National household survey data indicate that pharmacies are the most common point of care (14.7%) among Peruvians who experience health problems, surpassing public health facilities and private clinics.[29]

Peru's pharmaceutical sector has seen major consolidation in recent years, raising concerns about competition and consumer access. In 2018, InRetail Pharma, a subsidiary of Intercorp Perú, acquired Quicorp, which owned key pharmacy chains, including Mifarma, Boticas BTL, Fasa, and Arcángel. At the time, Peru lacked a regulatory framework for mergers. This deal unified over 80% of the pharmacy chain market under one group, reducing competition and creating a vertically integrated supply chain—from manufacturing (Cifarma) to distribution (QS Consumo, FP Mayorista), and retail (Inkafarma, Mifarma) (see Figure 1). This integration disadvantages independent pharmacies, limiting their access to distribution and preventing them from negotiating better prices. Following the merger, prices for essential medicines increased, raising concerns that market dominance may be driving up costs for consumers.[30]

Although further data would help clarify the scope of vertical integration in psychotropic medication production specifically, the existing structure suggests that pharmacy chains exercise significant control over which medications are stocked and prioritized. This influence is particularly concerning in the mental health field, where the dominance of branded or private-label medications can restrict access to affordable generics and shape treatment pathways according to commercial incentives rather than clinical need or rational use.

This concentration of power and vertical integration across the pharmaceutical supply chain generates structural dependencies that can distort public health priorities, undermining transparency, reducing accountability, and reinforcing a system in which corporate interests take precedence over equitable access to essential medications.

Figure 1. Vertical integration of Intercorp's pharmaceutical and health services operations



Sources: InRetail Perú Corp., *Informe Anual 2024*; Superintendencia del Mercado de Valores.

Institutional corruption in pharmaceutical retail

Corruption in health systems encompasses a wide range of behaviors that undermine public trust, distort service delivery, and compromise patient well-being. These include not only illegal acts but also more systemic and subtle forms of distortion. As Nahitun Naher et al. and Eleanor Hutchinson et al. have shown, corruption in health care often manifests as multifaceted institutional failures, such as informal payments, the manipulation of procurement processes, regulatory capture, and entrenched conflicts of interest.[31]

This paper adopts Lawrence Lessig's conception of institutional corruption as a guiding framework.[32] According to Lessig, institutional corruption refers to systemic and legal influences that, while not necessarily involving illegality, "weaken the effectiveness of an institution, especially by weakening the public's trust in that institution." Such influences tend to create dependencies—financial, political, or structural—that diverge institutional behavior from its public purpose. Unlike classic corruption, which typically involves personal enrichment or unlawful conduct, institutional corruption operates through legal but ethically problematic channels that erode the integrity of institutions over time.

This distinction is especially salient in Peru's health sector, where decades of pro-market reforms have prioritized private sector expansion and deregulation. While these reforms were intended to enhance supply and efficiency, they often outpaced the development of robust oversight mechanisms. As a result, institutional arrangements in the pharmaceutical sector have become increasingly shaped by commercial dependencies rather than public health goals. This creates fertile ground for institutional corruption: legally permissible practices that subvert the public interest, distort the delivery of care, and weaken rights-based oversight.

In this context, the role of pharmacy chains illustrates how market-driven structures can enable systemic exploitation. These practices can be grouped into five interrelated areas: price distortion, anticompetitive collusion, sales without prescription, conflicts of interest in service provision, and regulatory capture and lobbying. Each of these reflects a form of institutional distortion that, while not always illegal, undermines the right to health and weakens the state's capacity to ensure equitable access to essential care.

Price distortion

In Peru's highly concentrated pharmaceutical retail sector, pharmacy chains have adopted pricing strategies that, while permissible under the country's prevailing free-market framework, directly undermine the affordability of and equitable access to psychotropic medications. Dominant pharmacy chains such as InkaFarma and Mifarma routinely promote their own private-label psychotropic drugs as default options, a pattern reflected in staff recommendations that favor these products over lower-cost generics. These strategies are further reinforced by systematically withholding cheaper alternatives from store shelves. Even when generics are available, their prices are often set only marginally below those of branded or private-label products, limiting their appeal to cost-sensitive consumers and reinforcing the dominance of high-margin items.

A 2023 field investigation by Salud con Lupa across 31 pharmacies in Lima, the capital city, and Chiclayo, one of the most populous urban centers in northern Peru, found that in most cases, staff offered only branded versions of essential psychotropics despite the existence of cheaper generics.[33] For example, clomipramine (sold as Praminex in private pharmacies) was priced at approximately PEN 314 (approximately US$84), about one-third of the minimum wage at the time (PEN 1,025), while the generic version—if available in public pharmacies—would cost up to 15 times less. This pattern is not isolated: according to the Ministry of Health, several essential psychotropic medications are either unavailable in private chains or offered only as branded products, affecting both affordability and access.[34]

National data on the private market for antidepressants reveal similar distortions. Using price data from the Peruvian Observatory of Pharmaceutical Products, Javier Llamoza et al. documented multiple pricing anomalies in psychotropic medications sold in private pharmacies.[35] In several cases, the prices of branded generics and those sold under their international nonproprietary name (INN) were nearly identical, offering little real cost advantage. More strikingly, several branded generics were found to be as expensive—or even more expensive—than the innovator products themselves. For instance, in the case of fluoxetine, Genfar's branded generic for Prozac had a higher unit price than the original Prozac from Eli Lilly, while the INN-labeled version offered only a marginal difference. Consumers with limited financial means may mistakenly believe they are purchasing a lower-cost option when, in fact, the price difference is minimal or nonexistent.

Similar sales patterns have been documented in other therapeutic areas. A 2024 study by the Instituto de Defensa Legal found that InRetail-owned pharmacies systematically promoted their own branded products over lower-priced generics, with price differences of up to 18 times depending on the location.[36]

The National Association of Pharmacy Chains, which represents major retail chains, has argued that the availability of generic psychotropic medications depends on the laboratories that manufacture or import them.[37] However, many pharmacy chains are vertically integrated or maintain close affiliations with manufacturers and distributors, giving them significant influence over what is stocked and offered.

To contextualize these dynamics with quantitative evidence, future research and policy analysis should systematically monitor retail pricing and availability across time.

Anticompetitive collusion

Dominant pharmacy chains in Peru have not only shaped market dynamics through pricing strategies but have also engaged in overt anticompetitive practices that restrict consumer choice and reinforce corporate control.

A landmark investigation by the National Institute for the Defense of Competition and Protection of Intellectual Property (Indecopi) revealed in 2016 that five major pharmacy chains—including InkaFarma and Mifarma—colluded to fix the prices of 36 essential medicines, including widely used psychotropics such as alprazolam and fluoxetine.[38] Internal communications uncovered during the investigation detailed coordinated pricing strategies and agreements to maintain inflated prices across competing retail outlets.[39]

The 2016 ruling imposed fines exceeding PEN 9 million (approximately US$2.6 million) and revealed serious shortcomings in the oversight of Peru's pharmaceutical market. However, the structural incentives that enabled collusion remain largely unaddressed. Subsequent mergers and acquisitions have further consolidated the dominance of major pharmacy groups, while vertical integration in Peru's pharmaceutical sector continues to create favorable conditions for price coordination and supply manipulation.[40]

For example, in July 2024, Indecopi launched a new administrative sanctioning procedure against 15 pharmaceutical companies and five individuals for alleged collusion in 23 public procurement processes between 2006 and 2020, involving medicines purchased by the national government.[41] While the companies under investigation are not directly linked to retail pharmacy chains, the case underscores the broader systemic risks posed by market concentration and weak institutional safeguards across the pharmaceutical supply chain. It also highlights the vulnerability of state procurement processes to manipulation by dominant market actors.

Anticompetitive practices among retail chains restrict access to affordable treatment and contribute to sustained price increases, a situation particularly harmful in the case of psychotropic medications, which are often prescribed for long-term use.

Sales without prescription

Although psychotropic drugs are legally restricted to prescription-only sales, they are also commonly used without a prescription due to weak regulatory enforcement and the high unmet demand for mental health treatment. In Peru, the unauthorized sale of controlled substances, including psychotropic drugs, is a criminal offense under Law No. 30681, which amended the Penal Code to penalize such practices.

In 2012, the Ministry of Health reported that approximately 25% of private pharmacies were selling controlled substances without requiring a medical prescription, despite legal prohibitions and the known risks of dependency and overdose.[42] Subsequent field inspections have continued to uncover repeated violations, including the unsupervised sale of medications such as alprazolam, diazepam, and fluoxetine, as well as the absence of licensed pharmacists during operating hours.[43]

A 2019 hospital-based study in Lima found that 45.5% of service users had used benzodiazepines without a valid prescription, and among them, nearly 63% met the criteria for treatment due to substance abuse, compared to just 27% among those with a prescription.[44] Other local studies have shown that factors like perceived symptom severity, social influence, and convenience drive the demand for anxiolytics without medical oversight.[45]

The widespread sale of psychotropic medications without prescriptions reflects again commercial practices that exploit gaps in mental health service provision. In contexts where pharmacies serve as the primary point of access, these practices normalize unsafe dispensing and contribute to patterns of inappropriate medication use.

Conflicts of interest in service provision

In Peru, pharmacy chains have increasingly blurred the lines between retail and care, sometimes functioning not only as vendors but also as informal or emerging providers of mental health services. This convergence—selling medications while also facilitating or influencing their prescription—can create conflicts of interest, particularly in a market where psychotropic drugs are highly profitable and regulatory enforcement remains limited.

One expression of this convergence is the emergence of corporate-run telehealth platforms that offer remote prescriptions. Marketed as teleconsultations, these services operate with minimal oversight and primarily serve to direct consumers toward affiliated retail outlets. For example, Aliviamed—an online platform linked to major pharmacy chains—offers virtual consultations that can result in prescriptions for psychotropic medications, which are then filled through the same corporate network.[46] This example points to a wider regional trend: telehealth has expanded faster than regulatory capacity, raising similar concerns about oversight and accountability.[47]

These platforms emerge in a context where pharmacies already provide informal guidance about medication, often from staff with no formal clinical training. Research on pharmacy practice in Peru has long noted the absence of structured pharmaceutical care and the limited involvement of qualified professionals in patient counseling.[48] Staff frequently recommend medications, interpret symptoms, and advise on treatment choices in ways that go beyond their technical remit.[49] Although regulatory standards exist, such as requirements for qualified personnel and restrictions on prescription-only medicines, these interactions are rarely subject to systematic oversight. Moreover, investigations indicate that staff at major pharmacy chains routinely promote specific products—particularly high-margin private-label brands—regardless of clinical guidelines or individual user needs.[50] These commercial strategies, typically centralized and performance-driven, can facilitate inappropriate treatment, dependency, or overuse, especially when users receive guidance from nonprofessionals. Similar commercial pressures affect licensed professionals, whose ethical and professional judgment can be compromised when remuneration or sales incentives influence prescribing or dispensing decisions.

While pharmacy chains often function as the de facto front door to the health system in underserved areas, accessibility alone does not fulfill the right to health. The right to health also requires quality, safety, continuity of care, and access to reliable information—conditions that commercial dispensing models cannot guarantee in the absence of adequate oversight. Without effective regulation, this model risks normalizing a system in which commercial actors shape mental health care delivery without accountability.

Regulatory capture and lobbying

Pharmacy chains in Peru have not only expanded their market power but have also increasingly influenced the legal and regulatory frameworks meant to oversee them. Their ability to delay, dilute, or shape public health regulations reflects broader dynamics of regulatory capture—where private actors exert sustained influence over public institutions, steering policy and oversight mechanisms to align with commercial interests. This has been especially evident in debates surrounding access to generic drugs and the role of pharmacies in health care provision.

A notable example is the protracted and politically divisive process leading to Law No. 32033, passed in May 2024, which reinstated a requirement for pharmacies to stock a minimum percentage of essential generics.[51] The law traces back to Emergency Decree No. 007–2019, which mandated private pharmacies to carry 40 essential generic drugs identified by their INNs. Although supported by the Ministry of Health, the decree faced strong opposition from private pharmacies and industry groups.[52] As the obligation neared its expiry in early 2024, the government allowed it to lapse amid lobbying from interest groups.[53] Following public pressure from health advocacy organizations, the executive branch issued Emergency Decree No. 005–2024, restoring the mandate but requiring pharmacies to offer 30% of their total generic product list, without specifying which drugs must be stocked—thereby allowing broad discretion.[54]

Though Law No. 32033 reaffirmed these regulatory provisions on the stocking of essential generics, it has been criticized by advocacy organizations for not addressing structural issues such as market concentration or mandatory generic lists.[55] Pharmacies remain free to choose which medications to offer, potentially favoring high-turnover or more profitable items, and the law exempts small independent pharmacies. The latter exemption has been questioned as politically motivated, allegedly benefiting family members of congressional sponsors.[56]

Another key case is Indecopi's 2024 ruling overturning a Ministry of Health ban on in-pharmacy consultations and prescriptions.[57] The challenge, brought by three retail chains, including Mifarma, argued that the ban lacked a legal basis and violated the principle of free enterprise. The complaint was initially denied but later upheld on appeal. Industry groups welcomed the decision as removing barriers to care, while professional associations warned that it would undermine clinical standards and create conflicts of interest.[58] Later that year, Law No. 32033 reintroduced the restrictions, explicitly prohibiting in-person consultations, diagnostic tests, and sample collection within pharmacy premises. However, it did not regulate virtual services, leaving a gap that may allow pharmacy-affiliated telehealth platforms to continue issuing prescriptions remotely.

Most recently, Law No. 32319, adopted in April 2025, introduced changes to the regulation of bioequivalence and the substitution of brand-name drugs with generics.[59] The reform reduced the Ministry of Health's oversight role and shifted greater responsibility to prescribing physicians, who may authorize substitutions at their discretion. While proponents argue that this expands access, critics contend that it weakens pharmacological safeguards and opens the door to commercial rather than clinical considerations.[60] The law has been criticized for favoring the pharmaceutical industry by introducing partial obligations, allowing selective compliance, and avoiding more robust reforms that would curb the dominance of corporate chains or guarantee the availability of essential medicines.

Human rights implications

Applying the international human rights framework, including the right to health as enshrined in the International Covenant on Economic, Social and Cultural Rights (ICESCR) and CRPD, provides a vital perspective for analyzing pharmacy practices in Peru. These frameworks emphasize that health is not a commodity but a fundamental right to which everyone is entitled without discrimination. Viewed through this lens, Peru's mental health care system reveals gaps in service provision as well as a broader failure to regulate commercial practices that undermine equitable access and accountability.

Under article 12 of the ICESCR, states are obliged to ensure the highest attainable standard of physical and mental health. This is elaborated through the AAAQ framework: availability, accessibility, acceptability, and quality.[61] In Peru, dominant pharmacy chains play a central role in determining the availability and accessibility of psychotropic medications, often to the detriment of equitable access. Branded and private-label drugs are prioritized over affordable generics, while unregulated pricing and nonprescription sales erode both affordability and safety. The sale of psychotropic medications without prescriptions and the use of untrained staff in retail chains further compromises the quality of care. Taken together, these practices undermine the AAAQ standards and illustrate the risks of deflecting core health functions to private actors with limited oversight, in violation of the state's obligation to ensure the right to health. Intersectional barriers—based on factors such as location, gender, disability, or Indigenous identity—further entrench these inequities, deepening disparities in access to information, treatment, and support.

While the state is the primary duty bearer, international human rights law also imposes responsibilities on private actors. The United Nations Guiding Principles on Business and Human Rights establish that companies must avoid causing or contributing to human rights abuses and take appropriate action to prevent, mitigate, and remedy adverse impacts when they occur. In Peru, vertically integrated pharmacy conglomerates influence not only medication pricing but also prescription practices and regulatory decisions, effectively shaping treatment pathways. This convergence of commercial, clinical, and regulatory roles intensifies conflicts of interest and weakens safeguards for equitable care, highlighting the urgent need for stronger state oversight. These dynamics gradually divert public institutions from their intended purpose—not through isolated misconduct but through sustained commercial influence that reshapes regulatory priorities and public norms. Applying the United Nations Guiding Principles requires the state to fulfill its duty to protect, companies to respect human rights, and both to ensure access to effective remedies for those affected.

Transparency and accountability—cornerstones of the right to health—require that public health decisions, including those related to pricing, stocking, and prescribing, be subject to clear rules, public scrutiny, and effective grievance mechanisms. Yet in Peru, dominant pharmacy chains obscure pricing structures and restrict access to affordable generics, while expanding their influence through opaque lobbying and regulatory capture. These dynamics undermine public trust and compromise both affordability and transparency. To fulfill their obligations, Peruvian authorities must strengthen independent oversight, promote transparency in pharmaceutical governance, and ensure that regulatory frameworks are equipped to prevent and remedy conduct incompatible with the right to health.

The CRPD marks a paradigm shift in mental health provision, calling for a move away from coercive, biomedical-dominated models and toward community-based, rights-oriented approaches.[62] As the Special Rapporteur on the right to health has emphasized, the overmedicalization of mental distress, particularly through excessive reliance on psychotropic medication, can itself constitute a human rights violation when it results from structural coercion, lack of informed consent, or the absence of alternatives.[63] In Peru, the commercial interests of pharmacy chains intersect with the inadequacies of the public system to create a "pharmaceuticalized model" of mental health care by default. In practice, this results in a form of structural coercion: medication becomes the only available response to distress, though not necessarily the most appropriate. The absence of psychosocial alternatives and the commodification of care risk entrenching a system where medicalization replaces support and profit dictates care. Upholding CRPD obligations demands not only investment in public services but also a profound rethinking of medicalization, robust regulation of pharmaceutical practice, and a transition toward user-led, community-centered mental health supports.

Lastly, both the ICESCR and CRPD frameworks emphasize participation as a central pillar of health governance. This entails the meaningful involvement of affected populations—particularly those historically marginalized—in shaping laws, policies, and services. Yet in Peru, persons with psychosocial disabilities and service users remain largely excluded from regulatory and legislative processes.[64] Global mental health systems remain dominated by top-down approaches that concentrate power among biomedical and corporate actors, often at the expense of local knowledge, lived experience, and community-led alternatives.[65] Shifting toward participatory governance is essential to rebuild trust, correct power asymmetries, and ensure that reforms reflect the needs and rights of those most affected. Ensuring participation in oversight and grievance mechanisms would help realize these principles in practice and strengthen accountability toward those most affected.

Rethinking pharmacy power in mental health care

The systemic problems explored in this paper show that market-driven practices cannot be addressed in isolation. These practices reflect longstanding governance failures and demand structural changes in health system design and pharmaceutical regulation. Rights-based reforms must focus on restoring the public purpose of health institutions and ensuring that private actors operate within clearly defined legal and ethical boundaries.

While health advocates and pharmacy chains often diverge, there is broad recognition that the growing role of private pharmacies in mental health care stems from chronic underfunding and the limited reach of public mental health infrastructure. The widespread unavailability of timely, affordable care at the community level and the lack of psychotropic medications in state-run pharmacies leave many with no option but to turn to retail chains. This is compounded by a deeply embedded culture of medicalization that frames pharmacological treatment as the default response to distress.[66] Addressing these structural drivers requires both expanding public capacity and challenging embedded narratives about mental health and care.

While structural reform will take time, short-term policy measures can improve access to psychotropic medications in public facilities. These measures should avoid reinforcing a medication-centric model while ensuring safe and equitable access for those who need it, as part of broader care options. Recommended actions include expanding the Single National List of Essential Medicines through transparent, participatory processes; strengthening procurement; and promoting electronic prescriptions to inform public supply systems.[67] These efforts must be accompanied by strong public information campaigns to direct users toward public services, encourage the safe and informed use of psychotropic medication, and counter misconceptions about generics. Messaging should promote awareness of psychosocial alternatives and challenge the idea that medication is the only or default response to distress. Tools such as the Ministry of Health's Medicine Price Observatory, which promote price transparency, should be strengthened and more widely used.[68]

Despite the central role of private pharmacies, Peru's regulatory framework remains weak and poorly enforced. The Constitution enshrines free-market principles and limits state intervention in pricing, constraining efforts to curb exploitative practices. Since the 2021 introduction of Law No. 31112 establishing a merger control procedure, Indecopi has received 80 merger authorization requests, of which 66 have been approved, six have been withdrawn, four remain under evaluation, three are at the admissibility stage, and only one has been denied.[69] The Ministry of Health also faces chronic capacity constraints and high political turnover, with 18 different ministers serving between 2016 and 2025, averaging less than six months each. This instability undermines regulatory continuity and weakens enforcement. For instance, there has been little independent evaluation of recent emergency decrees or Law No. 32033 and their impact on access to generic medicines. Anecdotal evidence and comparative experience suggest that these measures may fall short in practice.[70]

To begin addressing current regulatory shortcomings—and in parallel with efforts to improve access to medications in state-run facilities—a set of short- and medium-term policy options could be considered. These may include:

1. mandating clear price disclosures and the publication of real-time data on generic availability;
2. accelerating the approval and market entry of high-quality, interchangeable generic psychotropic medications to increase competition and affordability;
3. strengthening conflict-of-interest regulations and prohibiting sales quotas for pharmacy staff;
4. restricting vertical integration between retail chains and pharmaceutical manufacturers;
5. banning virtual consultations that are directly linked to medication dispensing;
6. strictly enforcing prescription requirements for controlled medications, particularly psychotropics, and strengthening audits and supervision; and
7. enforcing existing obligations to display the INN alongside brand names, and establishing standardized substitution protocols to improve transparency and promote the rational use of medicines.

These proposals are not intended to be exhaustive or prescriptive. Instead, they reflect potential areas of intervention where reforms could contribute to greater transparency, equity, and accountability in pharmaceutical governance, while reducing systemic incentives that perpetuate overmedicalization and market-driven distortions in mental health care.

To ensure the effectiveness of such measures, regulatory authorities should also conduct regular audits, impose meaningful sanctions for noncompliance, and ensure that enforcement mechanisms are shielded from political and commercial pressure. These efforts should be supported by sustained investments in training for regulatory agency staff, digital infrastructure, and improved coordination between regulatory agencies and public health providers.

Conclusion

This paper has examined the convergence of systemic neglect, weak regulation, and market concentration in Peru's mental health care system. Despite reform efforts, chronic shortages of psychotropic medications in public facilities, combined with the underdevelopment of community-based services, have driven large segments of the population toward self-medication and dependence on private pharmacies. Within this vacuum, vertically integrated pharmacy chains have expanded their control over the supply, pricing, and even prescription of medications, often prioritizing commercial gain over public health. These dynamics expose deep regulatory and institutional gaps. In the absence of independent evaluation, transparent monitoring, and effective enforcement, recent legal reforms risk falling short and may ultimately entrench, rather than remedy, existing inequalities.

Responding to these challenges requires a structural shift in how mental health care is delivered and how pharmaceutical markets are governed. In Peru, restoring public confidence and rebalancing the influence of private pharmacy chains must begin with sustained public investment—not only to ensure the availability of affordable psychotropic medications through public channels but also to advance non-medicalized, community-based approaches to care that center user needs and reduce reliance on pharmacological treatment. At the same time, short- and medium-term regulatory reforms are needed to strengthen safeguards against conflicts of interest in prescribing and dispensing practices, promote transparency, and ensure that regulatory institutions are protected from lobbying and undue commercial influence. Further research is needed to explore how market concentration and pharmaceutical governance affect the realization of the right to mental health in Peru and comparable settings.

Ultimately, rights-based regulation involves more than legal enactments. It requires strong public institutions, independent oversight, and the political will to curb entrenched market power. Where public agencies are shaped by sustained commercial influence—whether through lobbying, conflicts of interest, or regulatory inertia—their capacity to serve the public good is systematically weakened. Building a transparent, accountable, and equitable mental health system demands both structural investment and targeted regulatory action. But neither will be effective without a clear commitment to prioritizing human rights and reorienting institutions toward their core public responsibilities.

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When Scaling Up Isn't Enough: The Impacts of Peru's Mental Health Care Reform on Adolescents

CAMILA GIANELLA MALCA

Abstract

In the last 15 years, coalitions of individuals and institutions worldwide have been calling for global policies to close the treatment gap for people living with mental disorders. This paper seeks to contribute to the literature on the effects of the diffusion of these global mental health polices by exploring their implementation and impact in Peru. Aligned with the Movement for Global Mental Health, Peru has carried out a mental health reform aimed at scaling up mental health care in public facilities. Using the human rights-based framework of availability, accessibility, acceptability, and quality, this paper examines the reform's effects on a population prioritized by global and Peruvian policies: adolescents. The analysis, based on qualitative research, illustrates how the reform's overemphasis on scaling up access to pharmaceutical treatment neglects critical issues such as health system capacity, the availability of trained human resources, the need for intercultural approaches tailored to adolescents, and information systems that adequately monitor policy impact. The analysis also highlights how a reform that promotes pharmacological treatment creates risks of abuse by private actors involved in the marketing of psychiatric medications.

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Competing interests: None declared.

Introduction

In the last 15 years, coalitions of individuals and institutions around the globe have been calling for policy reforms to close the treatment gap for people living with mental disorders. Specifically, they have been asking for mental health policies that adhere to two fundamental principles: evidence on effective treatments and the fulfillment of the human rights of people with mental disorders.[1] Although countries' adoption of such reforms are presented as positive changes aimed at improving the mental health of the population, these reforms have not been immune to criticism. Some authors have raised concerns regarding the biomedical approach adopted in policy recommendations to scale up mental health care, which could contribute to the reproduction of power asymmetries and victimization of people living with mental disorders, as well as the biomedical bias of the evidence used to inform policy development and practice.[2] Concerns have also been raised regarding forms of institutional corruption in which private actors exert an outsized influence over the design of public health policies and profit from public funds as a result of their implementation.[3]

The promotion of private interests against the public good is a risk in the design and implementation of any public policy, including global policies. Global public policies are not designed in a vacuum. They are shaped and promoted by experts from global epistemic communities, which have their own limitations, preferences, assumptions, and motivations, including profit ones.[4] Additionally, global policies are implemented in the context of varying institutional capacities to deliver the recommended services, as well as to control the potential abuse of power by private actors.

This paper aims to contribute to the debate on the adoption of global mental health policies to scale up mental health care by analyzing how Peru's recent mental health reform has impacted the treatment and experiences of adolescents in five regions of Peru. Mental health in this group (14- to 19-year-olds) has been recognized as a public health priority by the World Health Organization, which has urged governments to create adolescent-responsive health systems.[5] This urgency is reflected in the situation faced by adolescents in Peru. For example, the suicide rate among adolescents aged 12–17 is higher than among the general population (3.6 per 100,000 inhabitants and 2.2 per 100,000 inhabitants, respectively). Suicide is one of the leading causes of maternal mortality among adolescents in Peru.[6] Girls and adolescents are exposed to disproportionate rates of obstetric violence at health facilities.[7] During the COVID-19 pandemic, 1 out of 100 children and adolescents lost one parent or principal caregiver, increasing their risks of suffering sexual violence, failing or dropping out of school, and experiencing psychosocial problems.[8] Further, an estimated 62% of children and adolescents aged 5–17 in Peru experience multidimensional poverty, including 96% in rural areas and 50% in urban areas.[9] In this context, where there is a need for a health system that ensures adolescents' well-being, it is essential to analyze which institutional elements contribute to or limit the state's public policy efforts to address adolescent health, including mental health.

The analysis presented here is based on a qualitative study that triangulated three sources of information: (1) official reports and regulations issued by national authorities on mental health and adolescent pregnancy between 2013 and 2024; (2) reports and articles produced by nonstate actors, including nongovernmental organizations, multilateral actors, and academia, during the same period; and (3) 27 semi-structured interviews with health workers involved in mental health programs and with adolescent groups from five regions selected for their high rates of adolescent pregnancy relative to the national average (Amazonas, 21.1%; Ayacucho, 9.5%; Madre de Dios, 9.6%; Piura, 12%; and Ucayali, 21.1%; compared to the national rate of 8.2%). Additionally, the regions of Amazonas, Madre de Dios, and Ucayali rank among the country's top five regions with the greatest gaps in mental health care. Further, all selected regions are recognized as priority areas for exploring the intersection between mental health and adolescent pregnancy, as agreed by the Ministry of Health and civil society organizations (la Mesa de Concertación para la Lucha Contra la Pobreza).[10] The study protocol was approved by the Institutional Ethics Committee of the Pontificia Universidad Católica del Perú in Lima (approval number 573-33-20).

In presenting the empirical evidence, this paper draws on the human rights framework of availability, accessibility, acceptability, and quality (AAAQ) to analyze the outcomes of the mental health reform implemented in Peru since 2012. The AAAQ framework—developed by the United Nations Committee on Economic, Social and Cultural Rights and widely adopted by national governments and international organizations (including the World Health Organization)—provides a useful lens for organizing empirical data in line with well-established normative criteria.[11] Applying the AAAQ framework holistically, the paper aims to (1) assess the extent to which Peru's mental health reform has been implemented in accordance with human rights principles, and (2) analyze whether the diffusion of global mental health policies in the Peruvian context has allowed private actors to profit at the expense of the public interest through "institutional corruption." Peru provides an instructive case study on the limits and possibilities of public policy diffusion, given its history of adopting neoliberal reforms and its weak institutional capacity to prevent abusive practices by private actors, including substandard care, corruption, price fixing for medicines, and anti-competitive practices.[12]

It is important to note that Peru's national mental health policies are based on data from "burden of disease" reports.[13] This approach situates the mental health crisis within a biomedical model, focusing policy attention toward screening and treating individual conditions while neglecting to address social determinants of mental health.[14] Although this paper recognizes the importance of social determinants in shaping adolescent mental health, it examines the impacts of the mental health law on its own terms with respect to the health system.

The remainder of the paper is organized into four sections. The first provides background on Peru's health system and the recent mental health reform. The second section applies the AAAQ framework to examine the outcomes of the reform, focusing on how policy documents address adolescents (if at all) and on the indicators used to assess the policy impact on this group. The third section deepens the AAAQ analysis, focusing on adolescents' experiences with mental health services and drawing on qualitative findings from the study. Finally, the conclusion posits that while the mental health reform has positive aspects, without a more holistic AAAQ approach that takes into account Peru's sociocultural context and the institutional capacity within the health system, it opens the door for institutional corruption and fails to uphold adolescents' rights to mental health.

Background on Peru's health system and mental health reform

The Peruvian health system is highly fragmented and segmented, which constrains the state's capacity to deliver quality health care to all.[15] This fragmentation is reflected in both financing and service delivery.[16] Funding for the health system is complex, deriving from multiple sources (general taxation, results-based budgeting, and direct contributions) and allocated to different units (regional governments, the Ministry of Health, health facilities, and public insurers). Service provision is linked to different insurance schemes, with the government-funded Comprehensive Health Insurance (SIS) being the leading insurer in the country and the main buyer of medical supplies and health services from the private sector.[17] SIS is funded primarily through general taxation and targets those living in poverty, providing free health care for a set of prioritized health conditions. Within this structure, mental health has traditionally been neglected. Despite the high prevalence of mental health disorders, these conditions have often gone undiagnosed and undertreated at health facilities.[18] Furthermore, mental health policies have historically not been a priority. In 2011, the Ministry of Health allocated only 0.27% of its budget to mental health, 98% of which was directed to psychiatric hospitals.[19] This share increased to 1.4% in 2015 and 2.6% in 2023.[20]

Seeking to address the unmet need for mental health services, Peru enacted Law 30947 in 2019—commonly referred to as the Mental Health Law—establishing a "comprehensive legal framework to ensure the right to health and well-being through access to promotion, prevention, treatment, and rehabilitation services for mental health."[21] The law explicitly recognizes and defines the right to mental health (articles 7, 8, and 9); acknowledges the social determinants of mental health (article 5); and underscores the need for a multisectoral approach to guarantee the enjoyment of mental health, including the integration of mental health services into the general health care system and the promotion of community-based care (articles 2 and 19). Law 30947 explicitly states that the approach adopted for mental health care is based on human rights and on community and intercultural approaches (article 1).[22]

Law 30947 marks a milestone in the ongoing process of mental health reform in Peru, which began in 2012, and it incorporates two key features: (1) a focus on expanding access to mental health care within public health facilities and (2) the adoption of human rights language. In this respect, the Peruvian mental health reform aligns with the Caracas Declaration on mental health and human rights, as well as the aims of the Movement for Global Mental Health.[23] Its main goal is to scale up coverage of mental health services and treatments through primary care.

Budgetary efforts have accompanied the mental health reform. In 2012, SIS approved financial coverage for psychiatric consultations, treatment (including medication), and rehabilitation procedures such as individual, group, and family therapy.[24] Additionally, in 2015, the Results-Based Budget Programme 0131, titled "Control and Prevention of Mental Health," was established, providing financial resources to strengthen mental health services nationwide. Results-based budget programs (known as PpR programs), introduced in 2007 as part of the fiscal reform led by the Ministry of Economy and Finance, are a performance-based budgeting tool intended to improve the health system's capacity to respond to health problems.[25] This tool ensures continued program funding as long as specific goals and indicators are met. By 2024, the 12 health-related PpR programs represented 40% of the total health budget.[26]

In addition to financial measures, Peru has developed regulations adopting a human rights approach to mental health. For example, in 2015, Regulation 29889 established that mental health care provided at public health facilities must adhere to the principles of respect for human rights and the dignity of individuals, incorporate intercultural and community-based approaches, and aim to eradicate discrimination and stigmatization of people with mental health problems. The regulation also guarantees the right to access mental health care.[27]

To date, most of the research conducted on Peru's mental health reform has focused on its impact on coverage indicators, including the expansion of mental health services and the number of people receiving pharmacological treatment.[28] Less attention has been given to assessing the extent to which the reform guarantees the enjoyment of the right to mental health, especially for marginalized populations such as adolescents.

Impacts of the mental health reform on policies and adolescent health

The AAAQ framework

The AAAQ framework offers a useful lens for examining the Peruvian mental health reform.[29] The first pillar of this framework, *availability*, requires that health care facilities, goods, and services be continuously available. Availability requires a sufficient number of functioning health facilities equipped to receive adolescents with mental health issues; sufficient numbers of trained medical professionals available to diagnose and treat mental health conditions; and a sufficient supply of appropriate commodities, including pharmaceuticals. This includes the capacity of institutions to provide adequate follow-up to screened patients.

The second pillar, *accessibility*, includes four components as defined under international law: physical accessibility, economic accessibility, information accessibility, and accessibility on a nondiscriminatory basis. All of these factors are relevant to mental health care for adolescents.

1. Diagnosis and care should be universally accessible within a safe or reasonable physical distance, including for people in rural areas.
2. Economic accessibility is critical given that chronic diseases can generate catastrophic expenses for families.
3. Information accessibility is critical because it ensures that individuals have the opportunity to explore treatment options and understand the potential long-term side effects of pharmaceutical interventions.
4. With respect to nondiscrimination, mental health services must be available on an equal basis with physical health services and made accessible to adolescents as well as adults.

Acceptability requires culturally appropriate and medically acceptable care, which calls for respecting the dignity of patients. In particular, this includes respecting the right to confidentiality—meaning that those seeking treatment for mental health issues feel that information regarding their health status, information related to pregnancy, and any other sensitive information will be kept private.

Finally, *quality of care* calls for skilled personnel who are well-equipped to treat adolescents with mental health issues, together with appropriate medications and other health goods that are safe and effective.

These four elements of the AAAQ framework should be understood as interrelated; for example, barriers to geographic and economic accessibility of care in the medical system may be linked to inappropriate standards of quality and acceptability of care, such as the prescription of pharmaceuticals with little follow-up.

Applying AAAQ to the mental health reform

The Mental Health Law proposed adopting and scaling up a community-based mental health care model. This model represents a distinct approach to organizing mental health services, whereby health is acknowledged as a social good shaped by relationships within the family and community, rather than merely a biomedical issue.[30] It also seeks to guarantee respect for the dignity of people with mental health conditions or disabilities by establishing a legal regime of comprehensive protection and care that supports continuity of care, psychosocial rehabilitation, and social reintegration.

The community mental health care model was crystallized through the creation of public community mental health centers (CMHCs). By early 2025, the Ministry of Health reported 255 CMHCs nationwide. In terms of availability, one major constraint is the limited number of facilities. Under a territorial approach, each CMHC is expected to serve 100,000 people.[31] However, this approach has not closed the gap in mental health care. It is estimated that seven out of ten people with mental health problems still do not receive the services they need.[32] This could be due to various factors, including geographical barriers (since most CMHCs are located in urban areas) and limitations related to facility capacity (such as opening hours and number of personnel).

Furthermore, the mere existence of a health facility does not guarantee that it has the material and human resources necessary to serve the population under its coverage, which is required to meet the standard of "availability." Currently, the minister of health is proposing one CMHC for every 50,000 people.[33] Although the reform has led to an increase in human resources, such as psychologists working at public health facilities, it remains unclear whether there are enough professionals to meet the required profiles in each CMHC; this is due to shortages of mental health professionals, high turnover, and dissatisfaction with working conditions.[34] According to the regulations, each CMHC requires a psychiatrist, preferably with training in child psychiatry, as well as a psychiatrist or general practitioner with training in community or family medicine, and a psychiatrist with expertise in addiction.[35] The Ministry of Health acknowledges a shortage of these professionals. Each CMHC should also have at least eight psychologists, with expertise in children and adolescents, addiction, and psychotherapy. However, the ministry reports a shortage of 350 psychologists across CMHCs, and many of those working in these facilities do not have training in psychotherapy (i.e., they do not meet the profile). Furthermore, some primary care health facilities lack psychologists, which means that the referral system from non-specialized health facilities to CMHCs cannot be guaranteed.

In the case of adolescents, there are few mental health specialists in Peru who are trained to work with adolescents. As of 2025, the Ministry of Health reports only nine psychiatrists specialized in child and adolescent care nationwide—one based in a CMHC in the region of Tacna and the other eight based in hospitals in Lima.

This lack of specialists trained to work with adolescents raises questions regarding the availability, accessibility, and quality of care for this population. In terms of policies, most policy documents do not include specific interventions targeting this group, and they often group adolescents together with children and other adults. The overemphasis on general coverage ignores the need for targeted interventions for marginalized populations and the barriers that specific groups, such as adolescents, face in accessing care.[36]

In terms of the acceptability of care, as documented in other health policies, and despite the existence of an intercultural health policy (Supreme Decree 016-2016-SA), mental health services lack an intercultural approach.[37] The services offered are the same nationwide, and there is no analysis of the cultural relevance of the interventions and service packages offered.

Another critical issue is accessibility. Although CMHCs are described as a tool to bring mental health services closer to the community, their services are specialized. Individuals with moderate or severe conditions are expected to arrive after being referred from a primary health care facility.[38] Yet reports from the Ministry of Health show that people are not routinely screened for mental health problems in primary health facilities, which casts doubt on the viability of the model for early detection and referral.[39] For example, data on follow-up care after suicide attempts show the weakness of the health system in referring and following up on cases: in 2023, 87.32% of the reported cases did not receive follow-up within the recommended three-month period.[40]

Furthermore, despite adolescents being a prioritized group, significant gaps exist in the data collected by the Ministry of Health, which hinders the government's ability to assess the impact of mental health interventions on adolescents, the adequacy of these interventions, and the quality of care provided.

The emphasis on the economic burden of mental health conditions in Peru has produced some unintended effects. One such effect is the lack of data on prioritized and vulnerable groups, such as adolescents. National reports on the economic burden of disease do not provide data specific to adolescents' mental health, instead grouping information into the age ranges 5–14 and 15–49.[41] Adolescents aged 14 years and above are part of the economically active population in Peru. The statistics on the economic burden of disease focus on reporting the impact of mental health and other health conditions on the population's capacity to "produce." As a consequence, they fail to provide detailed information on the impact of the disease across population groups, such as adolescents aged 15–19.[42]

Beyond the narrow approach of the burden-of-disease reports, another critical weakness of the Peruvian health system is the fragmentation of databases and the absence of information systems to monitor the outcomes of health policies.[43] Peru's mental health reform has not addressed this problem. For example, different databases use different age ranges to define adolescents. Some official statistics (such as those on suicide rates) define adolescents as those individuals aged 12–17, while others (such as those on adolescent pregnancy) classify adolescents as those individuals aged 15–19.

Similarly, key goals of Budgetary Program 0131 (for example, screening for family violence and mental and behavioral disorders) group data into minors (up to 17 years of age) and adults (18 years of age and older).[44] Reports from the government body responsible for youth, the National Youth Secretariat, include aggregate data on young people aged 15–29.[45]

This lack of disaggregated data, which is a critical component of information accessibility, makes it impossible to follow the number of adolescents who are under psychiatric care treatment, the length of time they are under this type of treatment, and their adherence to such treatment.

The accessibility of information is important not only for patients on an individual basis but also for the transparency and integrity of the mental health system as a whole. Between 2017 and 2021, the Ministry of Health conducted nine corporate purchases, resulting in 5,930 contracts to provide the country with psychotropic medications, valued at US$12.7 million. Although 61 companies held sanitary registrations to market these products, only 14 companies won these contracts. In addition, 3,831 contracts (64% of the total), valued at US$9.1 million, were awarded without competitive bidding.[46] These purchases, which benefited a small group of companies, were made through a reverse auction mechanism designed, in principle, to allow the state to secure the lowest price; however, there is no evidence that lower prices were obtained. In some cases, a single company submitted the only bid for a product at a price that was three or four times higher than the government's forecast.[47] This dynamic of institutional corruption reveals the inability of the state to control private actors when it comes to the purchase of critical supplies in a highly concentrated market, such as the market for psychotropic drugs. Notably, the country's mental health reform, which promotes universal access to psychotropic medications, has not been accompanied by policy recommendations to prevent concentration in the drug market or to prevent private suppliers from abusing drug prices.

Despite the rise in public purchases of psychotropic medications, the supply system is irregular, and it is common for CMHCs to face drug shortages, creating barriers to treatment.[48] This is a serious problem because people taking psychotropic medication cannot risk interrupting their treatment, often leaving them with no choice but to purchase the drugs from private retailers. Peru has comparatively high out-of-pocket health expenditures relative to other countries in the region with similar income levels, and such expenditures have continued to rise, with medicines representing a significant share.[49] Among these, psychotropic medications are a primary source of out-of-pocket expenditures at private retailers.[50]

The lack of regulations allows private pharmacies to prioritize the sale of imported medications over those produced nationally, and of branded generics over generic ones, thereby increasing the cost of the purchased drugs.[51] This is not insignificant: in Peru, it is estimated that paying for a one-month course of treatment with brand-name innovative psychiatric drugs represents approximately 11.85 working days, compared to 11.4 working days for brand-name generics and 5.53 working days for generics with the International Common Denomination.[52]

This section's analysis highlights the challenges of implementing an ambitious mental health reform in a setting characterized by weak institutional capacity. There are not enough health workers to deliver the model adopted by the reform, which undercuts availability, accessibility, and quality of care. Further, deregulation and a lack of transparent data have enabled abuse by private actors, particularly in drug procurement. These structural conditions expose people to the risks of over-medicalization, negative impacts on their health due to a lack of treatment, and out-of-pocket expenses. They also foster institutional corruption by contributing to the abuse of power by private actors, such as the pharmaceutical industry and private pharmacies.

More broadly, the scaling-up approach embedded in the law reform follows a neoliberal understanding of health, which reduces policy indicators to a report of the number of services provided. Under this approach, health is framed as a private good, and the focus of the public health system is on offering cost-effective basic packages in which psychotropic drugs are a first-line therapy.[53] This results in an emphasis on the product provided and the coverage reached, instead of on the impact on people, which makes it difficult to evaluate the quality of the services. The overemphasis on general coverage ignores the need for targeted interventions and neglects the barriers that specific groups, such as adolescents, face in accessing care.[54] This lack of quality and outcome indicators is not exclusive to mental health interventions—on the whole, Peruvian health information is not standardized, and the poor integration of personal health data across health care settings makes it challenging to measure activities, care quality, and outcomes.

Listening to adolescents: Experiences with the services

The semi-structured interviews conducted for this study offer an additional layer of insight into adolescents' experiences with mental health services. Interviewees noted that the limited availability of health facilities and health professionals creates a barrier to accessing mental health care, and emphasized that long wait times are closely tied to the poor quality of public health services. The experiences recounted by adolescents also show a lack of trained health personnel to guarantee adolescents' right to autonomy, which creates barriers to accessing to sexual and reproductive care and mental health care. In the case of mental health services, a critical concern among respondents was adolescents' lack of trust in health care workers to maintain confidentiality, a key component of quality care. Interviewees reported that adolescents perceive public health services as insecure spaces, which forces them to seek care in private clinics and pharmacies, in turn leading to greater out-of-pocket expenses. As recounted by one adolescent:

> *We may have advised her to go to a psychologist, but she was afraid that the psychologist, upon finding out, might tell her parents, and the problem would become bigger.* (group interview with adolescents, City 5, May 27, 2025)

This distrust is further reinforced by adolescents' lack of autonomy in accessing health services. Although national regulations allow minors to access health services, health workers often interpret this as applying only to sexual and reproductive health services.[55] Thus, mental health facilities frequently require adolescents to attend consultations with an adult, which can place them at risk of violence and limits the possibility of having a safe space where they can be heard. One interviewee explained:

> *When making an appointment for a consultation at the mental health center, minors must be accompanied by their guardian. Still, at the time of the talk where the psychologist talks with you, I think you should be alone because some teenagers are afraid to talk about things they do not want their parents to know and that is why they should go alone so as not to feel any discomfort and be able to say everything.* (group interview with adolescents, City 3, April 15, 2025)

Health workers recognize major weaknesses in health services that obstruct adolescents' access to mental health care. Among the main factors affecting service availability are the physical limitations of health facilities, the lack of human resources, and the fear of mistreatment. Interviewees described problems with the infrastructure (lack of space), as well as a lack of resources to adapt CMHCs to adolescents' needs and to ensure quality care. For example, they pointed to health workers who are not trained to work with adolescents, operating hours that do not align with adolescents' schedules, excessive workloads among personnel, and long wait times. One health worker explained:

> *Now, another issue could be access, accessibility, or a slight difficulty in obtaining consultations. Sometimes, there is a bit of desertion because I am the only child and adolescent psychologist here. There are only four of us psychologists so that the agenda can be very full at times, and they have to wait 15 days, sometimes a little more, for attention. This can sometimes be a barrier. (interview 13, health worker, City 4, May 21, 2025)*

The lack of human resources poses a serious barrier to guaranteeing adolescents' access to quality and adequate mental health care. Moreover, indicators are overly focused on the number of visits provided, which obscures problems in the ability to access continuous treatment. This can ultimately lead adolescents who need care to abandon treatment, as demonstrated by the quote above.

As suggested earlier, a critical factor—one not often mentioned as a barrier to accessibility—is the practice of requiring the presence of an adult during consultations. For health workers, this is a nonnegotiable point, though their justifications vary, suggesting that the rule is enforced more out of habit than careful reasoning. There is little reflection on its impact on care. In the interviews, health workers justified this practice on administrative grounds (for example, an adult must sign the care sheet, such as the *formato único de atención*), but also, as the following quote shows, based on a conception of mental health that holds parents responsible for the mental health problems their children may be experiencing. Parents are seen as needing to be sensitized, and this is typically expected to occur during the same consultation:

> ***Interviewer***: *And is it necessary for an adolescent or an adolescent seeking health, mental health care, to be accompanied by an adult, his or her mother, or someone, or not?*
>
> ***Health worker***: *For me, yes … But now I think a rule has come out that the adolescent can come alone, but, for me, yes, because there are kids who don't even know what is going on with their mental health or with their life, so, and a little bit also to sensitize the mother. Why? Because the mother is: "Well, you have to do something at home," they start bombarding the adolescent, "You have to do something, well, you have to do something. You are going to have children, you have to do something." The adolescent feels bad. So it is a little sensitizing. Something will help, something will help, that at least the mother will think that she should not act like that with her daughter, that suddenly she has to be a little more understanding, right? So and so on. I think, I think it is like that.* (interview 2, health worker, City 2, April 11, 2025)

The practice of requiring parents to be present during consultations is deeply ingrained, even though it puts victims of sexual violence—a population that should be prioritized and protected by the health system—at risk. Although health personnel recognize these risks, they do not question the practice and continue to apply it. In addition, the absence of quality indicators and spaces for discussion on how to adapt services to this population's needs allows these practices to continue. One health worker illustrated the challenges created by this situation:

> *For example, one of the barriers, in the case of violence, is that, for example, when a child, and this is still happening, when a child denounces his parents for physical or psychological abuse, the parents are the ones who have the obligation to take the child, regardless of whether your child has denounced you, so the parents do not take them. They take you, already, because there is a court order from the Prosecutor's Office and from there. So it is not so much that the children do not want to come, but that the parents tell them: "Oh, you are going to go there? Surely it is because you want them to take me to jail." Or there are mothers who denounce their partners for abuse and the children were involved, but then the mother resumes her relationship with the partner, so, therefore, the mother abandons the treatment [for the children] so that the case is filed.* (interview 12, health worker, City 4, May 21, 2025)

In general, the interviews reveal a lack of critical evaluation of the mental health program's adaptability for Indigenous and rural communities, as well as for adolescents in general. As described earlier, the distribution of CMHCs is based on a territorial approach.[56] However, geographic accessibility barriers continue to compromise the ability to ensure quality treatment. This situation is especially evident in rural and remote areas, where health personnel often cannot travel regularly due to limited budgets. In these cases, although health workers and health authorities acknowledge that geographical and economic barriers exist for workers and service users, there is little questioning of whether the current model of care is truly the most suitable for rural populations.

This study found no reflection among the health workers interviewed on the need for an intercultural approach. "Culture" is reduced to a set of beliefs and framed as a barrier for the population, without consideration of other possible approaches to mental health beyond the biomedical model.

This restrictive view of culture was aptly illustrated by one health worker:

> *The issue of accessibility is that there are adolescents who come from very remote areas, making it difficult for them to attend the center. Another reason is that each district has its own beliefs, which sometimes do not believe in psychology, making it still taboo for them, isn't it? They believe in the shaman, in some districts here in Chachapoyas. (interview 7, health worker, City 5, May 27, 2025)*

In summary, the interviews show that the focus on coverage and the absence of quality indicators have enabled the delivery of mental health services that do not adhere to a holistic understanding of human rights principles (namely, the AAAQ framework) in practice. Interviewees identified challenges in the availability, accessibility, acceptability, and quality of mental health services. Coverage indicators used in the abstract are not sensitive to these problems, nor to situations where—due to the organization of services and requirements for adult accompaniment or authorization—the health of adolescents may be put at risk. These factors take on heightened relevance in the case of adolescents living in rural and remote areas, Indigenous adolescents, and adolescents who are victims of sexual abuse.

Conclusion

By zooming in on adolescents' access to mental health care, this paper has sought to illustrate how global mental health policies focused on scaling up mental health coverage are implemented in a context such as Peru. As a country with an underfunded and fragmented health system, Peru presents a context in which for-profit private actors, such as pharmaceutical and medical supply providers, have undermined the public interest by taking advantage of public resources. This case study shows that global mental health policies adopted uncritically by countries with weak institutional capacity can foster institutional corruption that benefits private interests while undermining the human rights of vulnerable populations, such as adolescents.

The analysis using the AAAQ framework demonstrates that the efforts undertaken by the Peruvian government, in collaboration with health professionals, to enhance mental health services in recent years have had some positive effects: increased financial and human resources for public mental health services, as well as the creation of specialized centers at the primary health care level. However, these advancements have not been sufficient in terms of providing the mental health care required by vulnerable groups such as adolescents. This is due to several institutional factors, including the persistent shortage (despite some progress) of material and trained human resources, inadequate health information systems, and administrative barriers generated by health workers that prevent adolescents from accessing health care. Furthermore, the lack of resources inhibits the effective implementation of the proposed model: the shortage of health professionals, supplies, and medications puts the health of people with mental illnesses at risk.

Further, the focus on quantitative coverage indicators ignores the importance of qualitative indicators. Although adolescents are a target population for screening and treatment, they face barriers to accessing health facilities on their own, which can sometimes put them at risk of (further) violence. There is also no information system to assess the impact of services on people's health outcomes.

The analysis also shows that although the mental health model adopted in Peru relies heavily on the provision of drugs that must be administered continuously—and despite knowledge of cases of anti-competitive behavior, such as the price fixing of medications—the country's mental health reform has not included efforts to strengthen the state's capacity to purchase medicines or to ensure that it is not dependent on a handful of suppliers. The data reveal abusive behavior by psychiatric drug suppliers and the failure of policies that attempt to lower drug purchase prices.

The Peruvian case highlights the limitations of a mental health reform that, despite embracing human rights principles in theory, adopts a global scaling-up approach grounded predominantly in a biomedical model. This approach prioritizes individual treatments and overlooks the social, economic, and cultural context, contradicting the World Health Organization's recommendation that mental health policy "address a wide range of topics, with a central focus on establishing a comprehensive network of services both within and beyond the health sector."[57] The World Health Organization has also stressed the need to recognize that biomedical approaches, such as the one adopted by Peru in its mental health reform, place too much focus on diagnosis, medication, and symptom reduction while overlooking the social and structural determinants of mental health and individuals' rights to inclusion and social protection.

Funding

The research project "Identifying Policy Implementation Gaps to Address the Intersecting Burdens of Mental Health Problems and Adolescent Pregnancy in Peru", was funded by IDRC (Project ID 110534, Global Health Program).

Acknowledgments

I am most grateful to Alicia Ely Yamin for her insights and suggestions which helped strengthen this paper.

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South Africa's Life Esidimeni Disaster and the Institutional Corruption That Opened the Door to It

SASHA STEVENSON

Abstract

In mid-2015, the Gauteng Department of Health in South Africa canceled a contract with Life Esidimeni, a subsidiary of a large hospital group that ran four facilities housing almost 2,000 people with mental illnesses. The termination of the contract and the chaotic transfers of people that followed resulted in enormous suffering and 144 deaths. Mental health care users died in conditions of neglect—emaciated, dehydrated, unmedicated, and with bedsores and gangrene. Their rights to health care services, to dignity, and to life were violated. The Life Esidimeni disaster occurred within the context of institutional corruption: a systemic and strategic influence that undermines an institution's effectiveness by weakening both its ability to achieve its purpose and the public's trust in it. Considering the institutional corruption that was the context for the Life Esidimeni disaster—including the overlap of political and administrative functions and the drive to save money, disguised as a desire for deinstitutionalization—this paper examines the public and legal processes undertaken to expose the disaster, to secure accountability, and to begin to deconstruct the conditions that allowed one of South Africa's most shameful human rights violations of the democratic era.

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Competing interests: None declared.

Introduction

South Africa's 30 years of democracy have seen impressive progress in improving lives, and devastating illustrations of a government whose institutions have been corrupted, causing huge suffering and human rights violations. The Marikana massacre of 2012 saw 34 protesting miners killed by the South African Police Service to protect the interests of a platinum mining company. The Stilfontein disaster in 2024 saw men being trapped underground and starving, in some cases to death, in the government's attempt to stop mining in abandoned mines near Johannesburg.

Life Esidimeni, despite its name meaning "place of dignity," will always be remembered for the deaths of 144 mental health care users. They died in circumstances of severe neglect—emaciated, dehydrated, unmedicated, and with bedsores and gangrene. Many mental health care users died alone, their families not having been informed of their move out of Life Esidimeni and into so-called nongovernmental organizations (NGOs) that were incapable of caring for them.

The widescale violation of the rights of mental health care users occurred despite South Africa's human rights framework—a legal shift from its apartheid past to one of the world's most progressive constitutions, protecting civil and political as well as socioeconomic rights. South Africa's ratification of the African Charter on Human and Peoples' Rights in 1996 and the Convention on the Rights of Persons with Disabilities in 2008 indicated its intention to align with global rights protections—an intention that was far from met in this case.

The disaster must be seen as a large-scale human rights violation within the context of institutional corruption: caused by inappropriate political involvement in the administration of health and the drive for cost-saving, disguised as deinstitutionalization.

While the institutional context in no way removes individual liability for the deaths, it did open the door to the violation of the human rights of particularly vulnerable people who were unable to speak for themselves. And this requires attention to protect the many people whose health and lives are in the hands of an institutionally corrupt state department.

The Life Esidimeni disaster

In October 2015, the Gauteng Department of Health notified Life Esidimeni (a private provider of chronic mental health care services) of its intention to terminate the contract between the parties, giving the contractually required six months' notice. People at Life Esidimeni had been diagnosed with a range of mental illnesses, intellectual disabilities, and sometimes also physical conditions. Diagnoses included schizophrenia, schizoaffective disorder, traumatic brain injury with cognitive impairment, severe intellectual disability, cerebral palsy, and bipolar mood disorder, among others. Around 1,700 mental health care users lived at one of the Life Esidimeni facilities at the time of the contract termination.[1]

As early as June 2015, concerns about plans to reduce the number of beds at Life Esidimeni by 200 each year (not, at that stage, to cancel the contract altogether) had been raised by the South African Society of Psychiatrists (SASOP). SASOP had argued that there were insufficient alternative options for the mental health care users at Life Esidimeni and warned of a "revolving door" of care, in which users who had been stable at Life Esidimeni would relapse and would need to be re-hospitalized in acute psychiatric units and specialized hospitals. SASOP also cautioned about longer stays in hospitals for mental health users without step-down facilities and warned further of a cycle of homelessness and incarceration.[2]

What SASOP did not know, until the termination of the contract was made public, was that the government intended not merely to reduce beds but to move all mental health care users out of Life Esidimeni facilities within just six months.

Once the full shut-down plan became known, these concerns and objections were echoed by others. The clinical heads of Gauteng's psychiatric hospitals wrote a warning to the head of the Gauteng Department of Health and its director of mental health, stating that they had grave concerns because most of the mental health care users in Life Esidimeni, who had previously been transferred from the psychiatric hospitals they led into Life Esidimeni, would not be fit to be discharged within the next six months; existing community-based care facilities were full; and promised renovations to hospital wards to accommodate further mental health care users would take several years.[3]

Families of mental health care users, the South African Depression and Anxiety Group, and the South African Federation for Mental Health, working with SECTION27 as their lawyers, all raised concerns. When multiple meetings produced no results, the concerned parties litigated against the Gauteng Department of Health, asking for the appointment of curators *ad litem* to protect the interests of the mental health care users. The department refused to consent to this appointment, but the case was settled out of court, where the department agreed, among others, to consult with families about the move of mental health care users and to endeavor to ensure that Life Esidimeni residents would, at new facilities, receive health and other services of no lesser quality than the services rendered at Life Esidimeni.

Between January and March 2016, a series of meetings was held between the department and stakeholders. The department still failed to disclose any plans or budgets for the move, appeared not to be assessing mental health users or NGOs, and quoted different numbers of users at each meeting.

In March 2016, at one of these meetings, it emerged that the department intended to move 54 people from Life Esidimeni to Takalani Home. Takalani Home was classified in the department's own documents as a facility for children with severe or profound intellectual disabilities. None of the people that the department intended to move to Takalani Home was a child, and the mental health care users had a variety of mental illnesses, including dementia and schizophrenia.

The families and their allies launched a second court action, aimed at stopping the move to Takalani Home and securing access to the information that the health department had been withholding throughout months of meetings.[4]

The department argued that Takalani Home was no longer a facility for children only and that all people who were being moved had been assessed and no longer needed mental health care. They would have been sent home but they did not have families. The court could not have known, as became evident later, that most of these statements were false. It ruled in favor of the Gauteng health department.[5]

Following the court decision, the department increased the pace of the project to remove everyone from Life Esidimeni and, by June 2016, had moved 1,711 people out of the facilities.[6] Most families were not contacted prior to the moves, and many had to scramble for days or even weeks to find the new locations of users by calling or visiting multiple NGOs across the province.[7]

Most of the NGOs had been recently established or, like Takalani Home, had recently undergone a change in scope. Many of the licenses issued by the health department to NGOs reflected inaccurate information, and most NGOs were not suitable for mental health care users. There were shortages of beds, food, and staff; a lack of security; and no ability to dispense medicines, twinned with difficulties accessing medicines from clinics. It was a cold winter, and the NGOs did not have sufficient heating or blankets.[8]

The member of the executive council (MEC) for health, Qedani Mahlangu, was deeply involved with the implementation of the project, despite her role as a political head and non-expert (she had qualifications in education and finance). She was the one who made the decision to terminate the contract and, later, to extend the notice period from six to nine months.[9] She chaired project meetings every two weeks and issued instructions.[10] She set deadlines and received reports on progress. The director of mental health in the Gauteng Department of Health, Makgabo Manamela, was not meant to be managing the project (she was assigned as deputy project manager), but in effect she managed the process. She was also involved in the moves, visiting NGOs and moving beds to increase the number of mental health care users who could be accommodated in each place.[11] She used the threat of the MEC's instructions to secure compliance by health department staff—a threat that was effective given that many officials were intimidated by and unwilling to stand up to the MEC.[12] The MEC prided herself on demanding that people in her department "do their jobs." This ordinarily welcome accountability stance, so lacking in many government departments in the country, resulted not in excellence but in muted compliance and fear. Manamela, a psychiatric nurse by training, failed to exercise her professional expertise to guide the implementation of the project or to advocate for extended time frames that could have rendered it safer.

There were three primary reasons given for moving mental health care users out of Life Esidimeni: the need to reduce costs; the problem with renewing a contract many times over many years; and the imperative to deinstitutionalize mental health care users.[13]

Leadership and officials within the Gauteng Department of Health were informed of the problems with both the conception and the implementation of the project but failed to take any action to protect the mental health care users.

Part of the reason for the poor conditions in NGOs, it turned out, was that the department did not have the required contracts with these institutions before moving people into them. Without these contracts, the department was unable to pay the NGOs. As a result, NGOs experienced delays of several months before they received state funding. Because many of the NGOs were new and did not have financial reserves, this delay in funding meant that NGO owners had to secure personal loans to enable their institutions to feed mental health care users.[14] NGO owners testified to being coerced to accept more users than they could handle, or people with comorbidities that they were unable to manage.

Almost immediately, mental health care users started to die. Deborah Phehla died within three days of being moved into Takalani Home. She died due to aspiration of blood from a perforated larynx, caused when she swallowed paper, cardboard, and plastic that was stored in the room she stayed in. Her periodical report from Life Esidimeni had noted that if not properly supervised, Phehla would eat rubbish.[15]

Over the following months, 144 people died. The causes of death included severe malnutrition, dehydration and gangrene, asphyxia due to aspiration of blood or food, and pneumonia.[16] While not all deaths were recorded as unnatural, what is clear is that mental health care users died in conditions of severe neglect. There was insufficient food, dehydration, cold and cramped conditions, and, in some cases, a lack of medication, poor access to physical health care services, and little or no access to mental health care services. Many mental health care users died without having seen their families, who did not know where they had been taken. Groups of friends from Life Esidimeni were separated. The "caregivers" being paid for their care often lacked the expertise and experience to meet the needs of the mental health care users. Moreover, in many cases, medical files had been lost in transit, meaning that even qualified caregivers would not have known what the users' specific needs were.[17]

It took many deaths for health authorities to start taking the pleas of families and the demands of activists seriously. After the MEC responded to a question in the provincial legislature on September 13, 2016, stating that 36 mental health care users had died (while underplaying the seriousness of her admission), the minister of health and others requested an investigation by the Health Ombud.[18]

The Health Ombud's investigation lasted less than six months. In February 2017, he announced that he had established that there had been 94 deaths of mental health care users and that he suspected more.[19] The Health Ombud's investigation had precipitated action by the minister of health, including the relocation of some mental health care users from particularly dangerous NGOs. Nonetheless, the investigation report included recommendations for securing the safety of surviving mental health care users, accountability for those responsible, redress for the rights violations experienced, and reform to the mental health care system to prevent recurrence.[20]

The years that followed have seen various processes designed to better understand what happened and why, and to seek justice for the victims of the Life Esidimeni disaster.

The first process was an arbitration. The arbitration agreement noted that the government did not dispute its liability for the deaths, nor did it dispute that the Life Esidimeni deaths were not natural, despite being recorded as such on death certificates. The agreement provided for the ordering of equitable relief by an arbitrator, who was to be appointed by agreement between the parties.[21]

The arbitration was held over the course of 43 days, with an additional two days of legal argument. Sixty witnesses gave evidence, including 12 senior state officials, five middle-management government employees, one senior police officer, the managing director of Life Esidimeni, three NGO owners and managers, six expert witnesses, and 31 affected family members. Former deputy chief justice Dikgang Moseneke was appointed as the arbitrator. Justice Moseneke found that the mental health care users and their families had suffered violations of their human rights, and he issued an award that included requirements for formal apologies, the development of a mental health service recovery plan, and the payment of damages, including constitutional damages.[22] Notably, little of the mental health service recovery plan has been implemented to date.

Despite an earlier attempt to secure a police investigation, it was only during the arbitration that the police started investigating in earnest. After more than a year of investigation and consideration of prosecution by the National Prosecuting Authority, a decision was made in 2019 not to prosecute but instead to refer the matter for an inquest.[23]

A judicial inquest was held over 130 court days from July 2021 until November 2023. All current and former government officials were legally represented in the inquest at the state's expense. Most NGO owners and managers were represented by Legal Aid South Africa, also at the state's expense. By contrast, 44 families of mental health care users were represented by SECTION27, a public interest law center funded through philanthropy, while four families were represented by AfriForum.

Judge Mmonoa Teffo of the Gauteng High Court in Pretoria found that the deaths of nine of the mental health care users were unnatural and were caused by the negligent conduct of Gauteng health officials Mahlangu and Manamela.[24] Judge Teffo's finding opened the possibility of prosecution by the National Prosecuting Authority. At the time of writing, the National Prosecuting Authority had not made a decision on prosecution.

In addition to compensation through the arbitration and attempts at criminal accountability through the inquest, each of the health care workers in positions of leadership within the Gauteng Department of Health were referred to their professional bodies for professional sanction. To date, no such sanctions have been issued.

Human rights violations

In the first paragraph of the Life Esidimeni arbitration award, Justice Moseneke describes the award as "a harrowing account of the death, torture and disappearance of utterly vulnerable mental health care users in the care of an admittedly delinquent provincial government."[25]

The human rights violations in the case were extensive and contrary to South Africa's international, regional, and domestic legal undertakings.[26]

The South African Constitution protects everyone's inherent human dignity, right to life, freedom and security of the person, and right not to be tortured or treated in a cruel, inhuman, or degrading way.[27]

The NGOs to which mental health care users were transferred were "treacherous" and were "properly dubbed death traps or sites of torture."[28] Food was insufficient or of bad quality, water was not provided to one mental health care user for fear that he would urinate on himself, medication was unavailable, security was inadequate, and NGOs were overcrowded and sometimes dirty.[29] The inadequacy of the subsidies paid to NGOs and the absence of other available funding to support the care of the mental health care users was a significant cause of these poor conditions. As described above, most NGOs received their first payments only weeks or months after they received mental health care users, due to problems with their service-level agreements. That people, but not money, could be transferred to NGOs where the terms of their care were yet to be agreed in writing is telling of the priorities of the Gauteng Department of Health.

The human rights violations suffered by the mental health care users who were moved out of Life Esidimeni included violations of their rights to life, to dignity, and to freedom and security of the person.

Mental health care users also suffered violations of their rights under section 27 of the Constitution, regarding access to health care services.

Justice Moseneke described, from evidence before the arbitration, the chaotic process of the moves of mental health care users out of Life Esidimeni, including the fact that individuals were not assessed by the multidisciplinary teams that ought to have been involved in the project, meaning that their individual needs were not taken into account. They were moved "without useful or any medical records; without access to clinical and other medical care and without access to appropriate or prescribed medication."[30]

He noted the inconsistency between South Africa's legal obligations and their implementation, finding that

> *since 1994 our State has erected a globally admirable and compliant regulatory regime for the care of mental health care users. Its provisions are by and large in sync with international human rights and mental health care norms of a very high order. But what stands out is the breadth and depth and frequency of the arrogant and deeply disgraceful disregard of constitutional obligations, other law, mental health care norms and ethics by an organ of state, its leaders and employees.*[31]

While Justice Moseneke did not address the right to health in as much detail as the other rights violations, he nonetheless included it in his reasoning for the award of constitutional damages—one of the first such awards in South Africa's constitutional democratic era.

It is difficult to imagine a more egregious example of the violation of the right to health than the Life Esidimeni disaster. This was a clear case of retrogression: the unlawful reduction in rights realization. Mental health care users who had received appropriate care at Life Esidimeni had such care removed, with terrible consequences.

This occurred in spite of the constitutional and international principle against deliberately retrogressive measures without careful consideration and justification by reference to the totality of the rights and the resources available.[32]

In the context of limited resources and inadequate provision of health care services to many people in the country, the mental health care users at Life Esidimeni were receiving the mental and physical health care that they required. That these services were taken away, to be replaced with conditions likened to torture, is a clear violation of their right to health.

The Life Esidimeni disaster in the context of institutional corruption

While there can be little doubt that individuals within the Gauteng Department of Health should be held personally criminally liable for their role in the Life Esidimeni disaster, the disaster took place in a particular institutional context, some of which was in fact fostered by the individuals concerned. This institutional context is one of institutional corruption.

The original definition of institutional corruption comes from Lawrence Lessig, who finds that "institutional corruption is manifest where there is a systemic and strategic influence which is legal, or even currently ethical, that undermines the institution's effectiveness by diverting it from its purpose or weakening its ability to achieve its purpose."[33] A classic example of institutional corruption is the complex problem of political campaign funding. While funding is required, it can create conflicts of interest that erode the functioning of a political actor and the trust of their supporters.

Dennis Thompson describes institutional corruption as being equivocal (the corruption may benefit the institution while undermining it by exploiting legitimate institutional practices that provide benefits to the institution and more broadly); impersonal (the individuals involved need not have corrupt personal motives); and generalizable (it is not only government but also other sectors or industries that may be institutionally corrupt).[34] This theorization has various benefits, including shifting the focus from deterring or removing corrupt individuals to changing the rules and procedures of the institution that open it up to institutional corruption. It also explains why institutional corruption is often difficult to see—because it can be so closely connected to the legitimate procedures and practices of an institution, its agents are not seen, and do not see themselves, as participating in corruption at all.[35] Thompson further notes that institutional corruption "manifests as a structural practice that has contemporaneous effects, of which the agents may be aware but which they have reason to regard as part of a legitimate (though flawed) process."[36] He notes that "individuals in a corrupt institution may still be motivated to serve the institution as best they can and may be following practices … that under a general description are legitimate parts of the democratic process."[37]

While some theorists of institutional corruption argue that corrupt individual motivation must be present for institutional corruption to occur, the majority find differently.[38] Institutional corruption, then, is quite different from corruption for personal gain, and rooting it out requires dealing with the systemic influences that created it.

The framing of institutional corruption is helpful in the case of Life Esidimeni because it explains how an organization tasked with protecting the public interest—in this case, the Gauteng Department of Health—could be undermined by influences and activities that, while not necessarily harmful, immoral, or illegal in themselves, lead the organization to systematically diverge from its role.[39]

The institutional corruption context of the Life Esidimeni disaster was one of the active and inappropriate political involvement in the administration of health, together with a drive to save money, which in this case was disguised as deinstitutionalization. These factors combined to create the conditions in which mass deaths occurred. And if they could be remedied, the Gauteng Department of Health would be a much stronger institution, able to prevent future violations of health and other rights.

Intrusion of political actors into the administrative realm

The Constitution envisages roles for both political and administrative leadership at the national and provincial levels. The model requires that political principals define policy and oversee implementation. Officials reporting to them, starting with the head of department, implement policy within a legal framework and should lend subject-matter expertise to such implementation.

Political leadership is provided for in section 133, which lays out the appointment, by the premier (the member elected by the provincial legislature to lead the provincial executive) of an executive council, the members of which are responsible for the functions of the executive assigned to them by the premier. The premier appoints MECs, assigns them powers and functions, and may dismiss them.[40] Section 195, in turn, requires a public administration that is professional, effective, impartial, and developmentally oriented.[41] Such a public administration is not the realm of politics.

Sarah Meny-Gilbert and Ryan Brunette argue that the "assertion of strong political control over [public administration] appointment processes gave, in the late 1990s and early 2000s, the new democratically elected government the ability to transform the composition and orientation of the apartheid-era civil service."[42] However, the overlap between the political and the administrative arms has created space for patronage and intersecting functions.

The total separation of politics and administration will never be possible. As Joel Pearson and Thatshisiwe Ndlovu note, "the daily work of state officials involves choices over the distribution of value—an exercise of power and politics."[43] However, public administration must be insulated from *inappropriate* levels of interference.

Public administration in Gauteng was not insulated from inappropriate levels of political interference. MEC Mahlangu was favored by the African National Congress in the province and was proud of her budget-management efforts in the health department, which had previously been experiencing growing accruals. She was also proud of her tough stance on performance, at odds with a civil service culture characterized by poor performance and limited accountability.

The way that this played out was to create a culture of fear. During the arbitration and the inquest, various officials (including the head of department) admitted to fearing the MEC.[44] The MEC's threats to "do your job or you will be fired" were taken to require compliance even with what officials recognized as being unlawful orders.[45] When the project manager asked for an extension on the notice period for the closure of Life Esidimeni, the MEC asked him in a project meeting if he was a spokesperson for Life Esidimeni.[46] This had the effect of silencing further protest and was raised by multiple officials as evidence that no one could push back against the wishes of the MEC.

The MEC's chairing of twice monthly project meetings meant that the pressure that she exerted was constant and direct, but also that the people within the department with expertise in mental health care were not managing the process. Instead, the political head, with no expertise in health, was doing so.

The lack of insulation of the public administration from politics, and a powerful political head in a department of civil servants that would not stand up to her, allowed the MEC's outsized political influence to overpower and divert the work of the department. It was in this context of institutional corruption that a mental health project, championed by the MEC, could be carried out against the interests of mental health care users.

Money-saving disguised as deinstitutionalization

Inevitably facing resource constraints, health departments will always need to use money wisely. The need to save money, however, cannot be allowed to divert or undermine the role of the department. In this case, the department instituted what it called a deinstitutionalization project but was in fact a cost-cutting exercise. None of the rights-affirming protections of deinstitutionalization were in place. The drive to save money created an institutional context that saw the Gauteng Department of Health deviating from its role of providing care.

Deinstitutionalization is the relocation of people from institutional settings into their communities and the closing of institutional beds to prevent further admissions.

General Comment 1 of the United Nations Committee on the Rights of Persons with Disabilities reflects the long history of the denial of legal capacity to persons with disabilities, along with the impact of such denial, particularly on people with cognitive or psychosocial disabilities. The general comment provides that

> *in order to comply with the Convention [on the Rights of Persons with Disabilities] and respect the human rights of persons with disabilities, deinstitutionalization must be achieved and legal capacity must be restored to all persons with disabilities, who must be able to choose where and with whom to live.*[47]

The drive for deinstitutionalization has gained widespread support around the world. While there are concerns about the argument that institutionalization and involuntary treatment are inappropriate in any circumstances, recognition of the well-documented abuse of people with mental illnesses and the overuse of institutionalization in many contexts makes clear the need to deinstitutionalize.[48]

South Africa has historically over-institutionalized mental health care users, and deinstitutionalization has been implemented in South Africa since the end of apartheid in 1994. The number of chronic mental health care beds in Gauteng Province decreased from about 70 per 100,000 residents in 1994 to about 35 per 100,000 in 2004.[49]

The Mental Health Care Act promotes mental health care in the least restrictive environment possible.[50] To support this aim, the National Mental Health Policy Framework and Strategic Plan 2013–2020 envisages the deinstitutionalization of some mental health care users following the development of community-based services. The document warns that "deinstitutionalization has progressed at a rapid pace in South Africa, without the necessary development of community-based services. This has led to a high number of homeless mentally ill, people living with mental illness in prisons and revolving door patterns."[51]

The approach laid out in the policy accords with the World Health Organization's guidance that "successful deinstitutionalization requires comprehensive community-based services, sufficient financial and structural investment, and a shift in mindsets and practices to value people's rights to community inclusion, liberty and autonomy."[52]

Ray Lazarus, formerly of the Gauteng Department of Health, had argued almost two decades before that it was "essential to retain a certain minimum number of chronic beds and the resources to adequately care for a minority of patients who are very difficult to manage in the community."[53] Mvuyiso Talatala, who was the head of SASOP at the time of the Life Esidimeni disaster, noted that the mental health care users in Life Esidimeni were often severely mentally ill and would be difficult to discharge.[54] Talatala noted that deinstitutionalization was not appropriate for everyone and that a small number of mental health care users would always need chronic care of the kind provided at Life Esidimeni.

Given what deinstitutionalization requires and the situation in South Africa at the time, how were the rapid moves of mental health care users from Life Esidimeni into what were effectively smaller and less well-resourced institutions framed as deinstitutionalization? The answer is that the project was never about deinstitutionalization and so none of the protections of a deinstitutionalization project was implemented. Instead, it was an attempt to save money in the guise of a deinstitutionalization process.

This is evident in the lack of preparation of the mental health care users themselves and of the NGOs meant to receive them. The usual process—including assessing the mental health care user and allowing repeated and progressively lengthened stays in the new community-based environment to assess appropriateness—was not carried out. Instead, mental health care users were discharged despite what their periodical reports indicated and without previously having visited the NGOs to which they were transferred. People were moved in groups rather than according to their individual needs, and most of the 1,711 people were moved in a period of three months.

Many of the NGOs were still in the process of renovation after the moves of mental health care users. They did not have the staff to provide appropriate care, and, importantly, while the plan had been for NGOs to access medicine for the mental health care users from local clinics, there were no resources or protocols in place to enable the clinics to deal with the increased demand for assistance from people with complex needs. Many of the mental health care users were transferred to NGOs far from their families and communities.

Most tellingly, rather than the money following the mental health care users into deinstitutionalized community-based care, there was an increase in the allocation to psychiatric hospitals and very small allocations to the NGOs that were tasked with caring for the majority of the mental health care users.[55]

Deinstitutionalization is neither easy nor inexpensive. Global experience and numerous studies have shown that moving mental health care users from institutions should not be used to save money because this can result in abuse, increased hospital admissions, and early mortality.[56] In fact, the World Health Organization recommends double budgeting for the period of deinstitutionalization to ensure that both the institutions and the replacement care are properly funded.[57] Such an approach could assist in catering to the perennial problem of underinvestment in mental health.[58]

The use of the term "deinstitutionalization" to justify the mass transfer of mental health care users into dangerous places, often far from their families' homes, was an abuse of an ordinarily rights-protective and rights-enhancing mechanism for mental health care users. It further disguised a shift of responsibility for care away from the state and onto mental health care users themselves, their families, and the unwitting owners and operators of NGOs that were offered small sums of money to provide extensive care without adequate support.

The disguise of a cost-saving exercise with a "deinstitutionalization" project is a clear example of institutional corruption. While the Gauteng Department of Health, like any health department, will always need to find ways to save costs, the need to do so cannot be met through misrepresentation and in a way that results in it deviating from its role of providing appropriate care.

Attending to the institutional corruption that made the Life Esidimeni disaster possible

The political overreach into the realm of health services provision, together with the drive to save money no matter the consequences, combined to create a weakened, institutionally corrupt department that was diverted from its proper role. This department was the context for individuals in leadership taking decisions and acting in a way that killed 144 people and caused the suffering of many more.

Institutional corruption requires change to the rules and processes of an institution, to rebuild trust and restore the institution's ability to perform its function. If the institutional context laid the foundations for the Life Esidimeni disaster, what needs to change to prevent further violations of human rights?

Leadership

It is frequently emphasized that good leadership is a prerequisite for a health system that meets the needs and realizes the rights of the people who rely on it.[59] Consistently good leadership has been sorely lacking in the Gauteng Department of Health for some time—there have been nine MECs and nine heads of department between 2009 and 2025.

Good leadership requires the prevention of inappropriate political interference in health. The Constitution provides for the political-administrative division of powers and responsibilities, but the reality has long been different.

Part of the solution must be for the right people to be appointed to political leadership. As a sector that is particularly prone to corruption, and one whose work so directly impacts rights realization, pressure needs to be put on the government to appoint better political leaders in health.[60]

Perhaps the more important element, however, is for the civil service to be professionalized and members to be empowered to act within their areas of expertise and to, where necessary, push back against inappropriate political interference. There have been moves in this direction, including through the publication of the National Framework Towards the Professionalization of the Public Sector.[61] The test of government's commitment to a competent and rights-protecting public service will be whether this national framework is implemented.

Commitment to human rights

Lazarus suggests that "to counter paternalistic and overly cautious attitudes towards the care of people with mental disorders, it is essential to maintain a focus on human and patients' rights, and to persistently challenge entrenched attitudes and practices in this regard."[62]

If the Life Esidimeni disaster demonstrates anything, it is the need to entrench human rights in health care, including mental health care.

Forefronting the dignity and equality of mental health care users begins to counter stigma and strengthen those pushing against institutional corruption to support rights. It illustrates the need to cater to each individual's needs, both within institutions and through deinstitutionalization processes.

Human rights framing, particularly in the South African context that recognizes both individual and collective rights, also allows for the interrogation of systems that themselves mete out violence and discrimination and hamper social justice.

Conclusion

The Life Esidimeni disaster must be viewed as a warning to health systems across the world. That this disaster happened does not mean (as has largely happened in South Africa) that all deinstitutionalization attempts must be stopped. It does mean, however, that deinstitutionalization should not be used as a cost-saving exercise. It also means that health system actors have been able to witness directly the effect of political overreach in health. This overreach cannot be allowed to continue or be mirrored in other settings.

The Life Esidimeni disaster was an example of more than individual suffering. It was an example of an institutionally corrupt health department that systematically failed mental health care users through political meddling and a drive to save costs in a way that harmed people. A commitment to human rights could have saved many lives.

In South Africa's constitutional democracy, such a recommitment is urgently needed. Without it, we risk the further entrenchment of institutional corruption in the Gauteng Department of Health and the repeat of the Life Esidimeni disaster in the years to come.

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VIEWPOINT

“Politicized” Science and Attacks on Public Health

JOSEPH J. AMON

On September 2, 2025, the secretary of the US Department of Health and Human Services, Robert F. Kennedy Jr., wrote in the *Wall Street Journal* that “politicized science had corroded” the purpose of the Centers for Disease Control and Prevention (CDC) and “squandered public trust.”[1] He laid out a vision for the CDC, focusing on infectious diseases and “effectiveness—not politics.”

Kennedy, a lawyer and politician, seems to define “politicized science” (or politicized public health) as scientific findings he does not agree with, particularly related to vaccines, about which he has said: “There’s no vaccine that is safe or effective.”[2] He has also claimed that “nobody knows the risk profile for any vaccine that is currently on the schedule.”[3] Both statements are false.

His efforts politicizing science go back more than a decade. In 2015, he wrote a book claiming that vaccines cause autism.[4] In 2023, Kennedy said that the COVID-19 virus was a genetically engineered bioweapon that may have been “ethnically targeted” to spare Ashkenazi Jews and Chinese people.[5] In response to a measles outbreak in Texas this year, Kennedy promoted the use of the unproven and risky medications budesonide and clarithromycin instead of vaccination.[6]

No sound scientific evidence supports these claims, but for Kennedy there is political capital to be gained. Although Kennedy says that his job “is to eliminate the politics from science,” his actions are the opposite: to inject his political views into the field of public health, foster division, and undermine public trust in science to advance his personal agenda.

“Politicized science” is not only about vaccines, of course. Special interest groups and politicians have conducted disinformation campaigns to cast doubt on scientific consensus on everything from gun violence to tobacco use, lead poisoning, and climate change. The goal is to limit regulations and maximize profits, regardless of public health consequences: more than 46,000 deaths from firearms in the United States in 2023; 7 million deaths worldwide annually from tobacco; and 5.5 million deaths from lead exposure.[7]

While scientists acknowledge limitations and uncertainty, Kennedy preaches certainty. Claims of

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Competing interests: None declared.

"politicized science" rally his supporters. But "politicized science" can have real impacts, both in turning people away from effective approaches and in making health workers a target of violence. As part of my work with the Safeguarding Health in Conflict Coalition, I have seen the consequences borne from politicized science and the subsequent mistrust and distrust of health workers that results.

Community health outreach workers, living and working in the community, are often put at risk when their work becomes politicized, whether because of misinformation and disinformation or because of the capture of public health campaigns to advance other goals, such as when the Central Intelligence Agency used a hepatitis B vaccination campaign in Pakistan to hunt for Osama Bin Laden.[8]

Between December 2012 and May 2014 in Pakistan, more than 60 polio vaccine team members were murdered. One attack, in April 2014, killed two women and injured two children when unidentified men hurled a hand grenade into the house of a polio vaccine worker.[9] In later instances, a polio worker from the Peshawar area was kidnapped from her home, tortured, and killed, and a police constable escorting a polio team was shot dead.[10]

Despite increased security, attacks on vaccination teams continued. On January 13, 2016, a suicide bombing at a polio vaccination center in Quetta, the capital of Balochistan Province, killed 15 members of Pakistan's security forces and wounded 23 other people as they gathered for a planned three-day vaccination campaign.[11]

This kind of backlash against vaccination workers is not limited to Pakistan. In Nigeria, in 2013, gunmen attacked two polio vaccination clinics in the northern city of Kano, killing at least 10 people after a radio station broadcast a story about claims of forced vaccinations. In Afghanistan, polio vaccinators have also been killed, and armed opposition groups have destroyed or confiscated vaccination supplies and equipment.[12]

During the global COVID-19 pandemic, fear and politicized science also stoked violence against health workers, with more than 400 reports of violence and threats against health care related to COVID-19 documented from January through December 2020.[13] Health workers were often targeted on their way to or from work because of fears that workers were spreading the infection. In other cases, people opposed to wearing masks or to being tested attacked health workers. Health facilities were also targeted; for example, in Hong Kong, makeshift bombs were thrown at four health centers after the government listed them as designated clinics for COVID-19 treatment.[14] In Mexico, three health clinics built to accommodate COVID-19 cases were targeted in arson attacks.[15]

Public health can be politicized in other ways too. In Bahrain, Turkey, and many other countries, health workers have been arrested for providing care to individuals protesting government policies.[16] In Syria, government forces and affiliated militias have arrested, killed, and tortured hundreds of patients and health workers. Hospitals and health clinics have been targeted and bombed.[17]

The criminalization of same-sex sexual relations, sex work, gender-affirming care, and drug possession and use can also be seen as a type of "politicized science," denying fundamental human rights and ignoring evidence that shows that criminalization impedes access to health care and increases exposure to police and community violence.[18]

Yet Kennedy somehow sees the CDC's work, grounded in science, tracking disease outbreaks, monitoring vaccination safety and coverage across states and by age and race, promoting pre-exposure prophylaxis for HIV, or conducting blood pressure screening as … politicized science?

Worldwide, in 2024, there were more than 3,600 incidents of attacks on health workers, ambulances, or facilities documented in 23 countries, including air, missile, and drone strikes; shelling; tank fire; shootings; arson; the looting and takeover of health facilities; and the arrest and detention of health workers.[19]

It seems unfathomable that health workers would be targeted for providing care to others, but reports show, over and over again, that attacks on health are commonplace and that the consequences are both immediate and long term, resulting in terror and trauma, as well as untreated illness and limited access to care, lasting for days, weeks, months, and longer.

The United States has never been included among the countries covered by the Safeguarding Health in Conflict Coalition's reports, despite periodic violence occurring in US health centers, such as attacks on health workers during the COVID-19 pandemic or violence targeting reproductive health care providers.[20] This is violence outside of the context of "conflict settings."

Or so I thought, until August 8, 2025.

While I do not think anyone would confuse suburban Atlanta with a conflict zone, the August 8 attack on the CDC in which a 30-year-old gunman fired more than 500 shots, shattering 150 "blast resistant" windows among six different CDC buildings and killing DeKalb County Police Officer David Rose, does not seem too dissimilar to the kinds of attacks against health that the coalition has documented in each of the reports we have issued since 2014.

If you are skeptical about the comparison, consider the description by CDC officials of their experience and response to the gunfire that occurred late in the afternoon on an otherwise unremarkable summer day.

Aliki Pappas Weakland, the associate director for policy, planning, and communications in the CDC's Office of Readiness and Response, said: "I dropped to the floor when the shooting started. The fear that gripped me as the gunfire continued in a steady stream … my knees are chafed and hurting from crawling on the floor with my colleagues as we scrambled to seek shelter."[21]

The director of CDC's National Center for Immunization and Respiratory Diseases, Demetre Daskalakis, told his staff, "We've experienced a horrific and intentionally targeted attack."[22]

The cause of the attack was clear to many CDC staff. Weakland identified the cause as "years of vilification of public servants and public health" in American politics.[23]

As a former CDC epidemiologist, the August 8 attack on the main campus of the CDC struck me as unmistakably political violence, resulting from the politicized science of Robert F. Kennedy Jr. and his fellow travelers who are responsible for ongoing misinformation and disinformation campaigns waged against vaccines. Indeed, the gunman reportedly blamed the COVID-19 vaccine for making him depressed and suicidal.[24]

CDC Director Susan Monarez, writing to CDC staff, said as much—"the dangers of misinformation and its promulgation has now led to deadly consequences"—and was then promptly fired.[25]

Of course, misinformation and disinformation are not the only causes of attacks on health. Easy access to assault weapons is a relevant factor, and the dismantling of the CDC's Division of Violence Prevention, which conducted research on gun violence and prevention, as well as other forms of violence such as child abuse and sexual assault, illustrates the unseriousness of the current administration in upholding its charge of protecting the nation's public health.[26]

In the days after the attack, Kennedy said that "public health agencies have not been honest" and that public health authorities should not be trusted, because "trusting the experts is not a feature of science or democracy, it's a feature of totalitarianism and religion."[27]

In the 2024 Safeguarding Health in Conflict Coalition report, most of the attacks on health we documented were partisan: nurses, physicians, and vaccination teams were attacked by opposition groups, including militias and military forces.

In some cases, however, health workers were attacked by their own government. In Yemen, health workers were arrested for "politically unacceptable" social media posts. In Cameroon, Myanmar, and Sudan, health workers were arrested for "aiding opposition forces," such as by providing medication or care to opposing parties in the conflict or joining pro-democracy movements.[28]

When I worked at the CDC, the furthest thing I could have imagined was what is happening right now to my former colleagues. The CDC is a shining light of expertise, dedication, and commitment to improving health in the United States. In addition to the recent violence it has endured, the CDC is under ideological attack from well-organized disinformation campaigns and from a secretary of the Department of Health and Human Services who is determined to do the opposite of the organization's mission to "improve health, safety, and well-being of America."

Robert F. Kennedy Sr. fought for the realization of human rights globally. His son's legacy is the politicization of science—something he claims to abhor.

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The State of International Human Rights Law on Sexual and Reproductive Health: An Overview

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Abstract

This paper provides an overview of states' current obligations concerning key areas of sexual and reproductive health and rights (SRHR) under United Nations (UN) international human rights law. It emphasizes that SRHR are grounded in international treaties and acknowledged as fundamental human rights, and highlights the importance of their ongoing development. The analysis focuses on UN treaty body standards related to maternal health, contraceptive access, abortion, and sexuality education, while also identifying gaps in standards—particularly in areas such as menstrual health, assisted reproductive technologies, and self-care. Despite notable progress in the realization of SRHR, significant inequalities and rights violations persist, disproportionately affecting marginalized populations. The paper stresses the significance of these standards and advocates for their continuous evolution, emphasizing the need for greater consistency between human rights bodies and identifying areas where legal and policy development should be prioritized to ensure equitable and effective realization of SRHR for all.

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Competing interests: None declared.

Introduction: Progress on sexual and reproductive health and rights since 1994

The 1994 International Conference on Population and Development was a watershed moment, putting sexual and reproductive health and rights (SRHR) on the global agenda.[1] The Beijing Platform for Action followed one year later, where states came together and agreed on the importance of SRHR for gender equality and advocated for universal access to comprehensive health care, safe motherhood, and autonomy over reproductive choices free from discrimination, coercion, and violence.[2]

Since then, significant strides have been made in integrating sexual and reproductive health into international human rights law. At the United Nations (UN) level, this is evident by treaty bodies' inclusion of sexual and reproductive health in their interpretations of a range of rights, including rights to life, health, privacy, education, information, nondiscrimination, and freedom from torture and other ill treatment. At the national level, many countries have reformed their laws and policies to align with their international obligations. For example, Colombia, Mexico, Nepal, and Northern Ireland, among others, have liberalized their abortion laws based on international human rights law obligations.[3]

Over the past three decades, feminist movements have achieved significant gains in gender equality and SRHR. Yet major challenges persist. Estimates by the World Health Organization (WHO) suggest that in 2023 more than 700 women died every day from preventable causes related to pregnancy and childbirth, with about 92% of these deaths occurring in low- and lower-middle-income countries.[4] Today's intersecting "polycrisis"—encompassing environmental, political, security, health, and economic spheres—has deep and far-reaching effects on SRHR. In many countries, women are facing increasing restrictions on abortion and reduced access to contraception, while domestic and international funding for sexual and reproductive health is declining, threatening essential services, comprehensive sexuality education, and accurate health information, especially for adolescents and young people.

Regressive actors are seeking to reverse the gains of past decades through legal measures and social messaging that is rooted in xenophobia, colonial legacies, racism, misogyny, and homophobia. These dynamics undermine democratic institutions, shrink civic space, and disproportionately harm marginalized groups—including LGBTQI individuals, sex workers, migrants, and racially or ethnically excluded communities—who already face systemic barriers to SRHR. Their rights are further compromised by the criminalization of identity, status, or sexual behavior, which compounds exclusion and harm.[5]

Against this backdrop, the paper outlines state obligations in key SRHR areas under UN international human rights law. It underscores that SRHR are firmly grounded in international treaties and recognized as fundamental rights, and offers a clear benchmark of progress while identifying critical areas for future action.

Scope and methodology

This paper focuses on four SRHR topics: maternal health, contraceptive information and services, abortion, and comprehensive sexuality education. We chose these topics because they align with key sexual and reproductive health interventions identified in WHO's *Universal Health Coverage Compendium*.[6] Together, they represent select areas in which human rights standards have been clearly articulated and developed. Our selection of search terms for the literature review was similarly informed by the sexual and reproductive health interventions outlined in the WHO compendium.

Human rights obligations related to other SRHR issues, such as gender-based violence (including sexual violence, abuse in childbirth, and harmful practices), have been explored elsewhere; in this paper, we integrate those issues only when relevant to our four areas of investigation.[7]

This review covers the period from 1999 to June 2025, beginning with the adoption of the UN Committee on the Elimination of Discrimination Against Women's General Recommendation 24 on women and health, which, together with the UN Committee on Economic, Social and Cultural

Rights' General Comment 14, issued in 2000, created a framework for the development of human rights standards relating to the right to health.

The search included views, concluding observations, and general comments of the UN human rights treaty bodies, as sources of binding international law, as well as Special Procedures mechanisms and the UN Human Rights Council.[8]

To ensure authoritative coverage and analytical breadth, we searched four well-established and complementary databases: the Universal Human Rights Index and Treaty Monitoring Database of the Office of the United Nations High Commissioner for Human Rights (OHCHR); bayefsky.com; and the University of Minnesota Human Rights Library.

Only English-language documents were included.

Background

SRHR are grounded in constitutional law and in regional and international human rights law, including treaties and conventions that affirm the rights to life, to health, to privacy, to equality and nondiscrimination, to benefit from scientific progress, to found a family, to information and education, to decide the number and spacing of one's children, and to be free from torture and other ill treatment, among other rights.

SRHR encompass a broad spectrum of entitlements related to sexual and reproductive health care—in public and private facilities—as well as rights related to the underlying and social determinants of health. They acknowledge that individuals have the right to make free and informed choices about their bodies and reproduction, without coercion, discrimination, or violence.[9]

Existing human rights standards

This section sets forth the findings from our research and summarizes existing UN human rights standards in the areas of maternal health, access to contraceptive information and services, safe abortion care, and comprehensive sexuality education.

Maternal health

Maternal health refers to the health of women during pregnancy, childbirth, and the postpartum period. Although each stage should be a positive experience, for too many women it is associated with preventable suffering, health complications, and even death.[10]

Human rights bodies have long recognized that access to quality maternal health care is an entitlement arising from the rights to life, health, and equality and nondiscrimination, among others.[11]

The provision of maternal health care is recognized as a "core obligation" under international human rights law, which means that states must guarantee minimum essential levels of services, even when there are economic or other challenges to meeting the obligation.[12] The right to maternal health includes access to these services, free from discrimination, coercion, and violence.[13]

States have an obligation to:

- Develop laws, policies (including budgetary and insurance policies), programs, and practices to ensure women's and girls' health and well-being throughout pregnancy, delivery, and the postpartum period.[14]
- Address and remove legal and practical barriers to accessing SRHR services, including through universal health care coverage, nondiscriminatory insurance coverage, and free services, where necessary, for pregnancy, childbirth, and postnatal care.[15]
- Make services acceptable to women, such as by ensuring that these services are provided in a manner that is respectful, dignified, and confidential, and sensitive to the woman's needs and perspectives.[16]
- Ensure access to essential maternal health services and providers, regardless of geographic location.[17]
- Ensure that the woman's life and health are prioritized over the protection of the fetus.[18]
- Collect, analyze, and disseminate disaggregated data necessary to understand and to adequately

respond to primary causes—direct and indirect—of maternal mortality and morbidity.[19]

- Provide interventions to prevent maternal mortality, including in humanitarian settings, by ensuring access to skilled birth assistance, midwifery care, prenatal care, and emergency obstetric care, including effective, quality referral systems for obstetric complications, abortion, and complications resulting from unsafe abortions.[20]
- Ensure that essential medicines for pregnancy-related complications are registered and available (e.g., misoprostol for abortion, and to treat postpartum hemorrhage and incomplete abortion).[21]
- Ensure that maternal health services meet the distinct needs, including midwifery care, of women and are inclusive of the needs of marginalized sectors of society, including those with elevated rates of maternal mortality, such as people with disabilities, young people, poor people, people from rural areas, racial and ethnic minorities, Indigenous persons, and migrant workers.[22]
- Reduce early pregnancy, as well as unwanted pregnancy, among adolescents by enhancing access to education and information on sexual and reproductive health and family planning, comprehensive sexuality education, and contraceptive information and services, and promote gender equality.[23]
- Address violations of the right to informed consent, abuse and disrespect, and the denial of women's autonomy in decision-making in prenatal care, labor, and childbirth.[24]
- Ensure access to the underlying determinants of healthy pregnancy, including potable water, adequate nutrition, education, sanitation, and transportation.[25]

Contraceptive information and services

Access to contraceptive information and services enables individuals and couples to determine whether and when to have children; contributes to their health and to equality, autonomy, and well-being; and promotes a satisfying and safe sex life.[26] Contraceptive information and services are important for preventing pregnancies, including those resulting from sexual violence, and for preventing the spread of sexually transmitted infections, including HIV.

Adolescents and young women face particular obstacles in accessing contraceptives and health services, which increases the risk of an unintended pregnancy and its consequences. Pregnancy complications and unsafe abortion are the leading causes of death for girls aged 15–19.[27] Young men also need information and services so they can take responsibility and be partners in preventing unintended pregnancies.[28]

UN human rights bodies have framed the lack of access to modern contraception as implicating numerous rights, including the rights to life, to health, to nondiscrimination, to decide the number and spacing of one's children, and, in some contexts, to be free from torture and other ill treatment.[29]

States have an obligation to:

- Ensure that the full range of good-quality, modern, and effective contraceptives, including emergency contraception, are available and accessible to everyone.[30]
- Ensure access to medications on the WHO Model List of Essential Medicines, which includes hormonal contraception and emergency contraception.[31]
- Make emergency contraception—which can prevent pregnancy following unprotected sexual intercourse—available without a prescription, and ensure that it is free for victims of violence, including adolescents. Adolescent girls in particular need to be informed about the potential benefits of emergency contraception.[32]
  - ▹ The failure to ensure legal and accessible emergency contraception for individuals who are victims of rape or other forms of sexual abuse is linked to physical and mental suffering, which may amount to torture or ill treatment.[33]
  - ▹ Special measures should be taken to ensure

that emergency contraception is available in conflict and post-conflict zones.[34]

- Eliminate legal and practical obstacles to contraception access, including those associated with high cost, marital status, and third-party authorization, such as consent from spouses, parents, or legal guardians.[35]
- Gather disaggregated data on the use of contraceptives and access barriers.[36]
- Address barriers to contraceptive information and services that may be particularly acute for marginalized groups, such as low-income individuals, people with disabilities, adolescents, ethnic and racial minorities, people living with HIV, and individuals living in humanitarian settings.[37]
- Guarantee the right to seek, receive, and disseminate contraceptive-related information. This includes providing access without discrimination to unbiased, comprehensive, and evidence-based information and services for family planning and contraception in a manner that is accessible and acceptable to all populations, including people with disabilities and adolescents and youth.[38]
- Adolescents should be given a legal presumption that they are competent to seek and receive preventative or time-sensitive sexual and reproductive health commodities and services. Age-appropriate information should be provided irrespective of age without parental or guardian consent, respecting privacy and confidentiality.[39]
- Contraceptive information should incorporate all available choices of contraception, including information on side effects and success rates.[40]
- Ensure that the use of contraceptives is voluntary, fully informed, and without coercion or discrimination. Appropriate attention should be given to groups who have historically been subject to coercive family planning practices, including forced sterilization. This includes, for example, people with disabilities, Indigenous women, poor women, Roma women, and women living with HIV.[41]
- Effective remedies must be available if violations occur with regard to informed consent or other irregularities associated with the use of contraceptives.[42]

Abortion

Human rights law and health evidence have long recognized the link between restrictive abortion laws, high rates of unsafe abortion, and maternal mortality. Barriers—both legal and practical—effectively deny access to safe abortion services. These barriers include restrictive laws, the criminalization of women and providers, mandatory waiting periods, biased counseling, refusals to provide abortions based on conscience, the physical obstruction of abortion facilities, harassment, and cost.[43]

Access to abortion is further limited by barriers to health information, unequal power dynamics, abortion stigma, and discriminatory gender stereotypes.[44] Human rights bodies have found that such restrictions violate the rights to health, to life (including life with dignity), to privacy, to benefit from scientific progress, to freedom from gender discrimination (including intersectional discrimination), and to freedom from inhuman and degrading treatment, among others.[45]

States have an obligation to:

- Recognize abortion as a fundamental right.[46]
- Decriminalize abortion in all circumstances, repealing all provisions criminalizing abortion and related assistance to which a pregnant person has given informed consent.[47]
- Legalize abortion and regulate it so that persons do not have to undergo unsafe abortions, including without limiting abortion to specific indications.[48]
- Ensure access to safe abortion and address legal and practical barriers to abortion access, including by
    - ▹ eliminating mandatory waiting periods and counseling;[49]
    - ▹ eliminating third-party authorization requirements, including spousal, parental, or

    guardian consent and judicial authorization;[50]
  - guaranteeing confidential services and their provision in a nonbiased and nonjudgmental environment;[51]
  - covering the cost of the procedure through public health insurance or providing it for free;[52]
  - ensuring that enough trained medical professionals are available to perform abortions across all geographic regions;[53]
  - preventing the harassment and stigmatization of individuals who seek, complete, or facilitate an abortion;[54] and
  - ensuring that the life and health of the pregnant person are prioritized over protection of the fetus.[55]
- Ensure that states where the practice of conscientious refusals by providers is permitted, this should not inhibit access to abortion and should be regulated, including by requiring referrals.[56]
- Ensure the availability and accessibility of medication abortion.[57]
- Implement WHO's guidelines on abortion.[58]
- Ensure that individuals facing multiple and intersecting forms of discrimination—including adolescents, people with disabilities, racialized persons, and persons with lower economic status—have full and equal access to sexual and reproductive health services, including abortion.[59]
- Safeguard existing access to abortion care and prevent any retrogressive measures that might restrict or diminish current abortion rights.[60]
- Ensure that persons receive confidential and adequate post-abortion care, regardless of the legal status of abortion.[61]
  - Eliminate and prohibit any requirements of doctors and other health personnel to report cases of persons who have undergone abortion and abortion-related care to law enforcement or other authorities.[62]
- Institute "safe access zones" (protective areas which anti-abortion demonstrators cannot enter) around abortion clinics and other facilities where abortions are performed, to prevent the harassment, stigmatization, and traumatization of persons seeking abortion.[63]

Comprehensive sexuality education

Comprehensive sexuality education (CSE) is defined as a curriculum-based process of teaching and learning about the cognitive, emotional, physical, and social aspects of sexuality. It aims to equip children and young people with the knowledge, skills, attitudes, and values that empower them to develop respectful relationships and realize their health, well-being, and dignity. This includes understanding their bodies, sexual and reproductive health, and human rights.[64]

Human rights treaty bodies have noted that under the rights to health, to information, to education, and to be free from discrimination, states have the following obligations in relation to CSE:

- Provide CSE that is inclusive, unbiased, based on evidence, scientifically accurate, in line with human rights, and age appropriate.[65]
  - It should include knowledge about the body, including anatomical, physiological, and emotional components. It should include content related to sexual health and well-being, such as body changes and maturation processes. Other information that should be included is contraception, including emergency contraception; the prevention, care, and treatment of sexually transmitted infections; the prevention of early pregnancy; counseling; maternal health services; and menstrual hygiene. Attention should be given to gender equality, sexual diversity, SRHR, responsible parenthood and sexual behavior, and violence prevention.[66]
- Ensure that the curriculum is nondiscriminatory—including on grounds of gender, sexual orientation, and disability—both in content and in teaching methodologies.[67] Ensure that curriculum materials do not perpetuate harmful or

discriminatory stereotypes, paying special attention to diversity and gender issues, including addressing gender stereotyping.[68]

- Ensure that CSE programs do not censor or withhold information or disseminate biased or factually incorrect information.[69]
- Ensure that CSE is part of the mandatory school curriculum, provided throughout schooling in an age-appropriate manner, and is provided without parental consent.[70]
- Ensure that information is appropriate to children's age and educational level and understandable and available in alternative formats, including for students with disabilities.[71]
- Ensure that individuals have access to information both within and outside formal education systems, in order to reach out-of-school adolescents.[72]
- Develop public education campaigns to raise awareness about sexual and reproductive health issues.[73]
- Ensure that teachers are trained to provide CSE and that youth are involved in the development of these education programs.[74]

Select areas for SRHR standard-setting

While many aspects of sexual and reproductive health would likely benefit from further attention by human rights standard-setting bodies, our analysis identified three areas in particular—assisted reproductive technologies (ARTs) and infertility, menstrual health, and self-care—that, although already addressed by the UN Human Rights Council and the OHCHR, could be further advanced. Not only are these issues fundamental to reproductive autonomy and bodily integrity, but they also expose persistent inequities, discrimination, and legal gaps.

While human rights principles—such as nondiscrimination, accountability, equality, participation, and the right to health framework—remain applicable and are state obligations across all SRHR issues, including ARTs and infertility, menstrual health, and self-care, the development of more targeted human rights standards in these three areas could provide crucial guidance to states on how to fulfill their obligations and ensure that everyone can exercise their rights.

Assisted reproductive technologies and infertility

For many individuals and couples, there is a gap between desired and actual fertility, implying constraints to people's ability to realize their reproductive goals for a variety of reasons, including infertility.

Governments have a multifaceted human rights-based responsibility to address infertility, which includes not only ensuring access to safe, affordable, and quality treatment, including ARTs, but also proactively preventing infertility by addressing its causes and combating the stigma, discrimination, and violence associated with it.[75] These government responsibilities are included in the rights to decide if and when to have children, and how many; found a family; privacy; benefit from scientific progress; and nondiscrimination.

These obligations, while less developed than for other sexual and reproductive rights issues, are increasingly being addressed by treaty bodies. The OHCHR issued a research paper in 2023 outlining key considerations for a more comprehensive rights-based approach to infertility. These include identifying laws and practices that inadequately address infertility, such as by limiting treatment options and restricting access to heterosexual couples or to those with access to education and financial resources. The paper identifies the failure to prevent and address human rights harms and violations that can occur leading up to and after an infertility diagnosis.[76]

To date, human rights bodies require countries to:

- Incorporate ARTs into sexual and reproductive health services.[77]
- Ensure access to up-to-date scientific technologies, including ARTs, on the basis of nondiscrimination and equality, including on the grounds of gender, sexual orientation, and gender identity.[78]

- Include persons directly impacted by ARTs in the development, adoption, and implementation of relevant laws and policies.[79]
- Prevent any person or entity from interfering with the right to participate in and enjoy the benefits of scientific progress and its applications.[80]
- Eliminate excessive restrictions on the use of ARTs. This includes addressing issues such as the criminalization of certain ART practices, gender-based and intersectional discrimination, restrictions on the right to make independent decisions about bodily autonomy, harmful regulations (such as those requiring the mandatory transplantation of embryos), and the lack of specific regulations.[81]

Surrogacy, as a method of family formation and a way to address infertility, can involve reproductive technologies and impacts the rights of multiple stakeholders. Human rights standards, to date, include:

- Protecting the child's rights. This includes their right to nationality, identity, and best interests.[82]
- Protecting the surrogate's rights. This includes
  - ▹ ensuring that surrogates are free from exploitation, coercion, and violence;[83] and
  - ▹ decriminalizing surrogates and releasing persons from prison for being surrogates.[84]
- Establishing clear legal frameworks that regulate surrogacy in a way that protects the rights of all involved, including provisions for support, information access, discrimination, and data management.[85]

Menstrual health

Menstrual health is a critical aspect of overall sexual and reproductive health and well-being, yet it remains shrouded in taboo in many societies. Stigmatizing and discriminatory attitudes lead to inadequate access to information, sanitation facilities, and menstrual products, as well as social isolation, all resulting in negative consequences for education, employment, and social participation and for individuals' physical and mental health. This is particularly acute in humanitarian settings, where displacement and disrupted infrastructure exacerbate existing challenges and create specific vulnerabilities.[86]

While the human rights to health, privacy, and nondiscrimination, among other rights, would apply to menstrual health, the treaty bodies have yet to address this issue in any robust way.[87] For example, the Committee on Economic, Social and Cultural Rights has referred only to the state obligation to take measures to modify negative "social misconceptions, prejudices and taboos about menstruation" in order to ensure that persons can exercise their rights to sexual and reproductive health.[88] The Committee on the Rights of the Child has recommended including "menstrual hygiene" in CSE.[89]

However, in 2024, a resolution on menstrual hygiene management, human rights, and gender equality was adopted at the UN Human Rights Council.[90] It highlights the essential role of menstrual hygiene management in advancing the human right to health and gender equality, and specifically calls for states to:

- Ensure that women and girls, especially in rural and remote areas, have access to affordable, safe, and clean menstrual hygiene products and facilities.
- Provide access to adequate water and sanitation facilities in public and private spaces, including schools, to support safe menstrual hygiene management.
- Eliminate or reduce all taxes on menstrual products and support those living in economic vulnerability with free or affordable options.
- Integrate menstrual hygiene management into relevant national policies—including water, sanitation, and hygiene programs—and promote women's and girls' access to appropriate and accessible information and education on menstrual hygiene management.

Self-care

Self-care in the context of SRHR encompasses a broad spectrum of practices, including menstrual hygiene management, contraceptive use, self-managed abortion, sexually transmitted infection testing, and the use of telemedicine, to name a few. These practices can empower individuals to exercise autonomy and take control of their health and well-being. WHO has been instrumental in advancing the field of self-care, developing evidence-based guidelines and recommendations for various SRHR interventions. However, while human rights bodies have articulated the right to certain methods of treatment that support aspects of self-care, such as medication abortion, they have not yet fully integrated the concept of self-care into their SRHR frameworks.[91]

A recent OHCHR report, issued in the wake of a 2023 Human Rights Council resolution, examines rights related to self-care and recommends that UN human rights mechanisms "further articulate the human rights dimension of care and support and corresponding State obligations, including on self-care."[92]

Discussion and conclusion

This paper has examined the existing UN human rights standards on SRHR, particularly those developed by the treaty bodies. It has found that long-standing standards are being consistently reinforced by these bodies and that there has been no retrogression on any issue, including on abortion.

Treaty bodies have, over the past 25 years, also been clear that states must adopt the measures necessary to eliminate the conditions that perpetuate inequality and discrimination in order to enable all individuals and groups to enjoy SRHR. Special attention should be paid to groups of persons who have experienced systemic discrimination, such as women, people with disabilities, racialized persons, LGBTQI+ people, Indigenous persons, and people living in poverty.

Given the increasing number of persons living in humanitarian settings, this review importantly found that the treaty bodies are continuing to emphasize that human rights apply in humanitarian settings, including in the contexts of climate crisis and conflict, including war, as mutually reinforcing and complementary to international humanitarian law.[94] This includes recognizing that the deprivation or denial of essential services and commodities (such as food, water, and medical assistance to pregnant women), as well as targeted attacks on medical facilities (including ART clinics and those providing maternal health services), are human rights violations. Such acts, including acts of reproductive violence, constitute violations of both international human rights law and international humanitarian law, are considered crimes against humanity, and may amount to genocide; as such, they demand urgent accountability.[95]

Our research also found that there has been some significant strengthening of human rights law, particularly on abortion, intersectional discrimination, adolescent rights, and sexuality education. However, more consistency across treaty bodies on SRHR standards, including on abortion, is needed. In addition, the treaty bodies should continue their work of developing more robust standards on ARTs, menstrual health, and self-care. For example, the Committee on Economic, Social and Cultural Rights' General Comment 25 on the right to enjoy scientific progress is significant because it sets a path for implementation of this little used but important right in the context of SRHR. It is critically important that autonomy, equality, and nondiscrimination (including on the grounds of sexual orientation and gender identity) form the foundation of the realization of these rights.

We also identified gaps in standard-setting in long-standing SRHR thematic areas. Despite public health evidence and the importance of services and commodities being accessible and acceptable, treaty bodies have yet to consistently underscore the role that task shifting could play in ensuring access to SRHR services. For example, treaty bodies could more clearly address the crucial role of community health workers and midwifery models of care in providing SRHR services.

A unifying theme is the need for human rights-based standards that protect bodily autonomy, ensure informed and voluntary decision-making, and eliminate discriminatory laws that criminalize marginalized groups. For example, the strong standards guaranteeing informed consent should be expressly applied in the context of *all* maternal health care at all stages of pregnancy, including during childbirth. Treaty bodies should continue to call for the decriminalization of surrogates but should also recommend the decriminalization of voluntary surrogacy altogether and the adoption of regulations that protect the rights of all parties and guarantee the bodily autonomy and decision-making of surrogates. Finally, it is crucial for treaty bodies to provide clear and specific guidance to states on the measures needed to eliminate intersectional discrimination. Current standards are helpful and increasingly specific, but stronger recommendations are needed to address the rights of persons belonging to groups that experience systemic discrimination and criminalization, such as sex workers and LGBTQI persons. This could include recommendations to decriminalize consensual sex work entirely and to promote protection on grounds of gender and gender identity, including transgender identity.[95]

The WHO guideline on abortion could help treaty bodies be more consistent, explicit, and unambiguous in, for example, recommending against limited indication-based exceptions to an otherwise restrictive abortion law and instead recommending that states allow abortion on request.[96] In addition, while the right to life and all human rights protections apply and have always been applied by treaty bodies only after birth, treaty bodies should clearly reaffirm that human rights begin at birth. This position aligns with the Universal Declaration of Human Rights' recognition that "all persons are *born* free and equal, in dignity and rights" and with the statement by the Committee on the Elimination of Discrimination Against Women that "under international law, analyses of major international human rights treaties on the right to life confirm that it does not extend to fetuses."[97] Finally, treaty bodies should continue to find that restrictions on abortion are a form of gender-based discrimination.

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HHR
Health and Human Rights

A Human Rights-Based Approach to Accessing Preimplantation Genetic Testing: The Case of Argentina

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Abstract

In 2013, Argentina enacted Law 26862, guaranteeing access to assisted reproductive technologies (ARTs) but it does not include preimplantation genetic testing (PGT). Judicial rulings have denied PGT coverage, citing legal protections for embryos and the absence of explicit regulatory approval. However, this paper argues that PGT should be included under Argentina's current ART framework, in alignment with human rights principles, scientific progress, and reproductive autonomy. Analyzing domestic legislation and the inter-American human rights system—particularly the case of *Artavia Murillo v. Costa Rica*—the paper demonstrates that restricting PGT disproportionately harms individuals with genetic risks, violating their rights to health, privacy, and family life. The judiciary's reliance on "life at conception" arguments is further undermined by Argentina's 2020 abortion law, which permits pregnancy termination. By comparing Argentina's approach to the UK's regulated PGT model, the paper advocates for the Ministry of Health to authorize PGT under strict criteria, ensuring equitable access while addressing ethical concerns. Recommendations include adopting evidence-based regulations to balance reproductive rights with embryo welfare, thereby advancing progressive health policies in line with international human rights standards.

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Competing interests: None declared.

Introduction

In 2013, Argentina passed Law 26862, recognizing the right to comprehensive coverage of assisted reproductive techniques and procedures. The legislation recognizes the rights of every person to parentage and to form a family, which are closely connected with the right to health. In addition, the law is also based on the rights to dignity, freedom, and equality of every human being (according to the Constitution and the foundations and principles of international human rights law).[1]

In 2019, six years after the law's enactment, Argentina reported more than 21,000 cases of assisted fertilization per year, with a birth rate of approximately 24%.[2] The legislation covers different treatments, but preimplantation genetic testing (PGT) is not one of them. During the debates in Congress, PGT was not addressed; however, in 2023, a deputy presented a bill to include this treatment in the law. However, the bill was never discussed by the representatives.[3]

Some individuals have filed petitions with the courts to request coverage of these tests. However, several judicial decisions have pointed out that it is not the courts' place to include treatments not authorized by Congress or the Ministry of Health, which is the public authority responsible for updating treatments.[4] Moreover, the courts have said that if PGT were covered, embryos with anomalies would be discarded, which contradicts the notion that life begins at conception, as established by Argentina's legal framework.[5]

However, in other cases—namely, cases where medical treatments for HIV/AIDS, rare diseases, and chronic illnesses were not covered by individuals' health insurance and there was no legal obligation to do so—the judiciary has ruled that patients must have access to such treatments, taking into account the right to health and access to the benefits of scientific progress.[6]

In December 2020, the Law on Access to Voluntary Termination of Pregnancy (hereafter the abortion law) was passed, which allows abortion until 14 weeks. Since then, no new regulation on PGT has been approved, nor has the judicial branch issued any new rulings on the subject.[7]

Against this background, I offer a novel contribution to the field of reproductive rights and genetic testing by framing the discussion of PGT as a comprehensive human rights-based approach. The paper uniquely focuses on human rights principles, social justice, and reproductive autonomy. By situating PGT within the broader context of Argentina's legal landscape and the inter-American human rights system, I show how current judicial practices and health policies can be seen as outdated and misaligned with international human rights standards. This framing not only addresses the legal and ethical implications of PGT but also emphasizes the need for a paradigm shift in how reproductive technologies are regulated, advocating for policies that prioritize individual rights and access to health care.

In the first part of the paper, I provide a brief explanation of PGT. I then describe Argentina's legislation and case law of assisted reproductive technologies (ARTs) and PGT. In the third part, I comment on the Argentine and international human rights frameworks on ARTs, focusing especially on the inter-American human rights system, of which Argentina is a part. In part four, I use a human rights framing to show why PGT should be covered. Finally, I make recommendations for advancing regulations that cover PGT in Argentina.

Preimplantation genetic testing

According to the Human Fertilisation and Embryology Authority (HFEA), the UK fertility regulator, PGT-M, previously known as PGT, is a treatment that involves checking the genes or chromosomes of an embryo for a specific genetic condition before deciding whether to transfer the embryo to a person's uterus.[8] Additionally, PGT-SR is a treatment that involves examining the chromosome structure of an embryo to identify where segments may have been deleted, duplicated, or inverted. It can be used for individuals with a known chromosome structural rearrangement to increase the chances of a healthy pregnancy.

The technique is primarily used to detect severe heritable disorders, such as Tay-Sachs or cystic fibrosis, which the parents wish to avoid passing on to their children. However, it can also be used for more controversial purposes such as selecting a child who can serve as a tissue donor for a sick sibling, choosing a child with a particular condition, such as deafness, or selecting a child of a specific sex. In nearly all countries with advanced fertility clinics carrying out PGT, the technique is limited by legal restrictions on its acceptable use.[9]

PGT-M treatment is very safe—there is no evidence that babies born following such treatments suffer from any more health or developmental problems than babies born using in vitro fertilization (IVF) alone. Although an embryo usually develops normally even when it has had some cells removed, there is a possibility that some embryos may be damaged by testing, which means they would need to be discarded and would not be used in IVF treatment.[10] Additionally, PGT-M and PGT-SR are not 100% accurate, so there is a slight chance that the tests provide incorrect information.[11]

In this paper, I have chosen to examine the HFEA regulations on PGT and see if they could apply to Argentina for the following reasons: (1) the UK has been regulating PGT for more than 20 years, so there is much experience to draw on; (2) the HFEA has been established specifically to operationalize the regulations; (3) it has detailed policy documents that describe the circumstances under which PGT can be used; and (4) all this information is accessible.[12]

In Argentina, the Ministry of Health is the central authority responsible for authorizing ART treatments, so it has a similar regulatory role to the HFEA. Countries such as the United States, Canada, and Australia have complex regulatory landscapes, where PGT regulations are decentralized to local state authorities.[13] Such an arrangement could also happen in Argentina, whose Constitution allows provinces some regulatory control, but that possibility is beyond the scope of this paper.

The HFEA authorizes the use of PGT-M and PGT-SR in five circumstances:

1. The person ended previous pregnancies because of a severe genetic condition.
2. The person already has a child with a severe genetic condition and wants to avoid this happening again.
3. The person has a family history of a severe genetic condition.
4. The person has a family history of chromosome problems.
5. The person has a history of recurrent miscarriage due to chromosomal abnormalities.

It is possible to use PGT-M to test for almost any genetic condition where a specific gene is known to cause that condition. However, the HFEA allows PGT-M testing only when the risk of transmission and the severity of symptoms in someone affected by the genetic abnormality meet certain legal criteria. That PGT-M is used only when embryo development might be seriously compromised, risking the embryo's survival, or the probability of a healthy life resulting, is important in my analysis in this paper.

Assisted reproductive technologies and preimplantation genetic testing in Argentina: Legal and judicial context

Law 26862 guarantees equal access to medically assisted reproduction procedures and medical assistance techniques. According to the Consideration of the Regulatory Decree, the law was drafted to promote a more inclusive, culturally diverse, democratic and fairer society.[14] Medically assisted reproduction is understood as any procedure or method, whether of low and high complexity, conducted with medical assistance to achieve a pregnancy.[15]

The law states that new methods and techniques developed through technical and scientific advances may be included in the definition, providing the National Ministry of Health authorizes them.[16] All authorized procedures, diagnostic tests, medicines, and support therapies are included in private insurers' policies and in the compulsory medical program of the free medical system (PMO, for its Spanish initials). A person cannot be excluded from medically assisted reproduction on the basis of sexual orientation or marital status.[17]

Regulatory Decree 956/2013 recognizes two types of procedures: (1) low complexity and (2) high complexity. Low-complexity procedures are "those that aim at the union between ovum and spermatozoid inside the female reproductive system, achieved through ovulation induction, controlled ovarian stimulation, ovulation triggering and intrauterine, intracervical or intravaginal insemination, or intrauterine, with sperm from the partner or donor."[18] High-complexity procedures are "those where the union between ovum and spermatozoon takes place outside the female reproductive system, including in vitro fertilization; intracytoplasmic sperm injection; cryopreservation of oocytes and embryos; oocyte and embryo donation and vitrification of reproductive tissues."[19]

The Civil and Commercial Code of the Nation (CCCN) establishes in article 19 that "the protection of the non-implanted embryo shall be the subject of a special law." However, this remains unregulated as there is no applicable law. Article 57 states that "any practice intended to produce a genetic alteration in the embryo that is transmitted to its offspring is prohibited."[20] PGT is not used to alter genetics in an embryo.

Currently, PGT is not covered by Law 26862, the decree, or regulations passed by the Ministry of Health, which provides a detailed list of approved procedures. PGT is not prohibited at a national level which has led some people to request that their medical insurance covers these tests. However, the judiciary has ruled that this type of test is not covered.[21]

In the case of *L.E.H. y Otros C/C/O.S.E.P. S/ Amparo*, a couple in the province of Mendoza requested their medical insurer to provide complete coverage of IVF with PGT. The couple were unable to conceive naturally, and by the end of 2011 had experienced four fertilization attempt failures with the last one ending in a biochemical miscarriage. They then needed further treatment in 2012 and after another unsuccessful pregnancy, a genetic disease was detected in the male which meant embryos resulting from his sperm were not viable. The use of PGT was indicated. However, the couple's insurance did not cover PGT so they submitted a legal claim against the insurance company.

This claim was channeled through an amparo, a legal action used in court to protect constitutional rights. Amparos also protect the Constitution by ensuring its principles are not violated by statutes, state action, or, in this case, inaction. They are an important legal instrument for protecting economic, social, and cultural rights.[22] All the judicial reviews, including the Cámara de Apelaciones en lo Civil, Comercial, Minas, de Paz y Tributaria of the Primera Circunscripción Judicial (Appeals Court for Civil, Commercial, Mining, Peace, and Tax Matters of the First Judicial District), the Mendoza Supreme Court of Justice, and the Supreme Court of Justice of the Nation, denied the request.

The main argument used by the Mendoza Supreme Court of Justice to deny the use of PGT is related to the legal definition that life begins at conception, according to the CCCN.[23] The court considered that PGT would have involved discarding more than 12 embryos whose destination were not precisely established in the legal framework. The court interpreted that the claimers' right to reproductive health is not absolute, much less in the face of the protection of human life, in this case, of the embryos not transferred. At that time (2015), abortion was not allowed under any circumstances in Argentina.

Mendoza's Supreme Court of Justice determined that the social security system cannot be obliged to bear the costs of "the experimentation and discarding of embryos, which deserve legal protection as human life. This is not a position against progress but one of respect for life."[24] The court did not consider that PGT-M does not mean to discard embryos automatically (they could be frozen, for example), but to determine if there is a genetic problem and to select an embryo that would be viable. Only nonviable embryos would be discarded.[25]

The court also noted that the requested benefit was not covered by Law 26862, is exceptional and high-cost, and is not among the benefits that the social security system is required to cover. In addition, although flexible, the PMO needs to be more adaptable to cover all the benefits without any limitations according to the court.[26]

After the Supreme Court of Mendoza's decision, the claimants went to the Supreme Court of Justice of the Nation, which decided that it could not allow treatments that the Ministry of Health had not approved. It ruled that the Ministry of Health, not the courts, have the authority to decide which treatments are covered.

In 2022, in the case *G.L.M. y otro c/ OSDE s/ leyes especiales*, the petitioners requested PGT so their embryos could be analyzed to enable them to have one implanted that did not have the genetic mutation suffered by both parents.[27]

The Federal Court of Appeals of San Martín (province of Buenos Aires) rejected the amparo action, following the previous Supreme Court decision, on the grounds that PGT is not included in the list of medically assisted reproduction procedures.[28]

It is essential to note that when the Federal Court of Appeals in San Martín issued its ruling denying the PGT, it did not use the argument that life begins at conception, even though this was the basis of the Supreme Court's decision. Although the Federal Court of Appeals does not state what the decision is based on, it is important to note that this decision was made after the abortion law was passed which allows abortions up to 14 weeks.[29]

To summarize, the two arguments used by the judiciary for not approving coverage of the costs of PGT in Argentina are as follows: First, life begins at the moment of conception, meaning that if PGT is covered, embryos with anomalies would be discarded (the possibility that they would not be viable with or without PGT, or they could remain frozen, or destined to scientific research were not analyzed). However, this argument was not used after the abortion law was approved. Second, PGT was not approved as a covered treatment by any resolution of the Ministry of Health in its capacity as enforcement authority of the law on reproductive assistance. The judiciary cannot replace the Ministry of Health. Therefore, it is not up to the courts to approve new treatments not included in the regulations.

Human rights framework

In this section, I argue that access to ARTs and PGT is guaranteed through several human rights covenants. International human rights treaties, which enjoy constitutional hierarchy due to their incorporation in article 75(22) of the Constitution, bind Argentina to fulfill its obligations to respect, protect, and guarantee fulfill human rights, including the right to the highest attainable standard of health.[30]

International treaties ratified by Argentina are binding since they have a constitutional hierarchy "under the conditions of its validity."[31] Such a precept applies to the jurisprudence of the international tribunals that interpret and determine human rights rulings. According to the Supreme Court, the jurisprudence of the Inter-American Court of Human Rights (IACHR) should be considered a guide for interpreting the American Convention on Human Rights.[32]

According to article 2 of the American Convention, the obligation to fulfill requires Argentina to adopt appropriate legislative, administrative, and other measures to realize human rights fully.[33] This obligation entails the duty to eliminate rules and practices that contravene the guarantees provided for in the convention, as well as to issue regulations and develop practices aimed at the observance of such guarantees.[34] Similarly, the IACHR has indicated that the duty to adopt measures of regulatory adaptation also applies to the rights enshrined in the American Convention.[35]

Concerning health, duties to fulfill include, for example, providing immunization programs against major infectious diseases, providing sexual and reproductive health services, and promoting health education.[36]

Artavia Murillo et al. ("In Vitro Fertilization") v. Costa Rica (2012) was the first case related to reproductive rights and ARTs decided by the IACHR. The main legal issue was determination of whether the prohibition against IVF arbitrarily affected the rights to personal integrity (article 5), personal liberty (article 7), a private life (article 11), and a family (article 17), as well as the prohibition against discrimination (article 1.1). The process was first to assess whether there was an interference with exercising those rights and, if so, to establish whether such interference was arbitrary or disproportionate. In analyzing the first step, the IACHR had the opportunity to set several legal standards for the first time.

According to the IACHR, personal liberty (article 7) includes "a concept of liberty in a broad sense as the ability to do and not do all that is lawfully permitted. In other words, every person has the right to organize, in keeping with the law, his or her individual and social life according to his or her own choices and beliefs." In addition, the IACHR has also underscored the concept of liberty and the possibility of everyone's self-determination and freedom to choose the options and circumstances that give meaning to their life, according to their own choices and beliefs.[37]

Private life (article 11) encompasses aspects of physical and social identity, including the right to personal autonomy, personal development, and the right to establish and develop relationships with other persons and the outside world.[38] The right to a private life is crucial for exercising personal autonomy and shaping the future course of events that impact a person's quality of life. Private life includes how individuals view themselves and decide to project this view toward others, and is an essential condition for the free development of personality.

The right to a private life and the right to personal liberty are closely related to reproductive autonomy and access to reproductive services, which encompass the right to access the medical technology necessary to exercise these rights. For the first time, the IACHR mentioned the right to "reproductive autonomy" protected by the convention as a derivation of the right to a private life and personal liberty. Moreover, the IACHR mentioned (also for the first time) access to scientific progress as a means of realizing the right to reproductive autonomy.[39]

Access to the benefits of scientific progress is not expressly formulated in the American Convention on Human Rights. But it is recognized in the Universal Declaration of Human Rights (article 27) and the International Covenant on Economic, Social and Cultural Rights (article 15). Accordingly, states must maximize their available resources to fully realize the right to participate and enjoy the benefits of scientific progress and its applications. While full realization of the right may be achieved progressively, steps toward it must be taken immediately or within a reasonably short period by adopting legislative and budgetary measures.[40]

In addition, General Comment 25 states that access to scientific progress should have a gender-sensitive approach and that state parties should provide access to modern and safe forms of ARTs and other sexual and reproductive goods and services based on nondiscrimination and equality. Particular attention should be given to the protection of women's free, prior, and informed consent in treatments or scientific research on sexual and reproductive health.[41]

Reproductive autonomy and sexual and reproductive health are also related to health care. They require access to good-quality facilities, goods, information, and services, including access to family planning, which is evidence-based, scientifically sound, and medically appropriate, and up to date.[42] This requires trained, skilled health care personnel and scientifically approved and unexpired drugs and equipment. The failure or refusal to incorporate technological advances and innovations in the provision of sexual and reproductive health services, such as assisted reproductive technologies, jeopardizes the quality of care.[43]

The right to reproductive health entails the rights of women and men to be informed about, be free to choose, and have access to methods of fertility regulation that are safe, effective, easily accessible, and acceptable.[44] The right to health also entitles everyone to unhindered access to health facilities, goods, services, and information.[45]

More generally, the right to health contains both freedoms and entitlements.[46] The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment, and experimentation. By contrast, the entitlements include the right to a system of health protection that provides equal opportunity for people to enjoy the highest attainable level of health.[47]

Discussion

Reproductive autonomy and proportionality test

To not allow the coverage of PGT, the judicial branch in Argentina interpreted that the right to reproductive health of the claimants was not absolute, much less in the face of the protection of human life, in this case, of the embryos not to be transferred. The discarding of embryos, a possible consequence of PGT, went against Argentina's definition of life, which "begins with conception."[48]

However, in 2012, in the case *FAL s/ medida autosatisfactiva*, the Supreme Court was asked to determine whether a woman's right to choose must yield under the absolute protection of the right to life of an embryo/fetus.[49] The court held that a balancing test should be applied, and that no absolute right to prenatal life exists. The court, rather than relying on case law, relied on international human rights conventions. In particular, the justices established that the right to life—recognized in article 1 of the American Declaration of the Rights and in articles 3 and 4 of the American Convention on Human Rights—was "expressly limited in their formulation so that the invalidity of an abortion like the one in this case could not be derived from them."[50] Therefore, the right to prenatal life is not absolute and must be interpreted together with the right to liberty, equality, and dignity.[51]

In *FAL*, the justices concluded that no absolute protection of the right to life was established in the international conventions on human rights, and explained that, under article 75 of the Constitution, legislators have the duty to promote positive measures to guarantee the protection of women's rights during and after pregnancy.[52]

On the other hand, in *Artavia Murillo et al. ("In Vitro Fertilization") v. Costa Rica*, the IACHR examined whether the state's interference with the exercise of rights was also arbitrary or disproportionate. The IACHR found that the ban on IVF did not meet the essential requirement of pursuing a legitimate aim and analyzed proportionality *strictu sensu* to perform a balancing exercise. For the limitation to be proportional *strictu sensu* in the specific case, it must satisfy to a significant degree the protection of prenatal life without nullifying the rights involved. The balancing was achieved according to three issues: (1) the degree of impact on the rights at stake (grave, intermediate, or moderate); (2) the importance of the satisfaction of the interest pursued by the limitation; and (3) whether the satisfaction of the latter justifies the limitation of the former. Concerning the degree of interference in the exercise of the rights involved, the IACHR affirmed that it was grave particularly relating to the couples whose only option to have a biological child was through IVF. It mentioned, among other aspects, the psychological impact derived from the lack of access to an existing procedure that enabled their reproductive liberty.

Regarding the importance of the satisfaction of the interest to protect embryonic life, the IACHR indicated that the evidence suggests that embryonic loss takes place in the context of both natural and IVF-assisted pregnancies, and was disproportionate to claim absolute protection of the embryo concerning a risk that is not only common but inherent to the natural process of conception.[53] Based on those findings, the IACHR concluded that the prohibition against IVF created a severe limitation to the rights to personal integrity, personal liberty, privacy, reproductive autonomy, access to reproductive health services, and starting a family. In contrast, the impact on the protection of the embryo is meager, given that embryonic loss occurs in IVF and natural pregnancy. Therefore, the IACHR affirmed that the protection of embryonic life had no basis under the American Convention, and the limitation of the rights at stake was disproportionate.

Taking these precedents into account, I now consider whether the decisions regarding PGT in Argentina are proportionate. Concerning the idea that life begins at conception, since 1921 in Argentina, abortion was not punishable in three circumstances: if the pregnancy was the consequence of rape, the life of the mother was in danger, or the pregnancy was inviable (the Supreme Court in *FAL* also pointed out these exceptions).[54] Moreover, at the end of 2020, the abortion law was approved by the Congress, allowing abortions until 14 weeks. In this sense, the limitation on PGT on couples or persons in Argentina nullifies numerous rights to protect the embryo's life. Concerning the degree of interference in the exercise of the rights involved, it was grave; couples who asked for access to PGT had a history of serious genetic problems, and it was their only option to have a child.

In addition, while the CCCN establishes in article 19 that "the protection of the non-implanted embryo shall be the subject of a special law," this remains unregulated. Given that the legal permissibility of PGT is tied to the legal status of non-implanted embryos, and this legal status remains unregulated, the current Argentinian framework presents a legal vacuum. Additionally, PGT does not violate article 57 of the CCCN, as it does not produce a genetic alteration in the embryo. In this sense, in the PGT cases, it is disproportionate to claim absolute protection of the embryo concerning a risk that is not only common but inherent to the natural process of conception; embryos that would not survive are being deselected, not all embryos. In this type of case, PGT does not harm the embryos; it is intended to protect the development of the embryos themselves—in other words, to prevent the transmission of a hereditary disease.

Disability, right to health, and preimplantation genetic testing

The IACHR also considered (in establishing the severity of the limitation) the fact that infertility can be viewed as a disability. The IACHR noted that individuals with disabilities are entitled to special protection due to the specific duties that the state must fulfill to comply with its general obligation to respect and guarantee human rights. In addition, the IACHR adopted a social model approach: disability is not defined exclusively by the presence of a physical, mental, intellectual, or sensory impairment, but rather by the interrelation of the barriers or limitations that exist in society, preventing the individual from exercising their rights effectively. The types of limits or barriers commonly encountered by individuals with functional diversity in society include those that are attitudinal or socioeconomic.[55]

In this sense, article 18 of the American Convention on Human Rights states that "everyone affected by a diminution of his physical or mental capacities is entitled to receive special attention designed to help him achieve the greatest possible development of his personality."[56] Both the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities and the Convention on the Rights of Persons with Disabilities emphasize that disability results from the interaction between an individual's functional limitations and environmental barriers that prevent the full exercise of their rights and freedoms.[57]

The IACHR recalls that it is not sufficient that the states abstain from violating rights; instead, they must adopt positive measures.[58] In this regard, states are obliged to facilitate the inclusion of people with disabilities by ensuring equality of conditions, opportunities, and participation in all spheres of society, thereby guaranteeing that these limitations are dismantled.[59] People with disabilities have the right to access the necessary techniques to resolve reproductive health problems, which can be inferred from article 25 of the Convention on the Rights of Persons with Disabilities.

Therefore, not providing access to PGT affects not only people's desired reproductive liberty but also their right to access the benefits of scientific progress and disproportionately affects people with disabilities, who, without it, cannot become parents. Furthermore, given that PGT is a recommended medical treatment for people who already suffer from infertility, a type of disability, and that it is only recommended in cases where people could suffer from a different kind of serious illness, denying them access to PGT through medical coverage disproportionately affects their right to health.[60]

Class, gender, and preimplantation genetic testing coverage

The IACHR also made an interesting point about gender and class, stating that not all infertile couples have the economic resources to travel to another country where IVF is permitted. Regarding PGT in Argentina, the tests are available; however, the discussion centers on whether they would be covered by health insurance. This fact may not affect wealthy individuals, but it does impact those who cannot afford to pay for PGT, which is a violation of the right not to be discriminated against. In addition, not allowing the coverage of PGT denies access to scientific progress, lacks a gender-sensitive approach and, as a result, state parties are failing to provide access to modern and safe forms of ARTs and other sexual and reproductive goods and services based on nondiscrimination and equality.[61]

The possibility of motherhood is a part of the free development of a woman's personality, and the right to a family is recognized in article 17 of the American Declaration.[62] In *Artavia Murillo v. Costa Rica*, the IACHR considered whether the decision to become a parent is part of the right to private life and includes, in this case, whether to become a mother or father in a genetic or biological sense.[63] In addition, while the role and status of women in society should not be defined solely by their reproductive capacity, femininity is often defined by motherhood.[64] Even when men can suffer discrimination for their infertility, the personal suffering of the infertile woman is exacerbated, and it can lead to stigmatization, especially in Latin American societies, in which motherhood is considered an aim of every woman.[65] This is especially relevant in the PGT case.

Courts in Argentina have supported petitioners' claims to various medical treatments, based on the right to health, even when this could have significant resource implications.[66] The Argentine government raised the public resource argument in a case where plaintiffs asked that the state ensure access to HIV/AIDS treatment in public hospitals. The state claimed that a finding in favor of petitioners would affect the distribution of resources for public health and that allocating resources for HIV treatment was a policy determination not subject to judicial review. The Supreme Court ruled in favor of the petitioners, stating that the court was not illegally affecting public resource distribution, considering that disease care is already a state obligation.[67] The Supreme Court took it upon itself to enforce a legal duty established in the Constitution and national law on HIV/AIDS.[68]

Furthermore, in a case concerning coverage for asthma medications, the justice pointed out that it is practically impossible for regulations to cover all medical situations that, from a constitutional point of view, should be included. There is a time lag between the enactment of such regulations and the emergence of new medical conditions that need to be addressed. The regulatory vacuum resulting from this situation can be interpreted in two ways: either the regulatory omission reflects the reluctance of the authorities to protect the right to health in all cases not expressly covered, or it represents an approximate level of protection that can be extended in certain circumstances by the courts. I consider the second interpretation as the plausible one. Under these principles, the fact that the drug or a treatment in question is not included in the norms is not sufficient in itself to exempt the obligation to assist when, as in this case, treatment is available.[69]

Similarly, according to the IACHR, the obligation to fulfill "is not limited to the constitutional or legislative text, but must extend to all legal provisions of a regulatory nature and be translated into the effective practical application of human rights protection standards."[70] In this case, access to PGT should be made available and considered a right to reproductive health service and autonomy. Since the list of ART treatments were last approved in 2018, and social rights should be progressively realized, it is time that Argentina adds PGT to the list.[71] In addition, in *SC and GP v. Italy*, the Committee on Economic, Social and Cultural Rights, regarding regulation of IVF and possible research on embryos and stem cells, the views of society have evolved significantly, and science and technologies are in a constant state of development. For these reasons, states should regularly update their regulations to align them with human rights obligations and the evolving needs of society and scientific progress.[72]

Conclusion

The coverage of PGT is essential for safeguarding several fundamental human rights, including reproductive freedom, the right to health, the right to form a family, and access to scientific advancements. The absence of coverage for PGT disproportionately impacts marginalized groups, particularly individuals with disabilities, women, and those from economically disadvantaged backgrounds. This lack of access not only undermines the principles of progressiveness and social justice but also exacerbates existing inequalities in reproductive health care.

Furthermore, the arguments posited by the judiciary regarding the definition of the beginning of life stand in stark contrast to the proportionality test established by the IACHR and the jurisprudence of the Argentine Supreme Court, particularly as highlighted in the landmark case known as *FAL*. These contradictions raise significant concerns about the coherence and fairness of legal interpretations regarding reproductive rights.

This situation necessitates an urgent and thorough reassessment of current regulations governing reproductive health to foster health equity and recognize the inherent rights of all individuals to make informed choices regarding reproduction. The Ministry of Health, endowed with the authority to approve new ART treatments, is in a pivotal position to drive this change. By formally incorporating PGT into Argentina's health care coverage, the country stands to benefit from advances in genetic science while simultaneously ensuring that reproductive health rights are upheld in accordance with global best practices. Regarding cost, Argentina could follow the HFEA's regulations, which authorize the use of PGT-M and PGT-SR in only five exclusive circumstances. This alignment would not only promote social justice but also enhance reproductive health outcomes for all, paving the way for a more inclusive and equitable health system.

Acknowledgments

Thanks to Susan Crockin and Guillermina Pappier for their reviews on the first drafts of this paper.

Funding

This work was supported by the Belén Ríos Health and Human Rights Scholarship, awarded by the O'Neill Institute for National and Global Health Law at Georgetown University.

Translation

All translations from Spanish to English were performed by the author.

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Women's Perspectives on Barriers to Skilled Birth Attendance and Emergency Obstetric Care in Rural Tanzania: A Right to Health Analysis

PRISCA TARIMO, GILLIAN MACNAUGHTON, TAREK MEGUID, AND COURTENAY SPRAGUE

Abstract

Tanzania is among the countries with high rates of maternal mortality. In 1976, Tanzania ratified the International Covenant on Economic, Social and Cultural Rights, which enshrines the right to health, including maternal health care. This right is further recognized in national law and policy. Despite these commitments, Tanzanian women continue to die from preventable maternal causes. Using a right to health lens, this qualitative study explored the barriers preventing rural underserved women from seeking skilled birth attendance and emergency obstetric care in Ngorongoro, Tanzania, where the use of such services has historically been low. Our study included a document review of maternal health-related laws, policies, and reports issued by governmental and nongovernmental entities, alongside interviews with 32 women of reproductive age. We found that the right to quality maternal health care was constrained by (1) low government budget allocations, (2) a lack of skilled health providers and maternal health care infrastructure and supplies, (3) long distances to health care facilities and a lack of transportation, (4) high cost of transportation and health facility delivery, (5) the tradition of home delivery, and (6) distrust that health care facilities would provide respectful and culturally appropriate care. We then generated key recommendations to overcome such barriers and thereby improve rural maternal health care and reduce maternal mortality.

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Competing interests: None declared.

Introduction

Maternal mortality—that is, deaths due to pregnancy- and childbirth-related complications—is a global public health and human rights concern. Worldwide, 800 women of reproductive age die each day from maternal causes that are highly preventable.[1] Countries in Sub-Saharan Africa account for an estimated 70% of global maternal mortality.[2] Tanzania is among these countries with high rates of maternal deaths. According to the World Health Organization, Tanzania's maternal mortality rate decreased between 2000 and 2020 from 760 to 238 deaths per 100,000 live births.[3] Nonetheless, the rate remains high, underscoring the need for the country to accelerate progress toward achieving Sustainable Development Goal target 3.1: to reduce the maternal mortality rate to fewer than 70 deaths per 100,000 live births by 2030.[4]

Maternal mortality can result from direct medical causes (such as hemorrhage, hypertension, sepsis, and obstructed labor) or indirect causes aggravating or aggravated by pregnancy (such as HIV, malaria, and anemia).[5] However, effective interventions to manage and treat the causes are widely known and can be administered during antenatal care and during and after birth.[6] Significantly, most maternal deaths can be prevented if (1) births are assisted by skilled birth attendants (SBAs) and (2) all births ending in complications (about 15%) receive emergency obstetric and newborn care (EmONC). EmONC refers to a set of nine lifesaving interventions defined by the World Health Organization.[7] In Sub-Saharan Africa, many women, particularly those in rural areas and poorer households, continue to die due to a lack of appropriate care.[8] This is an unacceptable injustice, as women's health is a fundamental human right.[9]

Article 12 of the International Covenant on Economic, Social and Cultural Rights recognizes the right of everyone, including pregnant women, to the enjoyment of the highest attainable standard of physical and mental health, also known as the right to health.[10] General Comment 14 on the right to health, issued by the United Nations Committee on Economic, Social and Cultural Rights, states that the right to health encompasses an *entitlement* to a system of health protection with functioning health facilities, goods, and services and, further, that governments have the *obligation* as duty bearers to ensure the availability, accessibility, acceptability, and quality (AAAQ) of services women need (see Table 1).[11] This includes the core obligation to improve reproductive, maternal, and newborn health care, including family planning, antenatal care, postnatal care, EmONC and access to information.[12]

In 1976, Tanzania ratified the International Covenant on Economic, Social and Cultural Rights, recognizing the right of everyone to health care, including sexual and reproductive health care. The National Health Policy of 2007 also recognizes the right to quality, equitable, affordable, and accessible health care and prioritizes vulnerable groups, including pregnant women.[13]

Moreover, since 2008, the Ministry of Health has implemented an integrated National Plan for Reproductive, Maternal, Newborn, Child and Adolescent Health. The plan (2016–2020 and 2021–2026) aims to reduce maternal mortality by improving the availability of basic EmONC to 70% of dispensaries and 100% of health centers, and the availability of

Table 1. The right to health AAAQ framework

Availability	Maternal health facilities, goods, and services, as well as the underlying determinants (e.g., drinking water, sanitation), must be available in adequate quantity in the country.
Accessibility	… must be physically and geographically accessible, economically affordable, accessible in terms of information (ensuring the right to seek, receive, and impart health information), and nondiscriminatory.
Acceptability	… must be respectful of medical ethics, culture, gender and life cycles, and confidentiality.
Quality	… must be scientifically and medically appropriate and of good quality (e.g., unexpired drugs, up-to-date equipment, evidence-based interventions, well-trained providers, safe and potable drinking water, and adequate sanitation).

comprehensive EmONC at 100% of hospitals and 50% of health centers.[14] Lastly, Tanzanian policy stipulates that maternal health services be provided free at the point of service.[15] These strategies align with Sustainable Development Goal target 3.1.

Despite these legal and policy commitments, many women, especially in rural and poor households, continue to lack access to SBAs and critical care during birth. While births with SBAs increased nationwide from 64% in 2015/2016 to 79% in 2019/2020, coverage remains lower in rural areas (42% to 55%), where about 70% of Tanzanians live, compared to urban areas (83% to 87%).[16] Moreover, lifesaving EmONC coverage for women facing obstetric complications, such as cesarean deliveries (C-sections), was lower in rural areas (5% coverage) relative to urban areas (10%).[17] The health sector plan (2021–2026) aims for 85% SBA coverage nationwide and 75% SBA coverage at district council levels and among the poorest households.[18] The extent to which these policies are actually benefiting women on the ground and reducing maternal mortality remains questionable.

Studies across low- and middle-income countries, including Tanzania, have found that high maternal mortality is attributed on the supply side to the poor funding of health systems, understaffing, and the absence of essential infrastructure for quality EmONC—factors that replicate societal inequities of access.[19] On the demand side, studies in rural Sub-Saharan Africa have found several barriers to the use of SBAs and EmONC, including women's social status (as it relates to education, income, obstetric knowledge, and autonomy), long distances to health facilities, lack of transportation, hospital fees and other costs, cultural beliefs, family responsibilities, and poor quality of care.[20] For example, researchers found that women who lived over 35 kilometers from comprehensive EmONC facilities, such as a hospital, were four times more likely to die of maternal causes than women living 0–5 kilometers from a hospital, as the long distance contributed to more home deliveries and delays in accessing emergency obstetric care.[21] Further, increasing evidence is unveiling how the mistreatment of women by health care providers in facilities makes women hesitant to access health facilities for childbirth.[22] Significantly, women in the poorest 20% quintile are three times more likely to deliver at home, relative to the wealthiest 20% quintile.[23]

In the context of addressing maternal mortality through a human rights lens, we found three studies conducted in rural Tanzania. Using the AAAQ framework, Thomas John et al. assessed health workers' perspectives on barriers to and strategies for fulfilling women's right to quality maternal health care.[24] Andrea Miltenburg et al. explored the human rights principles of dignity, autonomy, equality, and safety in their study of women's experiences of facility-based maternal health care.[25] Lilian Mselle et al. used Thaddeus and Maine's three-delays model to explore the experiences of women who developed fistula after prolonged labor.[26] Together, these studies concluded that there has been a failure to realize women's right to accessible and quality maternal health care, attributed primarily to inadequate health care resources, providers' negative attitudes, and inequitable access owing to long distances, poor transportation, and high costs. Additional context-specific, rights-based studies are needed to illuminate why rural communities are left behind and to inform context-appropriate, rights-based solutions. Accordingly, we applied the AAAQ framework to explore women's perspectives on barriers to using SBAs and EmONC in Ngorongoro, Tanzania, an underserved rural district.

Methods

Study setting

Ngorongoro is a rural district of Arusha, Northern Tanzania. Its estimated population of 200,000 consists predominately of Maasai pastoralists (80%) and agropastoral Watemi or Sonjo people (11%).[27] Historically, Maasai pastoralists in Ngorongoro and other areas of Tanzania have experienced marginalization and loss of land rights and other resources, which has made them socially and economically vulnerable.[28] We selected Ngorongoro due to its high maternal mortality rate (383 per 100,000 live births) compared to the national maternal mortality rate (238 deaths per 100,000 live births).[29] The district also has comparatively poor maternal health indicators. Only 55% of deliveries occur in a health facility, compared to the national average of 83%.[30] Generally, low utilization of SBAs during delivery has been persistent in the district.[31] The district is divided into three administrative divisions: Loliondo, Sale, and Ngorongoro. There are 33 health facilities—2 hospitals, 5 health centers, and 26 dispensaries—providing delivery care. Comprehensive EmONC, such as C-sections, is provided only in the hospitals.

Design and methods

We used a right to health framework (AAAQ) and qualitative methods to explore the perspectives of rural women on barriers preventing delivery in health facilities and utilization of EmONC. First, we conducted a review of international human rights law and policy on the right to health and preventable maternal mortality, as well as Tanzanian laws, policies, plans, reports, and surveys on health system strengthening and maternal health, to understand the policy background and progress to date. Examples of documents reviewed include the International Covenant on Economic, Social and Cultural Rights; General Comment 14; Sustainable Development Goal 3.1; Tanzania's Health Sector Strategic Plan (2015–2020 and 2021–2026); the National Plan for Reproductive, Maternal, Newborn, Child and Adolescent Health (2015–2020 and 2021–2026); the Health Sector Strategic Plan IV, 2015–2020 Review (September 2019); and the Tanzania Demographic and Health Survey (2015–2016).

Second, based on the document review and a 2018 pilot study, we created a semi-structured interview guide to conduct face-to-face interviews in 2021 with 32 women aged 18–49 with children aged 0–24 months. Participants responded to questions about where they had their last birth, why they chose facility or home delivery, and what barriers they perceived to health facility delivery and quality EmONC during emergencies. Two (of three) administrative divisions were purposively sampled: Loliondo (town) and Sale (remote). A trained field researcher recruited participants in person from eight health facilities (one hospital, five health centers, and two dispensaries) where they attended child-well clinics. The researcher obtained verbal informed consent from each participant for conducting and recording the interviews. Interviews ranged from 30 to 90 minutes, were conducted in Swahili, and were later transcribed into English by the first author. Data from the interviews and documents were analyzed thematically based on the AAAQ framework. ATLAS.ti software was used to analyze interview transcripts. The use of both document review and women's interview narratives increased the trustworthiness of the data, through the triangulation of information sources. Ethical approval for the study was obtained from Tanzania's National Institute for Medical Research (Ref No. NIMR/HQ/R.8a//Vol.IX/3430) and the University of Massachusetts Boston (2019187).

Findings and analysis

Demographic characteristics of participants

Of the 32 women, the majority were pastoralists and agropastoralists, signifying poor households. Fourteen were Maasai, 12 were Watemi (Sonjo), and the remainder belonged to other tribes; 21 were married and 11 were unmarried; 20 had completed primary school, 7 had finished secondary school, 3 held diplomas, 1 held a college degree, and 1 had no schooling. Regarding place of childbirth, 28 had given birth at health facilities and 4 at home. Including previous births, at least 11 women had had home births with traditional birth attendants (TBAs) or family assistance; 8 women had had only one birth experience. Facility-based deliveries included 10 at the hospital, 10 at health centers, and 8 at dispensaries; 26 women had experienced natural deliveries, while 6 had undergone C-sections.

Based on the AAAQ framework of the right to health (Table 1), we present the perspectives of these rural women on barriers to using SBAs and EmONC in facilities and place these perspectives in context utilizing our document review.

Availability

The right to health requires that health facilities, providers, goods, and services be *available* in sufficient quantity in the country to ensure that women can access and utilize SBAs before, during, and after birth.[32] Findings from the document review demonstrate that the Tanzanian health care system overall, and Ngorongoro District specifically, suffer a shortage of health facilities, providers, and supplies needed to ensure the availability of quality maternal health care. Women's narratives also reinforced this finding, illustrating how this lack of resources acted as a barrier for women to access and deliver in health facilities. States are required to ensure maximum available resources to finance maternal health care. Tanzania, however, a lower-middle-income country, spends little on health care. In 2020/2021 and 2021/2022, government health expenditure as a proportion of total expenditure was 6% and 8%, respectively, below the 15% recommended by the African Union Abuja Declaration.[33]

Regarding the availability of health facilities, the Primary Health Care Service Development Programme (2007–2017) aimed to improve equity of access to maternal health care by increasing rural primary health care facilities and requiring every village to have a dispensary, every ward to have a health center, and every district to have a council hospital. Nationally, achieving the program target required 16,487 health facilities of all types in Tanzania. However, by 2020, only 8,665 health facilities were available—just 50% of the program goal.[34]

At the Ngorongoro District level, there was an acute shortage of health facilities (60% shortage), especially for primary health care.[35] Although there are an adequate number of hospitals for comprehensive EmONC population-wise, the lack of adequate lower-level health facilities contributed to many women in remote areas giving birth at home. As one woman reported:

> *Of my five children, the first three were delivered at home because there were no health facilities nearby; I had gone to the wilds at Ngusero to herd cattle and there were no health facilities there.* (participant #14)

Another participant stated:

> *In this area, we do not have enough health facilities. They also have limited staff who have many patients to attend to.* (participant #28)

Regarding availability of health professionals, our document review found that Tanzania had a 52% shortage of the required health workforce. Only 95,827 of 208,595 available staff positions had been filled.[36] Regarding distribution, only 54% of the workforce worked in rural areas where 70% of Tanzanians live. In Ngorongoro, the shortage was higher: 72%.[37] Similarly, women reported insufficient health providers and their absence on-site when women needed help. Participants explained:

> *At the antenatal clinic, they will advise you to deliver in a health facility. The problem is that in our ward we have a new dispensary, but it is not providing health services yet due to lack of health care providers. As a result, we have to go to the health center, which is far from here.* (participant #30)

> *Yesterday … there was a woman who struggled to give birth … and lost her baby at the health center because there was no skilled midwife available to help her. The family later called a TBA who came and helped her give birth in the health center, but the baby died.* (participant #8)

Women described most primary facilities as lacking adequate medicines, supplies, and beds for labor and delivery. One participant lamented:

> *Sometimes the doctors do not have equipment, such as gloves, and this encourages women to give birth at home. If you come here and they do not have gloves, … they will just give you a referral or send you home. Sometimes women end up giving birth on the way before getting home.* (participant #15)

Another participant stated:

> *I was not pleased with the condition of the labor*

> *ward. They do not have enough beds. Each bed was shared by two or more women which I do not think is healthy.* (participant #3)

A dearth of funding, facilities infrastructure, and skilled health professionals also affected the availability of EmONC. Women reported that most health centers and dispensaries in rural areas lacked quality EmONC to stabilize women with complications, requiring referrals. Emergency referrals were also challenging because only one ambulance functioned in the district. Comprehensive EmONC was provided only at the two hospitals, despite guidelines requiring at least 50% of all health centers in underserved areas to provide comprehensive EmONC. One participant explained:

> *There is lack of advanced services at the dispensary. If a woman has complications, they have to call an ambulance from Loliondo to come and take her to the hospital. For example, if someone needs surgery, they have to go to the hospital in Loliondo, which is very far from here [150 kilometers]. We also have few health workers.* (participant #18)

Another participant exclaimed:

> *I could have died if I had delivered here at the health center because they do not have services for blood transfusion, and it would have taken longer for me to get to the hospital because of the long distance.* (participant #30)

Nationwide, basic EmONC is available at only 20% of dispensaries and 39% of health centers relative to the 70% and 100% required, respectively.[38] Comprehensive EmONC is available at only 80% of hospitals and 50% of health centers (but up from 17% of health centers in 2017), compared to the 100% and 70% required.[39]

Accessibility

Accessibility means that maternal health services must be within safe geographical distance, affordable, and nondiscriminatory, and must ensure access to information.[40] Evidence revealed that facilities' geographical inaccessibility hindered rural women from accessing skilled delivery care, including timely EmONC during complications. The district's remoteness and the limited number of facilities in rural areas put communities, especially pastoralist nomads, far from services, especially hospitals. Women from the Sale community (remote division) reported having more difficulty accessing services requiring C-section and blood transfusions at Wasso hospital (64–116 km), compared to Loliondo women (0–35 km). They also reported that women in isolated rural areas often gave birth at home due to the high risk of giving birth on the roadside while traveling to facilities. In most cases, facility care was pursued as the last resort, when home deliveries ended in complications. One participant recounted:

> *We live very far from this dispensary. Some women are worried that they might give birth on their way to the hospital. Even this child was born while on our way to the dispensary. I had traveled a long distance from home to here [64 km to hospital].* (participant #22)

Another participant explained:

> *Maternal deaths are unavoidable in this community because health services are very far from people's residences. For example, if you develop a major complication you will have to go to Wasso hospital, which is very far from here. You might lose your life before you arrive. If health services are brought near to us, we will be able to cut down a lot of maternal deaths.* (participant #30)

Poor transportation, one functioning ambulance, poor roads, and seasonal rains also hindered access to facilities, especially during emergencies. Many rural women reported walking long distances to health facilities (up to two hours) or using motorbikes (*bodaboda*). Those developing complications at home or at primary facilities would have to hire expensive private transportation to a hospital. Two participants elaborated:

> *Sometimes you have to travel 60 kilometers to reach a health facility. Unfortunately, at this place, bodabodas are the common means of*

> *transportation. However, motorcycles are not safe for a pregnant woman. She may give birth before reaching a health facility due to poor roads. Most roads are inaccessible during rainy season.* (participant #10)

> *Now there is only one ambulance that is also not reliable. We may request the ambulance, but the driver may not come … or by the time the ambulance reaches her, she is already dead and left the child behind. Sometimes both the mother and the child die.* (participant #1)

These conditions made transportation costs unaffordable for most women in rural areas. As one recalled:

> *I ended up giving birth at home because we did not have access to transportation. There were no motorcycles nearby and it was too expensive to hire a car.* (participant #15)

Hospital fees also encouraged home delivery. Maternal and child health services are exempted from user fees in Tanzania.[41] However, some women reported paying out-of-pocket fees for C-sections and birthing supplies required by facilities. Participants perceived hospitals as more costly than health centers and dispensaries, and therefore, pastoral and poor women avoided them. One participant recalled:

> *I paid for the operation [C-section] after I was referred to the hospital and for the equipment and supplies used. Those who give birth naturally bring only their own gloves and other supplies needed such as medicine for IV drips and delivery kit.* (participant #28)

Another participant explained:

> *Not all women are able to buy the supplies needed for childbirth. Sometimes because of lack of education and low income, it may be difficult for some women to prepare or pay for the supplies needed during childbirth.* (participant #9)

A Maasai woman reported that women unable to pay for services were sometimes denied services, an experience that discouraged them from returning: “Sometimes, you may be denied services and die just because you did not have money to pay upfront for the care needed” (participant #8). Another participant remarked, “Some of them [women] do not have money to meet their basic needs such as food while at the hospital” (participant #12).

Furthermore, facility rules that imposed penalty fees or deny care to women who did not comply with antenatal care attendance also encouraged home delivery. One participant reported:

> *Most of those who give birth at home are those who did not have a supportive partner to attend antenatal clinic with … as required. When they fail to attend antenatal clinic, they decide to give birth at home because some health facilities would charge them a fee when they go for delivery, as a penalty for not attending clinic, for services that they deserve to obtain free.* (participant #31)

Low community awareness of the importance of giving birth in facilities also impacted accessibility. Women in remote areas, those with poor antenatal care attendance, women with low education levels, Maasai, and those with language barriers had little awareness and limited access to health information. Also, some women reported that men’s low awareness of and involvement in maternal care limited facility delivery because most households and financial decisions were made by husbands:

> *Women may not be able to deliver in health facilities because their partners are not supportive. Low awareness makes people overlook the benefits of health facility delivery. Most education and counseling tend to focus on pregnant women without involving men. As a result, men may not be supportive of their wives delivering in health facilities.* (participant #10)

Other accessibility barriers included women’s household responsibilities and not having someone to accompany her to a health facility.

Acceptability

Acceptability means that maternal health services must be respectful of medical ethics, culturally appropriate, and sensitive to gender, age, and life-cycle requirements.[42] Women reported that the tradition of home births, distrust of facility birth practices, non-preference for young and male attendants, disrespect from health providers, and language were barriers to facility births.

Participants indicated that pastoral women were inclined to prefer home delivery because, like their ancestors, they trusted TBAs more than health facilities. One participant explained, "Within the Maasai culture, women still prefer and believe in TBAs to help them deliver safely, and that is the reason they continue to deliver at home with TBAs" (participant #2). At the same time, some participants recognized that TBAs lacked the clinical skills and supplies needed for safe delivery:

> *A lot of women die during birth. In Maasai communities, traditional midwives are the ones helping women give birth at home. TBAs do not have any tools to monitor labor progress. They just examine women manually and continue to hold them even when there is a problem. Your husband may listen to the TBA rather than your choice.* (participant #17)

Although TBAs have been banned by the government from assisting home deliveries, they can accompany women to health facilities and, when needed, assist deliveries under SBA supervision. Participants said that some TBAs have accepted this change but that in isolated areas, TBAs are the only help available.

Pastoral women also believed in natural births and disapproved of C-sections. Pastoral women were concerned that hospitals conducted "unnecessary" C-sections, and consequently, they avoided giving birth at hospitals. Others intentionally delayed seeking facility care after the onset of labor to avoid prolonged labor at facilities, which could lead to referral for a C-section. However, such delays put women at risk of delivering at home and did not reduce complications requiring C-sections. Participants also disliked multiple vaginal examinations. Some believed that excessive examinations obstructed labor and led to C-sections. One participant opined:

> *They believe that they will be operated on [C-section] if they stay at the hospital for a long time without being able to give birth naturally. Sometimes, a woman may be forced into surgery. Another thing, … they conduct women exams [vaginal examination]; this is too much … to the extent that you get swollen [cervix]. Every time a different doctor or nurse starts a shift, they check you with their fingers and frequently. In the end, they tell you that you are swollen … you cannot push … you need an operation. This is very discouraging to an extent you do not want to go back.* (participant #4).

Another participant explained:

> *They [women] believe that operations are hospital projects for getting money. A few know that C-sections are done to save the life of the mother and her baby.* (participant #10)

Other factors limiting the acceptance of C-sections included women's low education level, C-section costs, pastoral women's lack of autonomy in consenting, and long recovery times restricting participation in daily activities.

We also found that pastoral women, especially older women, disliked being attended by male midwives and younger birth attendants. Traditionally, TBAs have been older women. One participant recounted:

> *We do not feel comfortable being attended by male midwives. This is not something we are used to. For example, when I came to give birth, I was being helped by a young male doctor. I told the nurse that I do not want to be attended by someone who is young.* (participant #18)

Cold facilities and those disallowing family members to stay with women for emotional and physical support due to lack of space also created discomfort:

> *I went with my mother. However, she left before I gave birth because she was not allowed to stay. I was angry because of the pain. I wondered, "Did my mother bring me here and leave me to die alone?"* (participant #1)

Equally, women reported that their experiences of provider disrespect, mistreatment, and discrimination were barriers. Some participants felt ignored, neglected, and scolded concerning their needs. As one participant stressed:

> *As … Maasai, we are used to giving birth at home. At the hospital, they mistreat us so much that most Maasai women do not want to go back. When women cry for labor pain, or need help, they tell us we do not have any pain. When you feel that the baby is ready to come and tell them, they say you are not ready and chase you back. And … when you go wait outside and suddenly gave birth by yourself, they charge you fine [a cleaning fee] and become harsh at you although they are the ones who refused to help you.* (participant #8)

These women reported feeling helpless and not knowing where to complain about their mistreatment. The few who knew where to submit complaints (e.g., to the person in charge at the facility or village leader) feared future mistreatment if they complained. One participant stated:

> *I do not know … what to do and where to go if I have been mistreated or denied my rights as a patient. We need more education so that women know their rights during pregnancy and childbirth and where they can complain when mistreated. They should be informed whether such care is freely available or not.* (participant #4)

Language was another barrier to using facility services, especially for pastoral women with little education. Participants reported that most facilities were attended by "Swahili" providers (outsiders who could not speak Maasai or Sonjo) and lacked certified language interpreters. Usually, women unable to speak Swahili received help from a family member, another patient, or hospital staff who spoke both languages. However, this lack of privacy and confidentiality made the women uncomfortable about discussing their health issues. It also left participants feeling that their health care needs were only partially addressed. This experience also discouraged future facility care. One participant explained:

> *Language is a huge barrier for Maasai women to access health care because providers and women do not understand each other. A nurse may not understand the real health problem the woman has. I, myself, have helped some patients who did not speak Swahili with interpretation while I was at the dispensary to obtain care.* (participant #19)

Another participant suggested that "the government could also hire more doctors that speak Maasai language," noting that a Maasai woman may avoid going to a health facility because she felt disrespected by the doctor, when in fact it was largely a misunderstanding due to language (participant #25).

Quality

Quality means that health facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired medicines, hospital equipment, safe and potable water, and adequate sanitation.[43]

Most women who gave birth in a health facility were assisted by a nurse, a midwife, a clinical officer, or a doctor—all of whom, by definition, are skilled health professionals. Nonetheless, the majority reported experiencing poor-quality and unscientifically appropriate care, including waiting long hours to receive care. Some participants observed other women giving birth alone or with the help of a TBA, and women and babies died due to delayed care. According to participants, these delays and poor care were caused mainly by a shortage of skilled providers, provider absenteeism, limited service hours, and neglectful attitudes of some providers. One participant explained:

> *Currently, if a woman comes to the dispensary at night to give birth, the health workers may take longer time to respond. This is not safe because some women have already gone through a lot of pain by the time they get here because of the long distance traveled from home. Some women even give birth on the floor while already at the dispensary while waiting for help.* (participant #20)

Another participant similarly stated:

> *Sometimes the nurses are rude. When I got here at the health center at night and was desperately in need of help, the nurse who was here refused to assist me because it was not her shift. I was just*

> *outside lying on the floor waiting in pain without help.* (participant #10)

Limited space and beds in maternity wards also contributed to poor care, including delayed delivery, lack of privacy, and post-delivery discharge before the medically recommended time. One participant revealed:

> *They have few health workers who are overloaded by many patients … Also, there might be two women giving birth at the same time but only one delivery bed is available. As a result, they will tell you to stop pushing until the other woman finishes giving birth.* (participant #28)

Another participant reported:

> *Sometimes you are chased home [discharged] from the hospital even if you are still sick and need more close care. They chase us home so that they can have space for another patient. Some people go home and die because they were sent home early before they get better.* (participant #8)

Generally, the women rated the quality of health care in facilities using phrases such as "it was okay," "not very good," "50/50," "just normal." The hospital was perceived as providing better-quality care than health centers and dispensaries, followed by private (faith-based) health centers. Women's negative birth experiences influenced their decisions to give birth at home or to travel far distances for better care elsewhere. One participant viewed her past experience positively, prompting her to return:

> *I decided to give birth at this health center because they provide good services. Both my children were born here. I had received good care and support from the doctors for my first child and that motivated me to come back for my second birth as well.* (participant #27)

Discussion

Using an AAAQ framework, we conducted a document review paired with interviews with underserved pastoral and agropastoral women in rural Tanzania to identify key barriers limiting these women from exercising their right to SBAs and EmONC.

Availability

Our findings show that there are limited maternal health care resources nationally and in Ngorongoro District, which limits women's ability to exercise their right to health care during childbirth, including delivering in health facilities with SBAs and accessing EmONC. Findings revealed insufficient primary and EmONC infrastructure, including a shortage of health professionals and a lack of supplies needed to ensure service availability. For example, the district had a 60% shortage of health facilities and a 72% shortage of human resources.[44] The shortage of health professionals was evident, as women reported experiencing or seeing other women giving birth without an SBA (either by themselves or with a TBA), while the lack of commodities such as gloves required preventable referrals, an experience that discouraged women from returning to these facilities. Other studies in Tanzania and Sub-Saharan Africa have similarly found a shortage of health professionals, inadequate infrastructure, and lack of supplies as barriers to SBA and EmONC.[45] Meanwhile, the government's health care budget remains far below the 15% of total expenditure recommended in the Abuja Declaration. To improve maternal health outcomes, the government—as the duty bearer in fulfilling the right to health—must allocate adequate funds for health care and prioritize maternal health care resources.

Accessibility

In Tanzania, at least 90% of the population lives within 5–10 kilometers of a primary health facility. Our findings reveal, however, that women in remote areas of Ngorongoro, especially pastoral women, face significant barriers to accessing health facilities for maternal health care, especially EmONC. These barriers include long distances to health facilities, lack of transportation, poor roads, poverty, transportation costs, and unofficial fees. For example, although maternal health care is officially exempted from user fees in Tanzania, women reported paying for C-section deliveries and supplies used during birth at some facilities. These costs drove women to deliver at home with TBAs whose services were free and close to home. Women sought facility care mostly when home births ended in complications. Previous studies in rural areas of Tanzania and Sub-Saharan Africa similarly documented long distances, lack of transportation, and user fees as barriers to facility delivery in rural areas.[46] Both the John et al. and Strong et al. studies in rural Tanzania found pregnant women paying for exempted services, including C-sections.[47]

Additionally, some rural women with low awareness of where to access maternal health care and of the benefits of giving birth in a health facility succumb to misinformation, another barrier to facility delivery. Moazzam Ali et al. and others also found low community awareness and limited information access among nomadic populations as barriers to maternal health care utilization.[48] Beyond the fees documented by previous studies, we found that health facilities were imposing penalty fees for delivery on women who had not attended antenatal care. Rather than encouraging antenatal care, these penalties discourage facility-based delivery for those who cannot afford antenatal care or penalty costs. Our findings underscore that insufficient government funding limits effective implementation of the exemption policy for maternal health care, often forcing providers to ask women to help finance their health care.

Acceptability

Our findings reveal both structural and behavioral factors that normalize the mistreatment of women during birth and limit the provision of culturally sensitive and ethical maternal care.[49] Women reported distrusting health care providers and avoiding births in health facilities due to fear of and experiences of disrespect, mistreatment, and unsupportive care from health providers; pastoralist and poor women reported the worst treatment, including being scolded and neglected, having their movement restricted, and being silenced when they called for help. Pastoral women, especially older women, disliked being attended by male birth attendants and undergoing frequent vaginal examinations, and they were concerned about C-sections being performed without their consent. These fears encouraged births with TBAs, who, although unskilled, are female and support natural births. Interestingly, John et al. had similar findings. Although they interviewed health professionals rather than women, the authors found that acceptability barriers to facility births encompassed disrespect by health care providers, unfulfilled women's preferences, lack of emotional support, unacceptance of male birth attendants, and lack of confidentiality.[50]

Obstetric violence, including disrespectful care, decreases women's confidence to seek help during birth.[51] The Kate Ramsey et al. study in Tanga, Tanzania, concluded that the mistreatment of women during childbirth is systemic, rather than a series of isolated incidents, often normalized by system actors and even expected by women due to facilities' lack of resources, providers' pressure to perform, misaligned incentives, and poor enforcement of respectful maternity care policies.[52] Similarly, our findings demonstrate that women were likely to be ignored or scolded when they did not have the supplies requested (e.g., gloves), when there was one provider attending multiple women, and when women did not provide incentives (or a bribe) to a provider. Women also reported feeling alone during labor because health facilities did not allow a companion in the labor room due to a lack of space and the privacy concerns of other women sharing the space. Further, women reported that labor facilities were cold. To increase trust in the health system among pastoral women in Ngorongoro, interventions implemented include those allowing TBAs to accompany women to health facilities during birth to provide support and help with delivery while supervised by an SBA. However, due in part to language barriers (because TBAs, unlike providers, often do not speak Swahili), TBAs can sometimes end up interfering with SBAs during labor. Nonetheless, one West Africa study found that labor companions can reduce the mistreatment of women during childbirth, while providing emotional support.[53]

Quality

Women's narratives suggested that reaching health facilities alone does not guarantee receipt of skilled, quality care, especially when SBAs were not available on-site 24/7 or were insufficient in number to ensure timely quality care, and when infrastructure and material resources were insufficient to facilitate skilled and respectful care provision. For example, participants perceived EmONC at health centers to be of poor quality due to the lack of maternity wards and emergency vehicles to ensure timely referral care. Overall, participants reported delays, neglect, mistreatment, and language constraints, all signifying substandard care[54] These negative experiences encouraged home deliveries, while some women sought higher-quality facilities farther from home. Study participants wished for maternal health care to be timely, supportive, and respectful of women and their cultures. Other studies suggest that when a woman decides whether to give birth at a health facility, the quality of care—especially provider attitudes—may be as important as distance to the facility[55]

Conclusion

Using a right to health lens, paired with document review and interviews with underserved pastoral and agropastoral women in rural Tanzania, we elevated the voices of these women and their recommendations for maternal health care. The women desire delivery services that are humane—that is, timely, responsive, compassionate, and respectful—and that meaningfully engage women before and during procedures. In particular, they emphasized the need to increase resources to ensure women's access to the free maternal care to which they are entitled and to improve quality EmONC at primary facilities. In Table 2, we summarize further recommendations, drawn from our

TABLE 2. Recommendations to improve the quality and utilization of skilled birth attendants and emergency obstetric and newborn care

Availability	Improve the availability of funding, health facilities, health professionals, and health goods and services: • Spend at least 15% of the national budget on health per the Abuja Declaration. • Provide each district division with a hospital, each ward with a health center, and each village with a dispensary; ensure that 50% of district health centers have comprehensive EmONC. • Ensure sufficient health professionals, equipment, and supplies. • Ensure service availability 24/7.
Accessibility	Ensure accessibility (geographical accessibility, financial accessibility, nondiscrimination, and health information): • Ensure the equitable distribution of maternal resources for rural areas. • Provide incentives to retain providers in rural areas. • Support TBAs in hard-to-reach locations with training and supplies. • Expand maternity waiting homes in health centers. • Improve transportation, road infrastructure, and emergency communication to ensure effective referrals. • Expand maternal health services through mobile clinics. • Ensure free maternal care by adequately financing facilities and monitoring policy implementation. • Repeal facility penalty fees that punish women for not attending antenatal care.
Acceptability	Provide culturally appropriate and respectful care: • Enforce policies on respectful maternity care and nondiscrimination. • Provide training on respectful and compassionate maternity care. • Promote patient-centered care and ensure full informed consent and privacy. • Provide adequate resources and support to reduce health professionals' burden. • Train and hire more local health providers, more women, and certified interpreters. • Use culturally tailored approaches to educate communities on maternal health care. • Strengthen partnerships among TBAs, community health workers, and hospital workers to provide a coordinated support system for women. • Promote labor companions to safeguard women and ensure emotional support.
Quality	Improve quality: • Adhere to quality improvement guidelines, including accountability, adequate resources, continuous training, supportive supervision, visits by specialists, sufficient pay, and performance-based financing. • Ensure effective complaint mechanisms and remedies for women who are mistreated. • Improve facilities and maternity wards by ensuring sufficient space and beds, ventilation, heating, potable water, and sanitation.

evidence, to strengthen maternal service delivery and utilization so that Tanzania can meet its legal obligations to ensure the full realization of the right to maternal health, reduce preventable maternal mortality, and make progress toward achieving Sustainable Development Goal target 3.1.

Study limitations

Our findings are not generalizable to all rural areas of Tanzania but are likely to be relevant among other pastoral communities in Tanzania. Future research could apply other right to health principles—such as accountability, transparency, and participation—together with the AAAQ framework, in similar local and international settings.

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Harm Reduction Policing: A Scoping Review Examining Police Training as a Strategy to Overcome Barriers to HIV Services

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Abstract

Discriminatory laws and punitive policing practices have long been known to impede access to HIV and other health services. While the 2021–2026 Global AIDS Strategy calls for decriminalizing laws targeting key and vulnerable populations, progress toward this goal has largely stalled. To better understand the potential for working with police to ensure access to HIV services, we conducted a scoping review of peer-reviewed and gray literature examining outcomes of police training published between January 2000 and August 2024. Following a review of 639 articles and reports meeting our search criteria, we found 11 peer-reviewed articles and six reports that included outcomes of police training. Our review found that well-designed police training can benefit both law enforcement and communities. It can be a cost-effective public health investment. Best practices for police training included addressing police occupational safety concerns; using trainings as opportunities to build stronger relationships between law enforcement and communities; fostering support from police leadership; and embedding training in a broader effort to change policing. While changing police is complex, our review found a body of literature describing positive outcomes from training, including increasing recognition by police of their role to protect the right to health for key and vulnerable populations.

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Competing interests: None declared.

Introduction

Policing practices have long been shown to have a significant impact on access to HIV prevention, testing, and treatment services for criminalized and highly stigmatized populations.[1] Compelling research has found, for example, clear links between repressive policing and experiences of physical or sexual violence among key populations, which can increase their vulnerability to HIV.[2] Studies have documented policing practices such as confiscation of condoms, arrests and incarceration, and raids and displacement that act as barriers to HIV services for sex workers.[3] Such practices have resulted in both lower condom use and more difficulty negotiating condom use among sex workers.[4] For people who use drugs, research has found negative health outcomes as a result of syringe confiscation by police, and reluctance to carry syringes and rushed injection practices among people who use drugs due to fear of police.[5] Other studies have noted an association between policing and avoidance of harm reduction sites.[6] Criminalization and associated punitive policing practices have also impacted HIV vulnerability among men who have sex with men (MSM) and transgender women.[7]

To eliminate HIV as a global public health threat by 2030, governments must remove barriers that prevent key populations from accessing or being retained in HIV-related services. In support of this approach, the 2021–2026 Global AIDS Strategy includes a goal on the decriminalization of sex work, same-sex sexual relations, transgender people, and drug use, including targets related to removing punitive laws and reducing stigma and discrimination against key and vulnerable populations.[8] Removing such barriers is also a legal obligation for governments under international human rights law: the right to the highest attainable standard of health, which almost all states are legally bound to uphold, stipulates that states must take the necessary steps for the prevention, treatment, and control of "epidemic, endemic, occupational and other diseases."[9] This includes a duty to protect people at risk of infectious diseases from policing practices that put their health at risk.

However, despite global goals and human rights obligations, the criminalization of sex work, drug use, and sexual orientation and gender identity persists, bolstered by broad public support.[10] As a result, the policing of drug use, sex work, and sexual orientation/gender identity will likely continue well beyond 2030.

To better understand the potential for changes to policing as a strategy to ensure access to HIV services and the factors that contribute to positive outcomes of police training, we conducted a scoping review examining training outcomes, including both peer-reviewed and gray literature.

Methods

Over the last few decades, there have been numerous efforts to reduce the negative impact of policing on access to HIV and other health services, often initiated by community-led organizations that work closely with key and vulnerable populations. Interventions have included sensitization activities, the development of police-public health partnerships, community engagement, and regulatory reform.[11] A central feature of many of these interventions has been police education or training programs that aim to teach officers who frequently come in contact with key and vulnerable populations about these populations, public health goals, and occupational safety.

To broadly capture these initiatives alongside research studies, we conducted a scoping review of articles published between January 2000 and August 2024 using a modified PRISMA Extension for Scoping Review protocol.[12] We conducted three different searches in PubMed for each of the three key populations most commonly impacted by policing: people who use drugs, sex workers, and LGBTQ populations. Search terms included combinations of terms such as "police education" or "police training" or "law enforcement training" to identify articles related to police training; "substance use" or "drug use" or "people who use drugs" or "people who inject drugs" or "drug abuse" or "drug user" to identify articles addressing people who use drugs (and similar terms for LGBTQ populations and for sex workers); and terms such as "HIV" or "AIDS" or "hepatitis C" or "dependence" or "addiction" to examine specific outcomes. (See Appendix in the html version of this paper for more specific search details.)

All articles that substantively focused on HIV and police education or training programs and that described program outcomes were included. Articles that focused only on the impact of policing on HIV and key populations were excluded.

All articles were reviewed independently by two researchers, and information on outcomes and potential training best practices were noted. Researchers compared results and resolved any disparities through a reexamination of the article to ensure consensus and consistency with the inclusion and exclusion criteria.

Gray literature was identified through a review of websites of donors and implementing organizations working on this topic; through requests to public health professionals working in international organizations related to HIV and key and vulnerable populations; and by examining citations among peer-reviewed and gray literature for further sources.

Results

Our initial search yielded a total of 623 peer-reviewed articles and 16 gray literature reports. For the peer-reviewed articles, after we removed duplicates and conducted title and abstract reviews, 45 unique publications remained. A full review of these articles found that 11 articles contained data related to key outcomes (Figure 1). Of the 16 gray literature reports initially identified, six reports met the inclusion and exclusion criteria.

All of the peer-reviewed articles identified focused on police training programs for people who use drugs and sex workers; none concerned MSM or transgender populations (Table 1). In the gray literature, we identified six other publications, five which were published as a part of evaluation studies of countries participating in the Global Fund's Breaking Down Barriers initiative and one by the Open Society Foundations (OSF) (Table 2).

Key findings from the studies included how police training programs are conducted and what outcomes of police training are reported, including changes in knowledge, attitudes, and practices, as well as health outcomes and studies of cost-effectiveness. The results of the review are summarized by theme.

How police education programs are conducted

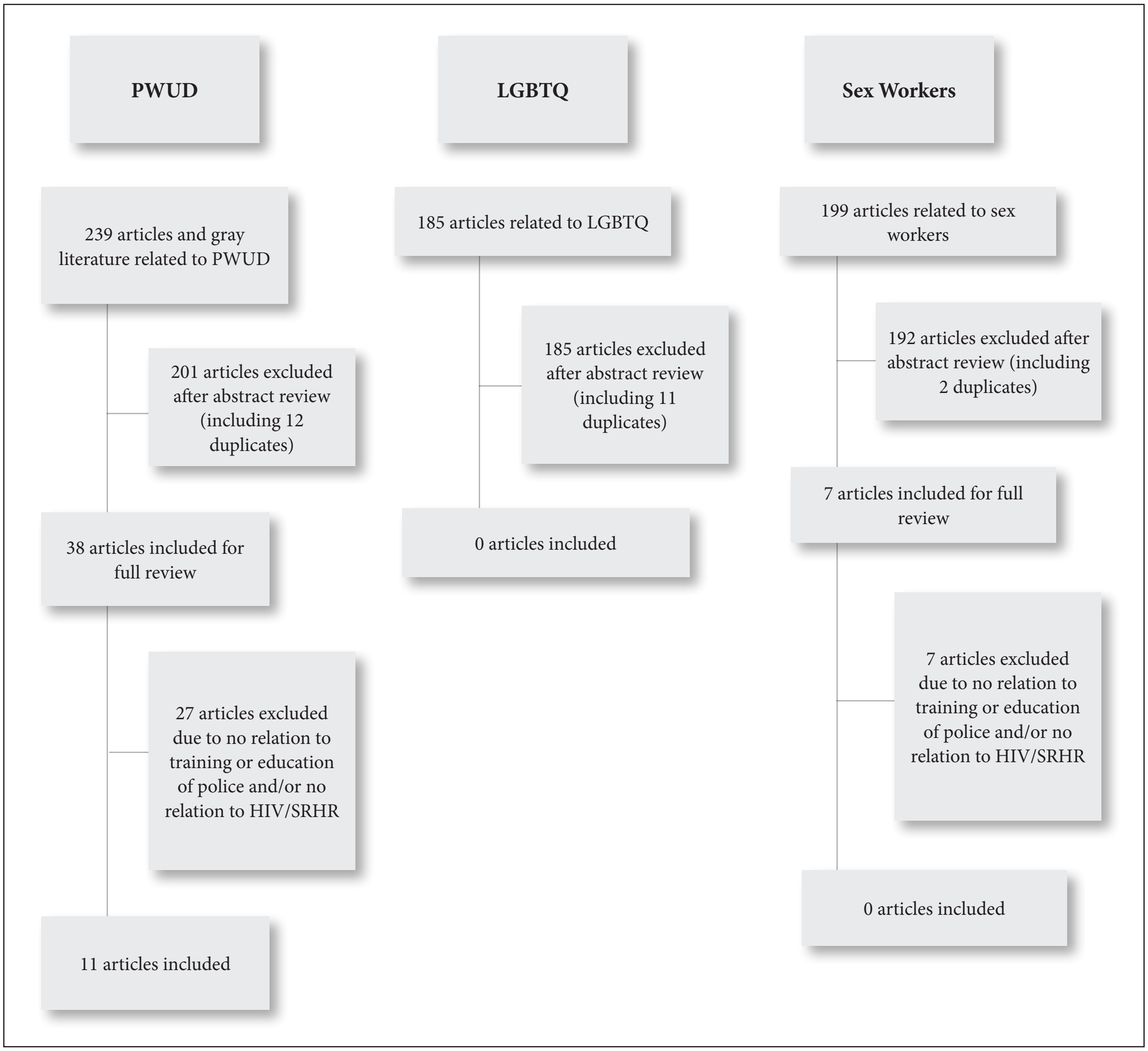
Our review identified a broad diversity in the focus and objectives of police training interventions implemented between 2011 and 2023. Notably, articles on police training published in peer-reviewed literature almost always addressed people who use drugs, while those identified from the gray literature included a broader range of populations, including people who use drugs, sex workers, and LGBTQ populations. Most programs were conducted for active police officers (in-service training); however, training in Ghana, Kenya, and Senegal described combinations of pre-service training (institutionalized through police academies) and in-service police education programs.[13]

While most of the police education programs were established as part of programming to reduce the impact of HIV among key populations, a few were also implemented as part of overdose prevention programming.[14] Most police education programs combined a variety of training topics, including information about HIV, hepatitis C, drug treatment, and overdose prevention; harm reduction programs; laws and policies related to HIV, harm reduction, drug use, and sex work; and occupational safety issues relevant to police, such as avoiding accidental needle pricks. Multiple police training programs described in the gray literature also provided general information about human rights norms and the rights of key and vulnerable populations.[15] By contrast, none of the peer-reviewed studies mentioned attention to human rights. Where these trainings mentioned a focus on law and policy, the focus appeared to be a narrow one on legal provisions such as regulating syringe access or establishing thresholds for criminal liability for possession of drugs.[16]

Peer-reviewed and gray literature reports on police training programs found similar outcomes, including positive changes in knowledge related to harm reduction, relevant laws and policies, and occupational safety practices. Less commonly reported outcomes included changes in relations between needle and syringe programs (NSPs) and police; willingness to refer people who use drugs to health programs and willingness to refrain from confiscating syringes; and changes in practices, including reduction in arrests and incarceration, reduction in transmission of HIV and STIs, and reduction in fatal overdoses. Some studies also calculated the value-for-money of training programs.

While most of the peer-reviewed studies reported positive outcomes of police education programs, in some cases the magnitude of change was modest. Among the gray literature, evaluations and case studies all reported positive changes. Yet sample sizes were often too small to allow for generalization, and outcomes were sometimes mixed or modest. In both cases, interventions were often implemented on too small a scale and for too little time to reach a critical mass and generate sufficient momentum to effect long-term change in policing practices and overcome a deeply ingrained distrust of police—and government authorities more generally—among key and vulnerable populations.

Figure 1. PRISMA flow diagram for peer-reviewed article selection



Changes in knowledge

Several peer-reviewed articles found that knowledge of participating police officers about HIV, public health interventions, legal standards and processes, and occupational safety had increased among training participants. For example, two studies that examined a police training program (Project SHIELD) in Tijuana, Mexico, found an improvement in officers' knowledge about drug policy and the law around harm reduction, including significant improvements in conceptual and technical understanding of laws around syringe and drug possession.[17] One of the studies showed that improved knowledge about syringe possession laws was sus-

TABLE 1. Relevant peer-reviewed literature on outcomes of police training programs

Study	Location	Type of training	Population	Year	Outcomes
Arredondo, Strathdee, et al., "Measuring Improvement in Knowledge of Drug Policy Reforms Following a Police Education Program in Tijuana, Mexico"	Mexico	In-service	People who use drugs	2017	Changes in knowledge on harm reduction, laws and policies, and occupational safety
Baker, Beletsky, et al., "Impact of SHIELD Police Training on Knowledge of Syringe Possession Laws and Related Arrests in Tijuana, Mexico"	Mexico	In-service	People who use drugs	2022	Changes in knowledge around laws, policies, and procedures and in policing practice
Beletsky, Agrawal, et al., "Police Training to Align Law Enforcement and HIV Prevention: Preliminary Evidence from the Field"	United States	In-service	People who use drugs	2011	Changes in knowledge on harm reduction, laws and policies, and occupational safety
Beletsky, Grau, et al., "Prevalence, Characteristics, and Predictors of Police Training Initiatives by US SEPs"	United States	In-service	People who use drugs	2011	Changes in relations between needle and syringe programs and police
Beletsky, Thomas, et al., "Police Education as a Component of National HIV Response: Lessons from Kyrgyzstan"	Kyrgyzstan	In-service	People who use drugs; sex workers	2013	Changes in knowledge of occupational safety, willingness to refer to health programs, and willingness to refrain from confiscating syringes
Beletsky, Thomas, et al., "Policy Reform to Shift the Health and Human Rights Environment for Vulnerable Groups: The Case of Kyrgyzstan's Instruction 417"	Kyrgyzstan	N/A	People who use drugs; sex workers	2012	Changes in knowledge of police instruction on harm reduction
Cepeda, Beletsky, et al., "Cost- Effectiveness of a Police Education Program on HIV and Overdose Among People Who Inject Drugs in Tijuana, Mexico"	Mexico	In-service	People who use drugs	2024	Changes in practice, including reduction in arrests and incarceration; reduction in transmission of HIV and sexually transmitted infections (STIs); reduction in fatal overdoses; value-for-money
Rivera Saldana, Abramovitz, et al., "Estimating the Impact of a Police Education Program on Hepatitis C Virus Transmission and Disease Burden Among People Who Inject Drugs in Tijuana, Mexico: A Dynamic Modeling Analysis"	Mexico	In-service	People who use drugs	2023	Changes in practice, reduction of HIV and STI transmission
Sightes, Ray, et al., "Police Officer Attitudes Towards Syringe Services Programming"	United States	In-service	People who use drugs	2019	Changes in knowledge on HIV and public health and laws and policies; changes in attitudes in terms of positive relationships with police and willingness of police to refer to public health programs
Strike, Watson, et al., "Relationships Between Needle and Syringe Programs and Police: An Exploratory Analysis of the Potential Role of In-Service Training"	Canada	In-service	People who use drugs	2017	Changes in attitudes: positive relationships with police
Winograd, Stringfellow, et al., "Some Law Enforcement Officers' Negative Attitudes Toward Overdose Victims Are Exacerbated Following Overdose Education Training"	United States	In-service	People who use drugs	2020	Changes in knowledge on HIV and public health and in competence to respond to overdoses

tained over a period of two years.[18] Another study on police officer training in Rhode Island, United States, found that training focused on the rationale of public health programs, occupational safety, and laws and regulations around law enforcement resulted in modestly better understanding of HIV risk from needlestick injuries, as well as increased knowledge about the law around syringe possession.[19] A study assessing the impact of a comprehensive overdose education and naloxone distribution training found significant increases in knowledge and self-reported competence to respond to an overdose situation.[20]

While the Breaking Down Barriers initiative assessments and case studies did not specifically report on changes in knowledge (with the exception of a case study from Kenya), they did report on other outcomes that undoubtedly relied on changes in knowledge.[21]

Changes in attitudes

Some peer-reviewed studies and evaluations also looked at changes in the attitudes of training participants, demonstrating, among others, that police officers who undergo training programs expressed greater willingness to help people who use drugs and refer people to safe syringe and harm reduction programs.[22]

The Côte d'Ivoire progress assessment reported changes in attitudes through a small survey among past participants of the Looking In, Looking Out (LILO) training program that focuses on reducing prejudice toward key populations. Since 2015, some 700 health workers, law enforcement officers, social workers, and religious leaders have attended.[23] Survey participants, including law enforcement officers, overwhelmingly reported that the training had significantly or very significantly changed their attitudes and professional approach toward key populations. One police officer noted that following the LILO training, "I'm more caring and attentive to [key populations'] concerns." In the Mozambique assessment, the Mozambique Republic Police, which provides training for officers on issues related to key populations (including HIV, human rights, and harm reduction), reported several attitudinal changes linked to the trainings, such as more welcoming attitudes of police management and officers toward key populations, including reports of MSM and transgender people becoming police officers; increases in the number of complaints about violations key populations filed with the police; and police officers taking reports of violence against key populations more seriously, even in cases where the police themselves are perpetrators.[24]

Table 2. Relevant gray literature on outcomes of police training programs

Study	Location	Type of training	Population	Year	Outcomes
To Protect and Serve: How Police, Sex Workers and People Who Use Drugs Are Joining Forces to Improve Health and Human Rights	Ghana, India, Kenya, Kyrgyzstan, Myanmar	In- and pre- service	People who use drugs; sex workers	2014	Changes in knowledge, attitudes, and practices
Côte d'Ivoire Progress Assessment, Global Fund Breaking Down Barriers initiative	Côte d'Ivoire	In-service	Key populations broadly	2023	Changes in attitudes
Ghana Progress Assessment, Global Fund Breaking Down Barriers initiative	Ghana	In- and pre-service	Key populations broadly	2023	Changes in attitudes by police to key populations and vice versa
Kyrgyzstan Progress Assessment, Global Fund Breaking Down Barriers initiative	Kyrgyzstan	In-service	Key populations broadly	2023	Change in police practice
Mozambique Progress Assessment, Global Fund Breaking Down Barriers initiative	Mozambique	In-service	People who use drugs; sex workers; LGBTQ individuals	2023	Changes in attitudes and practices by police to key populations; changes in perception of police by key populations
Nepal Progress Assessment, Global Fund Breaking Down Barriers initiative	Nepal	In-service	People who use drugs	2023	Changes in police practice

Four of the six case studies in the OSF publication also reported improved attitudes among police officers following training interventions.[25] For example, the Kenya and Ghana case studies reported a more welcoming attitude toward key populations, and the Kyrgyzstan case study noted increased willingness of police officers to refer people who use drugs to harm reduction programs.

Surprisingly, one peer-reviewed study that looked at outcomes of an overdose education intervention found that while attitudes of most officers toward people facing overdose had improved after the training, a significant minority of officers reported more negative attitudes toward them post-training. The study recommended experimentation with different training approaches to better understand these results.[26]

Changes in practice

Several studies looked at changes in policing practice following training interventions. A study in Canada, for example, found a positive association between, on the one hand, good relationships between NSPs and police departments and, on the other, in-service training of police on NSP goals and harm reduction.[27] A survey of syringe exchange providers in the United States found that these providers saw police training as key to improving their relationship with police.[28] Another study found that correct knowledge related to HIV, the law, and injection drug use was associated with significantly lower odds of reporting arrests among people who use drugs.[29]

The gray literature contains anecdotal evidence of improved policing practices toward key and vulnerable populations. In the Nepal assessment report, for example, sex worker-led organizations noted that when sex workers are arrested, trained police officers will often engage with local community-based organizations representing sex workers, facilitating their release without charges.[30] In Côte d'Ivoire, key population-led organizations mentioned that law enforcement officers who had gone through the LILO training played a key role

TABLE 3. Specific outcomes reported from police training in terms of police practices and health outcomes

Study	Variable measured	Outcome
Changes in policing practice		
Beletsky, Thomas, et al.	Likelihood of trained vs. untrained officers to refer people who use drugs to harm reduction programs	aOR 2.21 95%CI 1.33–3.68
	Likelihood of trained vs. untrained officers to have no intent to detain people who use drugs	aOR 1.92 95%CI 1.09–3.39
Strike, Watson, et al.	Association between the nature of the NSP-police relationship and training on NSP program goals	OR 7.7
	Association between the nature of the NSP-police relationship and training on needlestick injury prevention and basics of blood-borne virus transmission	OR 4.0
	Association between the nature of the NSP-police relationship and training on the health and social concerns of people who use drugs	OR 3.9
	Association between the nature of the NSP-police relationship and training on evidence about the impact of injection equipment distribution	OR 3.9
Changes in public health outcomes		
Baker, Beletsky, et al.	Reductions in police officers reporting arrests of people who use drugs six months after a harm reduction training	AOR = 0.63; 95% CI = 0.44, 0.89
Cepeda, Beletsky, et al.	Reduction in incarceration rate	21% reduction every three months during the two-year intervention period
	Reduction in new HIV cases	1.7% over the course of the two-year intervention period
	Reduction in overdose cases	12.2% over the course of the two-year intervention period

Note: aOR=adjusted odds ratio; CI=confidence interval; OR=odds ratio in helping them respond effectively to cases of gender-based violence, detention, and harassment against members of key populations.[31] The OSF case study and the Breaking Down Barriers initiative assessment report on Kyrgyzstan similarly reported that institutionalized police training, in combination with progressive legal changes, had resulted in a positive impact on policing practices, including better relationships between police and key populations, with some civil society groups reporting a decrease in the number of outreach workers detained by police.[32]

Changes in public health outcomes

A small number of studies examined the impact of police education programs on public health outcomes. These studies found reductions in HIV and other STI cases following police education interventions, reporting reductions in incarceration and, as a result, decreased HIV incidence and a decrease in overdoses as compared to pre-training trends (Table 3).[33] Although the authors characterize the impact of police training on HIV transmission (1.7% over the course of the two-year intervention period) and overdose (12.2% over the course of the two-year intervention period) as modest, this finding is notable. Relatedly, one finding from Project SHIELD in Tijuana found that police training could reduce the incidence of hepatitis C among people who use drugs.[34]

Cost-effectiveness

One consideration for donors in investing in police training efforts is the cost-effectiveness of such approaches. Javier Cepeda et al. conducted a value-for-money analysis of the police training programs against incarceration and health care costs, concluding that Project SHIELD was cost-effective: the program cost US$3,746 for every disability-adjusted life year averted, well below the recommended willingness-to-pay threshold for Mexico (US$8,347 in 2020).[35]

Discussion

As donors consider investing in more work with law enforcement, it is essential to build on best practices that have emerged from the two-plus decades of previous work. Peer-reviewed and gray literature identify a variety of lessons learned, outlined below, to strengthen the effectiveness of police training programs.

Addressing police concerns

Ensuring that police training sessions appeal to participants strengthens officer engagement. The OSF publication notes that "successful reform of police practice toward these groups must … identify incentives or ways of framing engagement to show that these efforts can help police protect themselves and do their jobs."[36] Reflecting earlier research findings, several publications argue for addressing occupational safety and avoiding needlestick incidents to engage officers in the trainings, with one noting that "training that combines occupational safety with syringe access content can help align law enforcement with public health goals."[37] The Kenya case study found that police were interested in developing better relationships with sex workers because information from them might prevent serious crime or assist in investigations.[38]

Involving and building relationships with affected communities

Several publications discuss the importance of not only involving key populations in trainings of police officers but also building stronger relationships between law enforcement and communities beyond specific training programs. The OSF publication notes that "police knowledge of criminalized groups is often shaped by the same stereotypes and moral judgments that are prevalent in society more generally. It has proven critical to train law enforcement about the realities of the lives of sex workers and people who use drugs."[39] The Ghana case study notes that "a key component in shifting police attitudes toward sex workers in Ghana was sex workers themselves speaking in these trainings of the impact that police repression and abuse had on their lives."[40]

Several Breaking Down Barriers initiative assessments argue for routine, direct engagement between police and impacted communities through community-police partnerships or dialogues.[41] Côte d'Ivoire's LILO trainings, which are part of a broader effort to empower community members to defend their rights through community paralegals, have created lasting relationships between police officials and community actors that have repeatedly helped end or address abuses against community members.[42]

Fostering ownership and support from police leadership

Engaging with law enforcement institutions that do not see health care access as core to their functions is a significant challenge to successful, long-term police training programs. Especially when trainings are organized by civil society organizations, law enforcement agencies' commitment to and ownership of such trainings may be lacking.[43] Several publications therefore emphasize the importance of ensuring support from police leadership.[44] For example, the OSF publication notes, "Given the hierarchical nature of law enforcement, it has been essential to secure the endorsement of police leadership for changing police practices toward sex workers and people who use drugs, and to get them to communicate this shift to less senior officers."[45]

Institutionalizing police training

Police training needs to be an ongoing intervention; one-off trainings have little impact because of, among other things, high turnover in police forces.[46] These trainings should be institutionalized with sustained resources and the routine training of officers and new recruits. Institutionalization can also help address the challenge of scaling up training.[47]

Studying and routinely evaluating police training programs

There is an urgent need for more peer-reviewed studies and robust, formal evaluations of police education programs. The dearth of such studies and evaluations is one of the reasons for the limited evidence base. Of the 15 progress assessments that discuss police training interventions, only five report key outcomes. Not a single police training intervention funded through the Breaking Down Barriers initiative has been formally evaluated. The same is largely true for US interventions: discussing a survey of syringe exchange programs in the United States about police trainings, Leo Beletsky, Lauretta Grau, et al., note that "only four [of 21] programs [that had conducted police trainings] reported having a formal evaluation component as part of their training; to date, none has been published."[48] Funders and program implementers should commission evaluations of police trainings to address the dearth of evidence.

Embedding training in a broader effort to change policing

Many of the police training interventions described in the literature were part of a broader set of interventions. In Tijuana, Mexico, for example, police trainings were held as part of an effort to facilitate the rollout of a policy change.[49] They helped bring about a dramatic increase in participants' technical and conceptual legal knowledge and awareness of human rights norms related to decriminalization for marijuana, heroin, and methamphetamine, as well as the legality of syringe possession. Other publications note that police training alone is often insufficient to sustain changes in policing. For example, Leo Beletsky, Alpna Agrawal, et al. argue that "management and peer-driven interventions, such as those incentivizing police and public health collaboration and censuring unauthorized syringe confiscation and other practices that run counter to public health goals, may be needed to reinforce training messages and shift entrenched attitudes."[50] Thus, police trainings should be part of a broader strategy aimed at removing policing as a barrier to HIV services for key populations.

Conclusion

Changing the culture of police forces and the constraints of legal and political environments in settings that criminalize key populations is not a simple task, and investment in programs to accomplish this has, for reasons that are not entirely clear, been insufficient. Nevertheless, for more than two decades, a growing body of literature has been advocating for and describing such programs. While the literature reporting on the outcomes of these interventions is still limited, it does provide some indication of best practices, what has not worked, and what may be promising strategies to address abusive policing. More research is needed, especially to expand the range of countries and populations studied. Currently, the peer-reviewed literature is narrowly focused on Mexico and people who use drugs. It is likely that police forces will question the validity of the results of police training in one country compared to the specific characteristics and political environment they face in another.

Nonetheless, the evidence from our review shows that well-designed police training can have benefits for both law enforcement and communities and can be a cost-effective public health investment. Importantly, training law enforcement on the control of infectious disease and the rights of populations at increased risk of contracting HIV also allows countries to fulfill their legal obligation to protect the right to the highest attainable standard of physical and mental health.[51]

With 2030 rapidly approaching, investing in programs that can reduce the negative impact of policing on access to HIV services for criminalized populations, along with more pointed research and evaluations of such police engagement programs, is essential. Taking this public health approach to policing requires scaling up programs and policies to change the social norms and punitive approaches that law enforcement institutions use in their engagement with key populations. It is not until there is sufficient, sustained investment in such work that the world will truly reach the last mile for key populations within the HIV response.

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PERSPECTIVE

New Legislation Criminalizing Sex Work in Kazakhstan Is Cause for Concern

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Introduction

In recent years, global trends in sex work legislation have been mixed, with many countries maintaining or expanding punitive approaches despite growing advocacy for decriminalization. Some governments, particularly in Eastern Europe, Central Asia, and parts of Africa, have intensified crackdowns on sex work under the guise of public health or anti-trafficking efforts, often increasing surveillance, fines, and police harassment.[1] At the same time, there has been a notable rise in grassroots and international human rights advocacy pushing for the decriminalization of sex work, citing its potential to reduce violence, improve health outcomes, and uphold the rights of sex workers.[2] However, progress has been uneven, and the global policy environment

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Competing interests: None declared.

remains largely hostile, with only a few countries, such as New Zealand and parts of Australia, adopting fully decriminalized models.[3]

Like many countries in the region, Kazakhstan has intensified enforcement measures under the banner of public order and anti-trafficking. Last year, President Kassym-Jomart Tokayev signed Law No. 110-VIII on Countering Human Trafficking.[4] Upon taking effect in September 2024, this law redefined the parameters of sexual services in the context of anti-trafficking efforts, which has raised concern among public health and human rights experts due to its potential consequences for those engaged in sex work. By broadly defining *potential* victims of human trafficking to include individuals in vulnerable positions due to socioeconomic factors, such as homelessness or unemployment, this legislation conflates sex work with trafficking and assumes that all individuals engaged in sex work are coerced. While the stated objectives—protecting women and children from exploitation—may be well-intentioned, the practical implications of this legislation may disproportionately harm women who engage in sex work, violating their fundamental human rights and undermining their health and safety.

Sex work in Kazakhstan

Kazakhstan's sex work profession is diverse and fluid, encompassing individuals of various ages, genders, and ethnic backgrounds, who work in public venues, informal networks, and private settings. The Kazakhstan Scientific Center for Dermatology and Infectious Disease (KSCDID), which is part of the Ministry of Health, conducts periodic surveillance of sex work in the context of HIV prevention program planning. In 2024, KSCDID estimated that there were approximately 21,980 sex workers in Kazakhstan; however, this may not capture the full extent of sex work in the country.[5] Our research identified additional groups of women who exchanged sex occasionally or exchanged sex for drugs, goods, or other services and who were likely not included in official estimates.[6] Additionally, official estimates exclude men who have sex with men and transgender individuals who engage in sex work, as KSCDID classifies these as a separate key population.

Sex workers are highly marginalized in Kazakh society. While there has been a focus on their sexual health, sex workers face a broad range of health and social challenges. In Kazakhstan, specialty clinics that serve sex workers are locally referred to as AIDS centers or "friendly clinics." These clinics provide HIV-related services, including testing for sexually transmitted infections (STIs), HIV testing, and referrals. Mental health challenges are often overlooked, although prior research has identified a 52.5% prevalence of past-week suicidal ideation among a sample of 400 women who exchange sex and use drugs.[7] Sex workers are subjected to violence from both intimate partners and clients, as well as from law enforcement, including coercion or extortion into providing sex to avoid being detained or arrested.[8] The Kazakhstani government has taken no measures to protect individuals engaged in sex work and has tried to downplay its existence.[9] Further, sex workers face high levels of stigma and discrimination in health care settings. According to the most recent (2024) Stigma Index report, nearly half (45.7%) of women who exchange sex and are living with HIV are afraid that health care professionals will treat them poorly or disclose their HIV status, and nearly one-third (28.6%) have had a prior negative experience.[10] Additionally, the COVID-19 pandemic led to changes in how sex work operated in Kazakhstan. Lockdowns and restrictions reduced clientele and drove sex work underground, eroding social networks and forcing some into more precarious work circumstances.[11] Law No. 110-VIII, which increases criminal-legal exposure, could make the risks of violence and exploitation from these changes even greater.

Legal frameworks for sex work

Sex work laws by country tend to fall into one of several legal frameworks: criminalization, partial criminalization, the "Nordic model," decriminalization, and legalization.[12] These frameworks are described in Table 1. Decriminalization is widely considered to provide the best protections for public health and for women engaged in sex work, and it is the model supported by sex workers, advocates, and international organizations such as the World Health Organization.[13]

Prior to 2024, Kazakhstan followed a partially decriminalized model of sex work regulation, where engaging in sex in exchange for goods or services was not deemed illegal, but soliciting in public locations (article 449 of the Administrative Code) and brothel-keeping (article 450) were.[14] Buying sex is generally not an offense in Kazakhstan, except where a client knowingly receives sexual services from a minor, which is criminalized. Recent amendments also introduced explicit criminal liability for providing sexual services online in real time (e.g., webcam prostitution). As mentioned, these laws were frequently abused by police, as women engaged in sex work are frequently harassed by police or detained for "administrative violations."[15]

Potential impacts of Law No. 110-VIII

The health and safety of sex workers in Kazakhstan will be severely compromised under this new legislation. Between 2016 and 2020, Kazakhstan opened 161 criminal cases related to sex work, the majority

TABLE 1. Legal frameworks for sex work

	Full criminalization	Partial criminalization	"Equality," "entrapment," or "Nordic" model	Decriminalization	Legalization
Criminalizes individual sex workers	Yes	No	No	No	No
Criminalizes clients	Yes	Yes	Yes	No	No
Criminalizes third parties (e.g., managers)	Yes	Yes	Yes	No	No
Impact on sex workers	Makes street-based sex workers more susceptible to frequent arrests and police violence and harassment; reinforces stigma	Organizing and soliciting sex work are illegal, making it impossible to safely vet clients and work in public venues	Sex workers can still face police surveillance, fines, arrest, and violence; forced to rely on income from criminalized clients, which increases economic instability and housing insecurity	Sex work can be regulated like other forms of labor and has more workplace protections; allows sex workers to organize for labor rights; can reduce stigma over time	Sex work is strictly regulated by the state; workers must procure licenses; this model excludes certain populations, such as migrants and undocumented workers
Impact on health care access	Severely impacts access to essential health care; undermines public health and harm reduction services	Impacts access to essential health care; sex workers likely to avoid clinics that may collude with law enforcement	Limits access to harm reduction programs if services focus only on "exit strategies" rather than offering health care without judgment	Increases access to harm reduction services and access to regular health care	Workers must complete consistent medical testing but are not necessarily provided with better access to services; however, this could increase testing and uptake
Impact on human rights	Infringes on sex workers' rights to health and safety as enshrined in the Universal Declaration of Human Rights and International Covenant on Economic, Social and Cultural Rights; increases risk of violence and exploitation	Infringes on sex workers' rights; forces individuals to engage in private, solitary sex work, making them more susceptible to violence and social isolation	Amnesty International, UNAIDS, and other human rights organizations oppose this model because it can harm sex workers; does not decrease risks of violence and exploitation	Recommended by World Health Organization, Amnesty International, and other major human rights governing bodies; reduces violence and exploitation; increases legal protection	Restrictive conditions may violate the rights of sex workers; creates a two-tier system where some workers meet the legal requirements and those who do not (e.g., undocumented workers) are criminalized

of which relate to organizing sex work; this is likely to increase under the new legislation.[16] Moreover, as we have seen in Canada and northern Europe, legislation that inadvertently or purposively conflates sex work with trafficking increases the policing of sex work communities in the name of stopping it. A robust body of prior research has documented the detrimental effects of increased policing in a context of partial and complete criminalization, including violence from clients, condomless sex, and HIV/STI incidence, which drive sex work underground and make women hesitant to seek care.[17] Policing can also can cause treatment disruptions for HIV.[18] In Europe and Canada, police surveillance and harassment of sex workers, under the guise of preventing trafficking, often intersects with racial profiling and migration policies.[19] Moreover, reforms to sex work legislation that stop short of full decriminalization do not reduce these negative effects. For example, in Canada, a 2014 shift from full criminalization to the Nordic Model (criminalizing the clients of sex workers) had no impact on reduction in violence.[20] In contrast, sex workers in New Zealand report that the country's 2003 shift to decriminalization improved relationships between sex work communities and the police, and made women more comfortable reporting abuse.[21] Increased policing under this new legislation will likely shift sex work in Kazakhstan into private and unregulated settings. This transition will increase the risk of exploitation and violence by partners and police, with additional barriers to seeking legal protection against such behaviors. By further pushing sex work into the shadows, the legislation also limits the ability of sex workers to engage in harm reduction services, such as HIV testing, pre-exposure prophylaxis uptake, and STI treatment. This diminished access may increase the likelihood of HIV/STI transmission not only among sex workers but also within the broader population. Our research and work lead us to believe that this criminalization will worsen social isolation, depriving sex workers of peer support systems that often act as lifelines for accessing resources and harm reduction services.

In the months since this law has taken effect, we have begun to see both predicted and unpredicted impacts. Local nongovernmental organizations (NGOs) have reported increased demand for support services across the country, as sex workers are persecuted by the police. There are rumors of extortion by the police, threats, pressure, fines, persecution, targeting, and public exposure of sex workers in the media. There is a lack of clarity among service providers working with those engaged in sex work. The change has created widespread confusion among service providers who work with women engaged in sex work, particularly in determining what routine services, or advertising for such services, may be construed as "facilitating" sex work. Many providers do not fully understand the changes to the law, and state agencies offer conflicting interpretations. This uncertainty has disrupted service providers' outreach to and support for sex workers. Finally, civilians often lack clarity on what constitutes "other sexual services," whether it be online advertising, third parties (organizers, apartment tenants, pimps), or strictly sex work. This ambiguity contributes to an environment where sex workers become the target of harassment and violence, reflecting a broader pattern in which vaguely defined and inconsistently enforced laws fuel fear, misinformation, and confusion.

Call to action

Reversal of this legislation and decriminalization of sex work is essential to ensuring the safety, health, and dignity of individuals working in the sex industry. At the very least, Kazakhstan should consider clarifying the law to distinguish between consensual sex work and trafficking, aligning with international public health guidance. However, in the meantime, the following steps are needed:

Ensure health care access

Kazakhstan's Ministry of Health should scale up HIV self-testing by increasing the number of distribution points and enabling individuals to order tests online. To ensure equitable access to care for sex workers, the Ministry of Health should expand low-barrier strategies by establishing more friendly clinics near sex work venues and integrating online scheduling tools for time-specific appointments. Additionally, friendly clinics should extend their operating hours into the late afternoon, evenings, and weekends to accommodate more schedules. These clinics could be transformed into one-stop shops by offering a broader range of services beyond HIV and STI testing and condom distribution.

Protect the rights and safety of sex workers

Immediate action is needed to protect the rights and safety of sex workers in Kazakhstan. NGO and medical service provider efforts should include educating women who exchange sex about their legal rights and the current status of sex work under Kazakhstan's administrative and criminal codes. NGOs should organize safety trainings that cover both physical and digital security. Centralized access to safety resources should be made available through dedicated websites and social media platforms. Additionally, an emergency panic button system should be developed and implemented to provide immediate access to protection. Free or low-cost legal consultations should also be offered at accessible and convenient locations to ensure that sex workers can seek justice and support without barriers.

Support nongovernmental organizations

NGOs that support sex workers in Kazakhstan require additional resources and structural support to effectively meet the needs of this population. Increased funding is essential to expand the scope of preventive, legal, medical, and social services provided by these organizations. Clear service guidelines should be developed to define the legal rights and limitations of NGOs working with sex workers, clarify mandatory reporting requirements (including protocols for sharing client data), and outline the legal support available to NGO staff. Medical and social service providers should receive training on how to work respectfully and effectively with sex workers, in alignment with international and community-led standards, and on documenting human rights violations in accordance with Kazakhstani legislation. Outreach workers also need enhanced training, particularly in responding to gender-based violence and making appropriate referrals, to better support women who exchange sex.

Strengthen legal protections for sex workers

Advocacy efforts should target key national and international actors, including Kazakhstan's Ministry of Foreign Affairs, Ministry of Health, and Ministry of Labor and Social Protection, as well as UN Women. Submitting shadow or alternative reports to United Nations bodies such as the Committee on the Elimination of Discrimination Against Women and the Committee on Economic, Social and Cultural Rights is also critical to holding the government accountable for protecting the rights of sex workers. Particular attention must be paid to the rights of migrant sex workers, who face heightened vulnerability and are often deterred from reporting violence due to fear of deportation. Efforts should be made to systematically document human rights violations against migrant sex workers, ensure that reporting abuse does not endanger their legal status, and develop dedicated support programs with trained specialists who understand the specific needs of this population.

The international community, including human rights organizations and public health advocates, must apply pressure on the Kazakhstani government to repeal harmful legislation and implement evidence-based policies that align with global human rights standards. While legal and policy reforms are underway, interim harm reduction strategies should be implemented to mitigate the direct harm experienced by sex workers and the broader societal consequences of criminalization.

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Conceptualizing the Child's Right to Oral Health: A Rights-Based Approach to Dental Caries

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Abstract

Dental caries is the most common noncommunicable disease globally and is a substantial burden for both adults and children, yet it remains largely neglected. The World Health Organization recognized the right to oral health in 2024. This paper introduces a comprehensive framework for children's right to oral health based on the provisions of the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of the Child. It demonstrates that although human rights treaties do not explicitly recognize the right to oral health, oral health, and particularly dental caries, is a matter of human rights. The first part of the paper clarifies how dental caries is a child rights matter, while the second part proposes a rights-based approach to the regulation of its risk factors.

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Competing interests: None declared.

Introduction

Oral diseases have been largely neglected in public health legal scholarship, even though they remain the most prevalent noncommunicable disease (NCD) worldwide.[1] Globally, untreated dental caries (tooth decay) poses a substantial NCD burden for children and adults; two billion people have untreated dental caries in permanent teeth and 514 million in primary teeth.[2] The disease is multifactorial—that is, its incidence is connected to a complex set of factors, including sugars ingestion, oral hygiene, fluoride exposure, and oral health care. If these factors are regulated adequately, dental caries is largely preventable.[3] Dental caries is also associated with health inequities; for example, its occurrence is more common among children of low socioeconomic status.[4] It has severe short- and long-term consequences; its prevalence in childhood predicts poor oral and general health outcomes in later life, and, via socio-behavioral factors, it presents a high risk of passing caries on to future generations.[5] A failure to address the underlying causes of dental caries fosters and exacerbates existing inequalities.

Oral health is rising on the global agenda, particularly with the World Health Organization's (WHO) 2024 adoption of the Global Strategy and Action Plan on Oral Health, which recognizes the right to oral health.[6] Although there is also increasing support for a rights-based approach to oral health in the dental and public health literature, a comprehensive analysis of the right to oral health remains unresolved.[7] A rights-based approach, particularly focusing on children's rights, is pertinent because it can offer a shift from the focus on individual responsibility toward addressing dental caries, particularly its prevention, at a population level. Accordingly, this paper conceptualizes children's right to oral health, based on the United Nations Convention on the Rights of the Child (CRC) and International Covenant on Economic, Social and Cultural Rights (ICESCR).[8] The analysis is restricted to dental caries in children, one of the main oral conditions and the main NCD among children globally.[9] In the first section, I describe the background against which the human rights analysis is conducted. Subsequently, I analyze how dental caries is a matter of children's rights and requires upstream measures for its prevention. I then explore what a children's rights-based approach to preventing dental caries entails, with particular attention to four risk factors that can be addressed by laws and regulations: (1) sugars ingestion; (2) oral hygiene; (3) fluoride exposure; and (4) oral health care attendance.

Background and methodology

The prevention of NCDs is a matter of human rights law; not only does human rights law provide a mechanism to hold governments accountable, but the interpretation of rights by treaty bodies can similarly guide the balancing of (legal) measures.[10] Substantively, scholars have extensively analyzed human rights in relation to NCD risk factors.[11]

Within the field of public health, including dental public health, a shift from an existing individualized focus toward upstream policies is simultaneously emerging.[12] Traditionally, dental professionals occupied a central role in the prevention of oral diseases, but it is increasingly recognized that population-level prevention and promotion practices must be strengthened.[13] Consequently, dental researchers have discussed the potential of integrating oral diseases into the NCD agenda.[14] The fact that oral diseases—in this case, dental caries—share risk factors with other NCDs provides an opportunity for states to jointly promote oral health and general health through the "common risk factors approach."[15]

A gap between the two bodies of scholarship—(human rights) law and oral health—remains when it comes to the right to oral health, although a few studies have considered human rights and oral health.[16] For example, David Manton, Jan Wollgast, Brigit Toebes, and I developed a right to health-based approach to dental caries, while Gillian Jean et al. provide a conceptual study on a rights-based approach to oral health.[17] The latter studies the practical status quo in the area of oral health: Is oral health recognized as a human right in existing policies and health systems?[18] Rightfully so, the authors conclude that "the rights status of oral health is not settled."[19] They come to this conclusion, however, following the assumption that "rights only exist when duty bearers accept the obligation to be accountable for progressive right realisation."[20]

In contrast to the above assumption, this paper analyzes the right to oral health based on human rights law on paper. Accordingly, the legal value of human rights as understood here arises from the fact that by acceding to and ratifying human rights treaties, states accept the obligations laid out in them.[21] I adopt a doctrinal method to analyze the content of children's right to oral health. The use of the phrase "the right to" does not imply that I wish to invent a novel, autonomous right (*lex ferenda*). Rather, I seek to analyze what children's right to oral health consists of within the context of the ICESCR and CRC specifically.

A common methodological challenge that human rights law scholars encounter concerns the risk of blurring the distinction between *lex lata* and *lex ferenda* in novel or progressive interpretations, as such interpretations inevitably rely on nonbinding interpretative practice and guidance offered by competent treaty bodies.[22] This paper therefore differentiates between hard law and authoritative interpretations. Treaty texts constitute hard law, which is interpreted with authoritative interpretations—namely, general comments, the reports of Special Rapporteurs, and concluding observations. General comments offer general interpretative guidance for the rights enshrined in the treaties, while the reports of Special Rapporteurs and concluding observations by treaty bodies provide guidance for domestic implementation. Finally, WHO reports and scientific literature are similarly used for the interpretation and concretization of the content of rights.[23]

Dental caries as a matter of human rights

The WHO's Global Strategy and Action Plan recognizes that "achieving the highest attainable standard of oral health is a fundamental right of every human being."[24] Human rights treaties do not explicitly recognize this right. However, because oral health is integral to overall health and well-being, it falls within the scope of the right to health as enshrined in article 12 of the ICESCR and article 24 of the CRC.[25] In line with the interdependence and indivisibility of human rights, the right to oral health goes beyond the domain of health.[26] This corresponds with the social determinants of health—the impact of conditions in which people live and "wider forces that shape the conditions of daily life" on health—which also asks for any health policies to be intertwined with wider (social and economic) policies.[27]

Given that oral health "encompasses psychosocial dimensions, such as self-confidence, well-being and the ability to socialize and work without pain, discomfort and embarrassment," poor oral health, including that associated with dental caries, is a critical matter of social life and functioning, thereby affecting those rights related to the development of children (e.g., articles 6(2) and 27(1) of the CRC).[28] The impact on the enjoyment of these rights is further exacerbated given that the prevalence of dental caries is greater among vulnerable groups, including children with low socioeconomic status, and it fosters existing health inequalities and disparities.[29]

Dental caries limits the full realization of children's right to health. In light of article 12(2)(c) of the ICESCR and article 24(2)(c) of the CRC, states are mandated to take measures necessary for the prevention of dental caries.[30] According to article 12(2)(a) of the ICESCR, states must take steps to ensure the healthy development of the child.[31] Given that childhood is constitutive of later (oral) health status and that dental caries in childhood has intergenerational and intragenerational effects, it is pertinent to target measures toward children to ensure the enjoyment of the right to health throughout life.[32] Finally, because severe untreated dental caries in children can affect eating, owing to pain, it may lead to underweight and stunting.[33] Therefore, under article 24(2)(c) of the CRC, states should consider dental caries as a potential cause of malnutrition.[34]

Further, the ICESCR and CRC indicate measures that contribute to the fulfillment of the right to health. Articles 12(2)(d) of the ICESCR and 24(2)(b) of the CRC prescribe states to ensure access to health care services in case of need, while article 24(2)(f) of the CRC requires the development of preventive health care services.[35] This corresponds with WHO's Global Strategy and Action Plan, which has universal health coverage at the core of its vision, because ensuring equal access to oral health care services is an important component of effectively addressing dental caries.[36] Yet the multifactorial nature of the disease—driven, among other things, by sugars intake—and the associated social and commercial determinants of health, requires a response beyond health care.[37] This is supported by research that demonstrates that an individualized care approach does not suffice for reducing caries incidence in all segments of society.[38] Although the measurable behavior is that of individuals, the determinants of those behaviors, including social and commercial ones, are largely structural in nature and consequently should be addressed as such. The right to health similarly requires a supplementary focus on upstream, preventive measures that address the underlying determinants of health—for instance, the provision of adequate nutritious foods and information (article 24(2)(c) and (e) of the CRC).[39]

Poor child oral health, including (severe) dental caries, is also associated with missed school days and reduced academic development, an issue of children's right to education (article 12(1)(e) of the CRC).[40] This is especially problematic in light of the increased prevalence of dental caries among persons of low socioeconomic status and the pertinence of socio-behavioral factors. Accordingly, article 6(2) of the CRC—one of the general principles prescribing the right to life (Article 6(1) CRC) and the obligation to ensure the development of children that should be interpreted "in its broadest sense as a holistic concept"—is at stake as well.[41] The best interest of the child, as one of the general principles of the CRC and stipulated in article 3, underpins all the above. As a substantive right, an interpretative principle, and a rule of procedure, the best interest principle mandates states to ensure that it is applied throughout its structures and in all processes, and to consider the potential impact of all decisions and actions on children's rights and interests.[42] Finally, in fulfilling the above rights and adopting measures, states are mandated to consider children's views in all matters affecting the child (article 12(1) of the CRC).[43]

A rights-based approach to addressing dental caries risk factors

To identify state obligations in the context of children's right to oral health with respect to dental caries, it is important to understand the etiology of dental caries and its modifiable risk factors. Doing so will inform a rights-based framework to guide the development of dental caries control strategies.

WHO describes the process of dental caries as the "destruction of teeth [that] results when microbial film (plaque) formed on the tooth surface converts the sugars contained in foods and drinks into acids, which dissolve tooth enamel and dentine over time."[44] In other words, frequent sugars consumption modifies the microbial balance of the plaque into one that is cariogenic. This cariogenic plaque is readily able to metabolize sugars, forming acids that dissolve the two dental hard tissues—enamel (the hard outer surface of tooth) and dentine (the layer between enamel and the dental pulp)—leading to carious lesion development.[45] To prevent caries, the creation and persistence of these acids must be interrupted.

Reducing the risk of caries development involves a combination of factors.[46] Given the primary role of sugars and their pathological influence on the dental plaque microbiota in dental caries development, it is important that the amount and frequency of sugars ingested be limited.[47] Dental plaque, which builds up on tooth surfaces, needs to be regularly removed by brushing with a fluoride toothpaste and interdental cleaning, thereby removing the cariogenic plaque (if present) and limiting the time it is present on the tooth surface.[48] Exposure to low levels of fluoride, either through toothpaste or community water fluoridation, strengthens the resistance of enamel to demineralization (dissolution or cavity formation).[49] Oral health practitioners play an important role in preventing and managing dental caries by identifying a patient's risk of developing dental caries, arresting existing carious lesions (that is, halting the progression of active carious lesions), and treating carious lesions with restorations or extractions.[50]

The remainder of this section is structured according to the aforementioned risk factors that can be addressed by laws and policies: (1) sugars ingestion; (2) oral hygiene; (3) fluoride exposure; and (4) the dental health care system.

Free sugars ingestion

Sugars ingestion is a key dental caries risk factor; limiting the frequency and amount of sugars ingested curbs the development of cariogenic biofilm and in turn significantly lowers dental caries risk.[51] Although dental caries development is fueled by all dietary sugars, it is important to distinguish between free sugars and intrinsic sugars.[52] Free sugars are considered nonessential nutrients whose intake is linked to a number of NCDs (including dental caries) and encourages further consumption.[53] Consequently, WHO strongly recommends that they represent less than 10% of total energy intake.[54] Intrinsic sugars are those naturally present in whole fresh fruits and vegetables and are recommended as part of a healthy diet.[55]

The right to health and the right to an adequate standard of living, including adequate food (hereinafter the right to adequate food), can inform upstream measures to address sugars consumption.[56] As signatories, states must adopt measures to prevent NCDs, including those related to diet.[57] The progressive realization of the right to adequate food implies that obligations stretch beyond ensuring "a minimum package of calories, proteins and other specific nutrients."[58] In fact, nutrition is among the key determinants of children's health, and the right to health mandates states to ensure the provision of adequate nutritious foods and combat malnutrition.[59]

The obligations under the right to health in this context are various. The obligation to respect the right to health can be interpreted to mean that states should not act in a manner that is likely to result in preventable, diet-related morbidity and mortality—such as by incentivizing the consumption of unhealthy products.[60] The obligation to protect requires states to regulate the activities of industries whose practices may be detrimental to their health.[61] The Committee on Economic, Social and Cultural Rights classifies the failure to protect consumers from practices detrimental to health by manufacturers of food as a violation of this obligation.[62] The obligation to fulfill means that individuals must be assisted with, among other things, the provision of nutritiously safe food and information.[63]

More particularly, treaty bodies and Special Rapporteurs have addressed "sugars" explicitly, especially in relation to the food environment. For instance, the Committee on the Rights of the Child refers to sugars in its General Comment 15, stating that "children's exposure to 'fast foods' that are high in … sugar … should be limited."[64] The committee also notes that the marketing of such foods should be regulated and their availability in schools limited.[65] The committee also referred to sugars in its concluding observations to Tonga in 2019, suggesting that the state "discourage school canteens from serving 'fizzy' drinks, junk food and food high in sugar."[66] Finally, the Special Rapporteur on the right to health, Tlaleng Mofokeng, directly signals the increased presence of sugars, among other substances, in food systems and food environments as drivers of health, specifically NCDs.[67]

Specific measures that have been suggested or identified as good practices by Special Rapporteurs and in general comments in the context of food include sugar(-sweetened beverage) taxes; advertising bans and restrictions for certain foods; mandatory (front-of-pack) labeling measures; fiscal measures and procurement policies to incentivize the agricultural production of, among other products, vegetables and fruits; the establishment of health-related requirements for investments by transnational companies; limiting the availability of certain food products in schools; and involving schools in health strategies.[68] In this regard, it must be highlighted that a number of these structural measures incur little or no cost for states and contribute to the realization of the right to health. In light of the *attainability* of the right to health, these measures should thus be prioritized.[69]

Oral hygiene

Oral self-care—toothbrushing and interdental cleaning—is crucial in maintaining a favorable oral environment; doing so removes the buildup of dental plaque. Apart from the question of which policy tools are available to states to regulate hygiene practices, it is important to first consider the extent to which state obligations stretch here: Can a state step into the bathroom and address children's brushing habits through legal interventions?

Articles 5 and 18 of the CRC provide guidance in this regard. Article 5 prescribes a hands-off approach and stipulates that states must respect the responsibilities, rights, and duties of parents in guiding their children in the exercise of their rights.[70] Article 18(2) sets out that states have to provide "appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities" to guarantee the rights enshrined in the convention.[71] In other words, states must strike a balance: they have to respect, and thereby not interfere with, the relationship between caregivers and children, while providing those caregivers with the means, such as funds and information, to ensure that children grow up in a manner that assures the furtherance of their rights.

Substantively, the right to health, along with the rights to information and education (articles 13, 24, and 29(1)(a) of the CRC), inform measures addressing oral hygiene as a risk factor for poor child oral health. Article 24(2)(e) of the CRC explicitly stipulates that, in pursuing the full implementation of children's right to health, states must adopt measures "to ensure that all segments of society, in particular parents and children, are *informed, have access to education and are supported* in the use of basic knowledge of … hygiene."[72] Under the obligation to fulfill (facilitate) the right to health, states must make an effort to "enable and assist individuals and communities to enjoy the right to health."[73] The provision of information as a public health intervention corresponds with the balance between articles 5 and 18 of the CRC, described above.[74] The information provided should be physically accessible, understandable, and appropriate to children's age and educational level.[75] The Committee on the Rights of the Child's General Comment 15 suggests that such information be communicated via school curriculums, health services, and in other contexts for children who do not attend school.[76] Parents should be informed via multiple channels, including media and public information leaflets.[77]

Fluoride exposure

Fluoride mitigates caries lesion formation because it favors remineralization of the enamel and dentine, providing resistance against acids. Fluoride can be provided by brushing with a fluoride toothpaste, receiving professionally applied fluoride treatments, or through fluoridated community water supplies, dietary salt, or milk.[78]

In its topical version, fluoride qualifies as an essential medicine. Fluoride-containing dental preparations were added to the 22nd WHO Model List of Essential Medicines and the 8th WHO Model List of Essential Medicines for Children in 2021.[79] This reinforces the framing of fluoride exposure as a matter of human rights law: since fluoride qualifies as an essential medicine, its provision falls within the core content of the right to health.[80] This means that this obligation is not to be realized progressively: rather, noncompliance with the obligation to make essential medicines available and accessible amounts to a violation of the right to health.[81]

Community water fluoridation has proven to be successful and has been rated as one of the 10 greatest public health interventions by the US Centers for Disease Control and Prevention.[82] As a population measure, it provides safe and equitable access to all and can in turn reduce oral health inequalities.[83] In this form, fluoride is a non-essential nutrient, which means that its intake is not needed for the body to perform essential physiological functions.[84] It must also be noted that the excessive intake of fluoride—for example, in contexts where fluoride is naturally present in water or food—can potentially be harmful.[85] In this regard, the so-called AAAQ (which stands for availability, accessibility, acceptability, and quality) framework offers guidance for fluoride provision: it must be (1) available, (2) physically and economically accessible in a nondiscriminatory fashion, (3) culturally and ethically acceptable, and (4) medically appropriate and of good quality.[86]

The right to health offers discretion as to its precise implementation.[87] Rather, the standard set under the CRC and the ICESCR pledges that nutrients and medicines, including fluoride, must be administered (medically) appropriately.[88] This implies that states' obligations include providing appropriate amounts of fluoride, for which there are guidelines.[89] In this regard, the obligation of states stretches to guarantee the rational and appropriate dispensation, sale, and usage of essential medicines so as to prevent adverse health effects.[90] The decision on the exact method of fluoride delivery is left to the state. In addition to this, individuals in all segments of society should be informed about the importance of fluoride exposure and the means of such exposure, and should be supported in making informed decisions about fluoride and their health.[91]

Oral health care

Health care plays a multifaceted role in caries management, ranging from preventive care to curative treatment.[92] In many countries, however, unmet needs for dental care still remain. This is related to, among other factors, limited coverage of dental care (for adults) (thereby leaving oral health care attendance dependent on individuals' financial means), the unequal distribution of the oral health care workforce, and a preference for technology-based curative treatment.[93]

The right to health similarly reflects these roles.[94] Primarily, the obligation to fulfill the right to health mandates states to ensure the provision of health care.[95] There are multiple general factors that established health care systems must address, including the AAAQ requirements and the appropriate training of health care workers.[96] In addition, especially when it comes to children, the health care system should encompass not only curative services but also "prevention, promotion, treatment, rehabilitation and palliative care services."[97]

The right to health requires the appropriate allocation of resources to prevent overt and covert forms of discrimination.[98] It is pertinent to note that the Committee on Economic, Social and Cultural Rights stipulates that "investments should not disproportionately favour expensive curative health services … often accessible only to a small, privileged fraction of the population, rather than primary and preventive care, benefiting a far larger part of the population."[99] NCDs should also be addressed in preventive health care services, integrating "a combination of biomedical, behavioral, and structural interventions."[100]

Many countries face difficulties ensuring access to oral health care for all, and the lack of universal coverage for oral health is signaled as a main concern in debates on oral health.[101] Considering the large number of countries in which oral health care services are provided by private parties and expenses are covered by out-of-pocket payments, the obligations concerning the economic accessibility of health care facilities and services (alternatively known as affordability) under the right to health must be highlighted.[102]

The child's right to health is clear: universal access to primary health care services, into which oral health care and essential oral health care should be integrated, for children should be of primary concern, and the inability to pay should not result in the denial of the child's right to access health care.[103] Payment for such services should still be based on the principle of equity so that they remain affordable for all.[104] Accordingly, states have a special obligation to ensure that those with insufficient (financial) means have the necessary health insurance and that insurance is affordable for all.[105] In establishing such a system, states must make use of risk-pooling mechanisms that rely on equitable, means-based contributions.[106] Regardless of whether the insurance system is of public, private, or mixed nature, the responsibility remains with states to ensure its affordability.[107]

Finally, besides universal access to health care facilities and services, and the further requirements of health care provision, the right to health offers guidance concerning the environment in which health care is provided. In this regard, states

TABLE 1. The child's right to oral health: A framework

<table>
<tr><th colspan="4">Rights affected by dental caries incidence</th></tr>
<tr><th>Issue caused by or related to dental caries</th><th>Connected provision(s)</th><th colspan="2">State obligations (non-exhaustive)</th></tr>
<tr><td>Consequences for (oral and general) health</td><td>Best interests of the child
CRC, art. 3
Right to health
CRC, art. 24(1); ICESCR, art. 12(1)
Right to development
CRC, arts. 6(1), 27(1); ICESCR, art. 12(2)(a)</td><td colspan="2">• Prevent diseases, including dental caries
• Ensure the highest attainable standard of (oral) health over the life course by addressing dental caries risk factors during childhood
• Address caries as a potential cause of undernutrition
• Ensure the healthy development of children
• Inform all segments of society about child health and nutrition</td></tr>
<tr><td>Impact on personal life and inequalities</td><td>Best interests of the child
CRC, art. 3
Right to development
CRC, arts. 6(2), 27(1); ICESCR, art. 12(2)(a)
Right to health
CRC, art. 24; ICESCR, art. 12(1)
Right to education
CRC, arts. 28(1)(e), 29(1)(a)</td><td colspan="2">• Ensure the development of children and provide for an adequate standard of living for the child's development
• Take measures to encourage regular attendance at schools</td></tr>
<tr><th colspan="4">Rights that can inform dental caries prevention policies</th></tr>
<tr><th>Risk factor</th><th>Relevant provisions</th><th>State obligations</th><th>Illustrative policies (non-exhaustive)</th></tr>
<tr><td>Sugars consumption</td><td>Right to health
CRC, arts. 24(1), 24(2)(c), 24(2)(e); ICESCR, arts. 12(1), 12(2)(a), 12(2)(c)
Right to adequate food
CRC, art. 24(2)(c); ICESCR, art. 11(1)</td><td>• Combat malnutrition and ensure the provision of nutritious food
• Disseminate information concerning lifestyle and nutrition, also in relation to oral health</td><td>• Sugar taxes
• Advertising bans or restrictions for products high in sugars
• School health strategies
• Front-of-pack nutrition labeling</td></tr>
<tr><td>Oral hygiene</td><td>Responsibilities of primary caregivers and states
CRC, arts. 5, 18
Right to information
CRC, art. 13
Right to health
CRC, arts. 24(1), 24(2)(e); ICESCR, arts. 12(1), 12(2)(a), 12(2)(c)
Right to education
CRC, art. 29(1)(a)</td><td>• Assist parents and legal guardians in their child-rearing responsibilities
• Respect freedom of parents and legal guardians in raising their children
• Ensure that parents and children are informed about (oral) hygiene practices</td><td>• Inform children about oral hygiene via school curriculums, health services, and contexts for children who do not attend school
• Inform parents in multiple ways (for example, via media and public information leaflets)</td></tr>
<tr><td>Fluoride exposure</td><td>Right to health
CRC, arts. 24(1), 24(2)(f); ICESCR, arts. 12(1), 12(2)(a), 12(2)(c)</td><td>• Ensure the AAAQ of essential medicines, including fluoride
• Help individuals make informed decisions about their health</td><td>• Ensure appropriate access to fluoride exposure, either topical or systemic
• Provide information on the effects of fluoride exposure</td></tr>
<tr><td>Oral health care attendance</td><td>Right to health
CRC, arts. 24(1), 24(2)(b), 24(2)(f); ICESCR, arts. 12(1), 12(2)(a), 12(2)(c)</td><td>• Provide preventive and curative oral health care services and ensure that they meet the AAAQ requirements, particularly affordability
• Create an environment in which health-seeking behavior is encouraged</td><td>• Put an affordable (oral) health care system in place, including preventive services
• Provide (oral) health services within schools, to promote health-seeking behaviors</td></tr>
</table>

Notes: CRC = Convention on the Rights of the Child, G.A. Res. 44/25 (1989); ICESCR = International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966) should create an environment in which children and parents are enabled and encouraged to adopt health-seeking behavior.[108] Such an environment should encompass not only the availability of services but also high levels of health knowledge.[109] An example of such a stimulating environment includes the provision of health services within schools to promote health-seeking behavior.[110]

Conclusion

Child oral health and the prevention of dental caries has clear human rights dimensions. Oral health is an integral component of general health and affects children's current and future health and development. This makes it a crucial component in ensuring the fulfillment of multiple rights. Reflecting on the analysis of state obligations to address risk factors, the need for upstream measures stands out, especially given resource restraints in many states. On the one hand, the current barriers to realizing the right to oral health care and its associated costliness indicate the shortcomings of policies focused primarily on oral health care. On the other hand, upstream measures—such as implementing a sugar tax, requiring front-of-pack labeling, or restricting advertising—can be implemented at minimal or no cost. The adoption of an upstream approach thus increases the attainability of the right to health, which increases the stringency of obligations arising from the right to health.

Table 1 summarizes a proposed framework for children's right to oral health. This framework can be used by policy makers, advocates, and researchers to further public oral health, particularly in the context of dental caries as a disease. Additionally, it can inform future research on rights-based approaches to oral diseases, other NCDs in general, and associated risk factors. The rights identified can serve as legal tools to hold policy makers accountable and inform policy and practice in the field of oral health and childhood caries.

Human rights, especially children's rights, can inform the development of a comprehensive approach to addressing dental caries incidence and risk factors, supplementing the current individualized approach with upstream measures.

Acknowledgments

I am grateful for the feedback provided by and the stimulating discussions with my supervisors and colleagues I am grateful for the feedback provided by and the stimulating discussions with my supervisors and colleagues at JRC and the University of Groningen. I also thank the Danish Institute for Human Rights for organizing a PhD course on human rights research methods in November 2023, where I presented and discussed the methods adopted for this paper.

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Trialing Over-the-Counter Mild Pain Medication Access in Queensland Prisons: The Experience of Women Prisoners

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Abstract

In Queensland, Australia, adults in custodial facilities do not have discretionary access to over-the-counter (OTC) medications for mild pain relief and management. This study evaluated a trial allowing prisoners in male and female units at a regional Queensland correctional facility to purchase OTC medications from the prison store. The trial aligned with human rights legislation, international obligations, and the requirement for community equivalence of health care for prisoners. Queensland is the first jurisdiction in Australasia to undertake such a trial. We analyze the results from focus groups

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Competing interests: The authors were funded by Queensland Health's Office for Prisoner Health and Wellbeing to undertake the trial evaluation.

and surveys, comparing male and female prisoner experiences, by applying a gender impact assessment to examine pain management as a gender and health rights issue. Pain is gendered, and women's pain is often downplayed, not taken seriously, or not treated appropriately. Prisoners reported that being able to manage their pain relief gave them agency and decision-making ability that affirmed their human and health rights while living in a controlling environment. While this initiative has a positive impact on gender equality—because women are better able to self-manage pain—there are continuing opportunities to improve women's health care and address challenges of equivalence and the gender pain gap in prison systems.

Introduction

Prisoners often have complex health needs and high rates of physical and mental illnesses, substance abuse, chronic illness, and other conditions that can benefit from ready access to pain relief.[1] While access to self-managed over-the-counter (OTC) mild pain medications (e.g., paracetamol) is standard practice in many American and European prisons, across Australasia medications are dispensed by prison health staff. Prisoners are generally unable to keep any medications in their possession.[2]

When the Queensland government introduced human rights legislation in 2019, statutory bodies were compelled to align their practices with the new law's provisions, including health rights alongside gender-based equal opportunities and anti-discrimination, enshrined in federal and state laws and international agreements.[3] Collectively, these frameworks provide broad guidance, rather than prescriptive rules, for upholding the principle that prisoners should have access to health care, including pain relief, equivalent to that of the wider community.

We document the impact and experience of an OTC medication trial in a regional Queensland prison, addressing gendered experiences of pain and pain management. The medications—paracetamol (a simple analgesic) and ibuprofen (a nonsteroidal anti-inflammatory drug)—do not generally require a prescription in small quantities and can be sold in non-pharmacy settings, including supermarkets. Previously, prisoners had access to these medications only via prison health center clinicians. The trial permitted limited amounts of paracetamol and ibuprofen to be purchased (at a cost of ~A$1 for a pack of 10) from the prison store (or "buy-up"), weekly in the women's prison and fortnightly in the men's prison. The "buy-up" system—also known as the prison store—allows prisoners to purchase approved personal items, such as snacks and toiletries, using their account funds. While this OTC medication trial addressed the rights consideration of equivalence of health care, the trial evaluation raised gender impact and mainstreaming considerations. Gender plays a role in experiences of the legal, justice, and corrections systems. We examine how women in prison experience pain, and the impact of the OTC medications trial. Focusing primarily on prisoner voice, we present findings from the trial evaluation (via focus groups and surveys) and apply gender impact assessment (GIA) ex-post to examine the difference between male and female prisoner participant experiences.

Women in prison and their pain experience

Women are a significantly smaller proportion of the prison population than men. The 2023 prison population in Australia was 41,929 people, of whom 8% were female.[4] Furthermore, Aboriginal and Torres Strait Islander prisoners accounted for 33% of all prisoners, of whom 9% were female.[5] Nationally, the median age for all female prisoners was 35.5 years, and 36.3 years for males. In Queensland, the total prison population was 10,226, of whom 10% were female. Aboriginal and Torres Strait Islander peoples accounted for 37% of Queensland's prison population.

The Queensland Human Rights Commission (QHRC) identifies a high incidence of mental and chronic health conditions among female prisoners.[6] According to the QHRC, "fewer female prisoners than males reported they had been able to readily see a GP or nurse while in prison."[7] A high percentage of female prisoners (87%) have experienced gender-based violence and trauma during their lives, which can correlate with mental health and chronic health conditions.[8] Indigenous women, who are overrepresented in the prison population, can be disadvantaged in health care in prison despite the "equal treatment" principle.[9] Due to health care inequity in the broader community, for some prisoners, access to health care in prison can be more consistent.[10]

Critical questions for authorities in the OTC medication trial were whether prisoners could be trusted to independently manage OTC medications and whether risks could be sufficiently mitigated or self-managed by prisoners. Managing pain in a way that addresses human rights within prisons requires the navigation of risk and trust, which for some authorities can be a trade-off. In Australia (and globally), pain is a topical gender and health issue, with the Victorian state government opening a public inquiry into women's pain and a major pharmaceutical company presently raising awareness about the "gender pain gap," recognizing gendered specificities in the treatment and causes of women's pain.[11]

The OTC medication trial as a step toward equivalence of health care

The evaluation of the 2022 Queensland prison trial addressed the benefits and challenges of changing how prisoners access paracetamol and ibuprofen as unscheduled OTC medications. Paracetamol is Australia's most widely used pain medicine, with 65 million packs sold in 2021 from supermarkets, pharmacies, convenience stores, and toilet vending machines.[12] Paracetamol is sold in a pack of 20 outside of pharmacies, and in packs of up to 100 tablets in pharmacies. It is widely available and low cost, making it a convenient option for people to self-treat pain without a doctor's appointment or prescription. When taken as recommended, paracetamol is safe. However, it can be dangerous at high doses, causing acute liver toxicity. Australia's Therapeutic Goods Administration recently reviewed access to paracetamol in the community due to concerns about intentional overdoses and decided to reduce the pack size of paracetamol starting in February 2025.[13] Even with mildly increased restrictions, paracetamol remains highly accessible and available to people in the broader community, raising considerations of equivalence for prisoners.

Internationally, OTC medication access occurs in prisons in the United States (since 2003), Canada (since 2014), and the United Kingdom (since 2015).[14] This provides prisoners with better access to consistent and self-managed pain relief, reflecting human and health rights as per the 1955 Nelson Mandela Rules (updated in 2015, where prisoners are entitled to health care commensurate with that available in the community) and addressing known challenges in prison health care.[15] Standard practices in prison, such as strip searching, can deter women from seeking medical and counseling support.[16] The Bangkok Rules, adopted by the United Nations in 2010, specifically refer to female prisoners and assert that gender equality is not achieved by treating female and male prisoners the same.[17] Queensland's Human Rights Act of 2019 states that "every person has the right to access health services without discrimination."[18] Because adults can easily consume paracetamol and ibuprofen from supermarkets in the community, allowing access to these medications during "buy-up" aligns with international, national, and state obligations.

The trial emerged from discussions with

Prisoner Advisory Committees as part of the 2018 Offender Health Services Review and 2021 Health Consumers Queensland consultations. Among its recommended changes, the 2018 review called for clinical service redesign to increase efficiencies in medications management. This specifically referred to the development of "appropriate policies and processes for prisoner self-medication, targeted at appropriate prisoners and applying only to medications deemed safe and not at risk of diversion within correctional centres … [including] ready access to PRN medications (e.g., analgesics that, in the community, are available 'over the counter' without a prescription)."[19] The trial was subject to risk mitigation and safety guidelines that are consistent with the recommended use of OTC medications. In the trial this included limits on amounts available for purchase and storage (10 each of paracetamol and ibuprofen) and measures to improve prisoner health literacy.

Health and pain control medication in prison settings

Pain management is a significant issue in prison. Epidemiological studies show that people in prison experience complex health issues, with some of the worst health outcomes of any population group across all health domains.[20] They experience higher levels of physical and psychiatric illness compared to the general population, and stressors imposed by incarceration further contribute to negative health outcomes.[21] They also experience health issues as a result of incarceration, including the development of health problems typically associated with aging that can benefit from pain relief.[22] Consequently, medical services are in higher demand in prisons than in the broader community.[23] The recognition of prisoners' entitlement to the same level of care available in the community underlines the provision of health care services in carceral settings.[24] Access to medicines and medical products is a critical dimension of health rights and quality of care, particularly in relation to pain management.[25]

Research addressing the availability of pain control medication in prison settings tends to focus on pain management in cases of illnesses such as cancer or acute injury, rather that the treatment of day-to-day pains such as menstrual pain or toothache.[26] It is also acknowledged that males are less likely to proactively manage their health care.[27] Other research focuses on medication-prescribing for older prisoners, as well as the frequency of prescribed analgesia in prison.[28] It does not tend to explore in any detail the supply of OTC substances such as paracetamol and ibuprofen, noting that access to such medication is restricted and available through application to custodial personnel in the Australian context. Available research also raises the tension between security and patient-centered care, trust in prison health care delivery, and workload implications.

Women's pain can also be treated differently in health care settings (it can be dismissed) and is a topic identified as requiring more research.[29] As Kimberly Templeton explains, "women are more likely than men to experience a variety of chronic pain syndromes and tend to report more severe pain at more locations than do men."[30] International research indicates that women's pain is frequently downplayed, mistreated, psychologized, and disregarded due to the proliferation of gender stereotypes and biases.[31] Emily Bartley and Shreela Palit's study of 19 European countries found that significant gender pain inequalities are evident across Europe, referring to a "gender pain gap."[32] Inequality, stereotyping, and bias in care, as well as the undertreatment of pain, are also reported in studies of gender, race, and pain, indicating a need for greater intersectional and gender awareness of equity in health care.[33]

Further research is needed on women's pain management experiences in prisons. A rights-based approach is responsive to needs that Shirley Gabel describes as "duty bearers hav[ing] a clear-cut duty to meet needs and if they do not, are violating the rights of rights holders."[34] In the Bangkok Rules, women's specific rights include access to gender-appropriate health care. A 2023 UK National Health Service review of health and social care in women's prisons found that gender-sensitive health and social services are not consistently available and that current service provision is not fit for purpose.[35] While not addressing pain specifically as part of gender mainstreaming, the Council of Europe recommends "a gender-specific framework for health care in women's prisons, which emphasises reproductive and sexual health, mental health, treatment for substance abuse and counselling victims of violence."[36] Recognition of gender equality and mainstreaming is intrinsic to a rights-based approach. We compare the female and male prisoner experience, applying GIA principles as a framework to examine the impact of an OTC medications trial.

Methodology

This study evaluated a 2022 trial allowing prisoners in female and male units at one regional Queensland correctional facility to purchase OTC medications in the "buy-up." The evaluation of the trial was undertaken by an interdisciplinary team of design, psychology, nursing, and pharmacy researchers. Experiences of the trial were evaluated through focus groups involving 37 prisoners (16 women and 21 men) and paper surveys with 75 prisoners (23 women and 52 men) in the facility. The average age of participants was 36.5 years for females and 44 years for males.

Three researchers conducted qualitative research in person, with one leading conversations while others took written notes. Written notes were analyzed using inductive thematic analysis to reveal the themes that were common across participant experiences.[37] A paper survey was distributed to prisoners, who then returned them by post. The survey posed questions about the frequency, type, and location of pain experienced by prisoners, behaviors and preferences in relation to pain relief medication and management, and their perceptions of the change of policy. The correctional facility also provided access to internal records of OTC medication purchasing. The research team aimed to understand user experience by adopting a "view from below" approach to explore issues of power and rights in prisons, recognizing prisoners' voices and enabling prisoners to share their stories and experiences.[38]

GIA is applied as a lens for discussing the thematic findings acknowledging the gender dimensions of health rights in relation to pain management in the prison context.[39] GIA can be applied to policy, program, and regulatory interventions to evaluate how they address a particular issue and the extent to which they contribute to gender equality.[40] This approach has affinity with rights-based approaches given that rights are gendered, and women's rights and equality are articulated in charters and rules. Gender impact was not examined when the OTC medication trial was developed, and we apply it ex-post as a useful evaluative framework. GIA specifically focuses on the gender relevance of a policy or program initiative, addressing its direct and indirect impact through differences in access to resources. It particularly stresses the use of gender-disaggregated data to examine gender inequalities, including access to resources such as health and the exercise of fundamental rights on the basis of gender.

Findings

Prisoner participants were positive about the trial, valuing the trust placed in them to manage their own pain relief. As discussed below, thematic analysis revealed two core themes—agency and risk—as critical dimensions of trust that have specific implications for women. The first theme highlighted the importance of the initiative in affirming agency, dignity, and self-reliance, with access to additional health resources better equipping them to manage their pain. Participants indicated not only that they felt trusted but also that they can be trusted. In focus groups, female prisoners said they were "so grateful for it," while the male prisoners said that it took the "unnecessary aggravation out of the system, improving prisoner dynamics because pain was better managed." In both focus groups and surveys, prisoners reported that being able to self-manage access to pain relief meant that they did not need to continually contact officers or the prison clinic to seek treatment for common ailments (toothaches, headaches, sore muscles, period pain), which was positively transformative. The second main theme reflected the understanding of and being realistic about risks associated with the initiative and provision of equivalent health care.

Theme 1: Giving back agency, self-reliance, and dignity

Records retained by the prison show purchase patterns over a 12-month period among the ~800 male and ~200 female prisoners. Overall, 9,372 packets were purchased—nearly 3,000 packets each of paracetamol and ibuprofen in the male prison, and just under 2,000 packets of each in the female prison. This averages to about 9.5 packets per person in both prisons over this time frame, or less than one packet per person per month. On average, female prisoners purchased about 20 packets per year and male prisoners purchased about 7.5 packets per year. Sales started at around 100 packets each of ibuprofen and paracetamol per month in May 2022, slightly increasing to ~160 per month in the women's prison and doubling in the larger men's prison to ~250 packets per month a year later, in May 2023. Because prisoners reported some difficulties in obtaining pain relief from clinicians, this may partly account for the increase. No clinical or custodial adverse events were reported from the trial.

The purchase figures align with the survey responses on frequency of OTC medication use. The overall figures reflect the survey findings in which women reported more regular use of OTC medication. A higher percentage of female participants (48%) than male participants (34%) reported using pain medication every day. A slightly higher percentage of female participants (22%) than male participants (20%) reported using pain medication once or twice a week. However, a higher percentage of men reported using them several times a day, even though they otherwise reported less frequent use of pain killers. A higher percentage of women (96%) than men (83%) indicated that they had purchased OTC medications from the prison store, and 26% of females and 19% of males reported using medications more often after the OTC medications became available for purchase. Most participants (57% of females and 69% of males) reported that their medication use has not changed, indicating that the availability of medications is not driving their use.

Survey results indicate high approval of the initiative, with most female (78%) and male (75%) participants responding that the initiative is a good idea. Participants feel that the processes used by health care staff for assessing whether a prisoner is eligible (70% of females and 71% of males) and then monitoring the use of mild pain medications (61% of females and 56% of males) are working and appropriate. However, more women (70%) than men (33%) find the eligibility screening process—in which assessments are performed by individual clinicians to manage perceived risks—to be restrictive.

Participants agreed that having a pack of paracetamol or ibuprofen in their cell provided significant peace of mind, enabling them to proactively manage their own pain via a process that was "handy, convenient, and cheap." They greatly valued the dignity of being able to manage their own pain medications, as this change restored their sense of agency and control, enabling them to "doctor ourselves" and "giving back our self-reliance, control, and power—to look after ourselves and initiate self-care." The availability of OTC medication was seen as a privilege, which "gives more benefits than not" as "no one was mis-using it" and it was a "no brainer." Both female and male participants liked the convenience of being able to make decisions for themselves and not having to wait for consultations with prison medical staff. As one participant explained, "When I have an ache it is easily accessible. And I don't have to wait or I'm not in pain for long time." This is particularly important at night because the medication "can [be taken] during night when nurse not here."

Female participants expressed gratitude and relief, describing how they lived with period pain and greatly appreciated the "independence of it, to take when needed, and being trusted to self-medicate." Participants consistently reported that 10 paracetamol was insufficient and that they were "running out." Consequently, the ability to have access to more would be appreciated, but the dominant feeling was gratitude for being trusted to independently self-medicate. As one participant described, it is "AMAZING. We are so very appreciative and grateful of this change." Female participants reported that some clinicians did not trust them to take pain medications safely, which they found to be patronizing and offensive because "we are not children, we are adults." Many female participants described living with injuries, chronic pain, and menstrual-related pain and reported that they were often treated with "mistrust, and dictation of what we can and can't have" from some of the prison clinicians. In having to seek permission to take paracetamol, both female and male participants expressed their sense of disempowerment and infantilization, which is more commonly experienced by women in health care settings.

Women more strongly support the trial, with 100% of female participants and 85% of male participants indicating that prisoners should be able to buy OTC medications from the prison shop. Participant responses to questions of agency indicate that access to OTC medications not only positively impacts their sense of well-being but also contributes to a peaceful atmosphere in the prison (96% of females and 73% of males). Male participants used words such as trust, choice, freedom, and control to describe their experience, indicating that agency has an overall benefit for prisoner well-being. As stated by one male participant, "It gives us a little control over our health, and as an extension, our mental health." In contrast, women used terms such as gratitude and appreciation to explain that they value the agency of managing their pain without clinical intervention, which potentially reflects their clinical experiences. Almost all (100% of females and 81% of males) agreed that rolling out the initiative across the state would have a positive impact on prisoners' ability to self-manage pain.

Theme 2: Being realistic about the risks

Both female and male participants were pragmatic about the risks of overdoses and hoarding, which they saw as minimal because prisoners can access only ~10 pills at a time. Officers monitored and searched cells regularly, and prisoners asserted that they understood how to responsibly take pain medications. Both female and male participants stressed that as adults ("not kids") they are capable of managing medications; as two female participants explained, "if you are old enough to go to jail, you are old enough to take Panadol" and "I am 41 years old and know how to take prescription drugs."

Participants also affirmed the importance of having access to OTC medication and noted that they should not be punished or denied because of others' misuse. A female participant said that "we should be able to have a packet of Panadol in our rooms in case of headaches or mild pain, if things worsen go to medical but not sure about midnight pains so we'll need Panadol coz probably no nurse or doctor available at midnight." Participants also said that trading was not an issue, identifying a comparatively low risk of pressure to sell, trade, or share their supply (83% of females and 65% of males said no). The quantities purchased (average of 9.5 packets per person per year) also indicate that purchasing habits are consistent with personal use.

Approximately half (48% of females and 46% of males) said that they were aware of the potential for "bad outcomes" (overdosing, hoarding, or on-selling medications), and the vast majority said that it was "not too risky to let prisoners buy mild pain medications through the prison shop" (78% of females and 90% of males). Although participants were aware of potential "bad outcomes," they regard the availability of OTC medication as low risk. In focus groups, few recalled seeing prison-specific safety material but noted that there was standard health and safety information in the pack, while in the survey most (78% of females and 75% of males) said that sufficient safety measures have been implemented. Prisoners understood risks; one participant explained that "an overdose is a slow death" and that taking only two is ingrained. Participants suggested including information in the "arrival book," supplemented by very simple print and in-cell prison television content. Given that some prisoners cannot read, all recommended the display of low-literacy informational posters that "dumb it down."

Participants indicated that the prison has appropriate systems in place to manage the risks

(100% of females and 71% of males), even though women in particular experience the eligibility screening process as restrictive. Participants also expressed distrust of the system; they are concerned that access to OTC medication could be revoked. Participants greatly value being able to access OTC medications through buy-up and recommended expanding the selection to include a "health and well-being" section that offers antacids, vitamins, personal care, first aid, and other everyday items.

Gender-disaggregated findings

This study finds that although both female and male participants value and rely on the availability of OTC medications—which has enhanced prisoners' agency and sense of worth—gender-based differences remain evident in their experiences of pain and OTC medication use. A higher proportion of women than men purchased OTC medications and in higher quantities, reflecting a greater need among women for OTC medications. Women reported that the eligibility screening was restrictive or difficult. This is possibly indicative of a gender pain gap and biases in health care, but requires further research. Women described their experience in terms of "convenience" and "gratitude." Both women and men want to be treated like adults, not children, which is a meaningful assertion of capability. Although both women and men would like access to more OTC medications, the women's prison provides more frequent buy-ups than the men's prison. This potentially highlights unmet need among female prisoners, some of whom report long wait times to consult clinicians. Participants also indicated that they are not always provided with OTC medications by clinicians, particularly if they have purchased them in the buy-up. However, statewide policy requires that the prescription of pain medications occur irrespective of their availability via the prison store.

Discussion

Prisoner experiences with OTC medications highlight the interplay of rights, gender, risk, and trust in the provision of equivalent health care.[41] From both a rights and a gender perspective, this study addresses a health rights issue that has not received sufficient attention in relation to incarcerated women. Clear differences between female and male OTC medication use suggest that greater gender and intersectional sensitivity could improve the health impact of this intervention. The granting of the same quantities of pain relief for both women and men may not reflect women's pain experiences, their need for and capacity to self-manage OTC medications, or the adequacy of prison health care.

Internationally, the application of the Bangkok Rules resulted in the HM Inspectorate of Prisons in the UK introducing gender-sensitive "expectations" in 2014.[42] Policies and programs that seek to address pain management must also consider systemic gender biases in their application. Evidence possibly indicates that a gender pain gap may be amplified in the prison setting due to a gendered burden of illness, the tendency of males to neglect their health care, and the complex health needs of prisoners.[43] Applying GIA as a framework for this discussion foregrounds gender awareness in evaluating the provisioning of pain relief in prisons while also indicating opportunities for further learnings in the continuing alignment with human rights obligations.

Female and male prisoners are held in separate facilities and access health care within those settings. Survey responses indicate limited access to clinicians, with participants reporting long wait times and restrictive eligibility screening, contributing to a lack of agency and a sense of powerlessness. The convenience and affordability of OTC medications available through buy-ups support prisoners' capabilities for self-care and control.

Among female participants, reports of chronic and menstrual pain highlight how pain management needs may differ by gender. These patterns suggest that existing systemic disparities in how women's pain is recognized and treated in the broader community may also shape health experiences in prison. This disparity—often referred to as the "gender pain gap"—is likely intensified in correctional settings, where trauma, violence, and limited access to appropriate health care are more prevalent.[44]

The availability of OTC medications in the buy-up does not prevent prisoners from accessing paracetamol and ibuprofen *for free* through health center processes, which aligns with the Nelson Mandela Rules. Providing prisoners with easier access to consistent and self-managed pain relief aligns with access in the broader community. For prisoners, this equates to being "treated like an adult" and exercising the freedoms and choices that adulthood confers even when incarcerated. Given that prisoners express some dissatisfaction with access to medical care within the prison, the availability of OTC medications is seen as addressing a gap. Further research into prison health care, particularly from a gender perspective, is warranted because it can potentially lead to more gender-sensitive approaches that address gender bias and women's rights in clinical practice, a policy learning for prison systems seeking to implement similar programs targeting health literacy and agency.

Our findings indicate that prisoners view themselves as capable decision-makers, knowledgeable of the risks, and deserving of trust to manage OTC medications. Prisoners in this study were pragmatic about the risks of overdoses and hoarding, arguing that they are not only aware of risks but also able to manage their pain and safety. The relational dimensions of trust (which involves tensions of agency and risk) was also acknowledged: "the prison needs to give inmates more trust." Other research also reports how effective prisoner-patient pain management is challenged by the perception among staff—and among the public at large—that prisoners report fictitious pain to obtain analgesia for secondary gain rather than actual pain relief.[45] Because pain is often unseen and misunderstood, staff may react to this perceived lack of prisoner credibility by restricting the prescription of certain drugs, requiring evidence beyond self-report to verify suffering, and expressing anger and frustration when prisoners are seen as deceitful or manipulative.[46]

This study provides important evidence to assuage fears regarding the potential negative outcomes or abuse of health-related autonomy given to prisoners, as well as insights into the secondary benefits of such empowerment, such as reduced animosity toward custodial staff and mood regulation. A growing body of evidence encourages a paradigm shift toward recognizing prisoners as trustworthy and capable agents in managing their own health care and underscores the value of providing equivalent health care in prisons.[47] A rights approach calls for gender mainstreaming that builds trust and mutual recognition of system actors. However, prisoner agency remains contingent on prison staff and the authority and institutional legitimacy that they represent.[48] In prison settings, where prisoners experience disempowerment, prisoners are not confident that their requests for pain management will be addressed or taken seriously by staff.

Prisoners demonstrated awareness of the risks and concerns in relation to the relaxed availability of paracetamol and ibuprofen. For example, female participants suggested that education be provided about the safe usage of these medications. As the government of Queensland extends this initiative to other prisons across the state, it is essential to develop a complementary suite of resources on pain education and management to accompany its implementation.

Women's more frequent use of OTC medications since they were made available for purchase indicates gendered differences in pain experiences and management. It could also indicate that women's pain had been undertreated prior to the trial. Barriers to timely access to medical care are created by the tension between the security needs of the institution and the delivery of patient-centered care.[49] This is evident in the cultural conflict between correctional and health care systems and has been highlighted in relation to recent public health challenges such as COVID-19.[50] In recognizing the challenges of providing equivalent care in prisons and the complex health circumstances of many incarcerated people, Gérard Niveau argues that a better strategy is to exceed community standards rather than compromise them.[51]

With the availability of OTC medications, the self-reported prisoner experience shifted from being controlled to being trusted. For some, this conferral of "adultness" was appreciated, although it also plays into fears that the access might be revoked. In relation to gender, trust is particularly challenging, for researchers have found that female patient reports of pain are regarded as less trustworthy or more exaggerated.[52] This and other types of invalidation of women's pain by clinicians results in women's loss of rights.[53] The concept of equivalence of health care is not self-evident, as the organization of health care can necessitate adaptions in response to the prison setting.[54] Further, Sacha Kendall et al. argue that "equal treatment" is insufficient for equitable health care given that some groups carry a higher burden of illness.[55] Health care providers need to understand why women prisoners are using OTC medications more frequently than men. The study findings suggest that equivalence and equal treatment benefit from sensitivity to gender and intersectional and individual circumstances, while patient-centered and trauma-informed approaches ensure that women have the necessary access to resources.

Conclusion

This evaluation of the OTC medication trial in Queensland prisons has shown the value of enabling access to simple analgesics commonly used for minor pain conditions (e.g., tension headache, menstrual discomfort, and musculoskeletal pain), alongside strict and medically informed safety and risk-reduction strategies in terms of the quantities permitted. It is one pathway to realizing the human rights obligations of state government agencies contained in legislation and international agreements.

As well as enabling prisoners' independent pain management and health literacy, the evaluation suggests a broader potential benefit from the reduced reliance on medical and nursing services for minor and low-acuity conditions, although more research and data are needed to quantify this potential impact. This evaluation has shown that enabling access to OTC medications that are commonly available in the community is a positive step toward health rights, equivalence, and improving prisoner health care and health literacy. It demonstrates that prisoners are responsible and can be trusted to manage these OTC medications, as no problems or adverse events were reported in the evaluation. This is a strong indication that rights and risks can be managed within prisons to provide equivalent health care.

Here, we have adopted an explicit gender impact lens to highlight both the importance and limitations of the "equivalence" of health care requirement. We suggest that, alongside global human rights initiatives, gender impact should be consciously considered in the development of prison health care initiatives to ensure that biases within both the correctional and health systems are addressed. The significant difference between female and male OTC medication requires further research. Just as COVID-19 and HIV/AIDS pressured prison health systems to be more responsive and adaptive, this trial provides policy learning to improve prison health care's alignment with rights.[56]

This study highlights the need to integrate gender awareness into prison health care and health promotion as an essential component of a rights-based approach. "Equivalence" should not mean the reproduction or amplification of systemic biases in the prison system, which potentially results in a gender pain gap; rather, it requires a more reflexive synthesis of gender, intersectionality, and rights in the prison context. Gender mainstreaming and gender impact assessments can enable more targeted strategies to advance gender equality in prison health care. While this initiative responded to human rights obligations and greatly benefited women, it was not introduced with an intentional consideration of gender. Prisoner voices—as the view from below—make gendered pain experiences explicit. The issue of women's pain and pain management in prisons also warrants further research addressing patient-centered and trauma-informed considerations.

Acknowledgments

We are grateful to Queensland Health's Office for Prisoner Health and Wellbeing for driving the development and implementation of the OTC initiative (which was approved by the Prisoner Health and Wellbeing Leadership Group) and for funding this evaluation, and to Queensland Corrective Services for enabling access. We would also like to thank the staff and prisoners at the case study site for welcoming us. The lead author acknowledges and thanks Conor Brophy, chair of the Queensland University Human Research Ethics Committee, for an invaluable conversation about the project's approach, processes, and methods and for feedback that greatly facilitated and streamlined the ethics application and process.

Funding

This project was funded by Queensland Health's Office for Prisoner Health and Wellbeing.

Ethics approval

Formal research ethical approval for the project was granted by Queensland University of Technology (#6631) and subsequently approved by Queensland Corrective Services.

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A Narrative Review of Dual Loyalty Conflicts in Custodial Settings and Implications for Community Practice

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Abstract

Dual loyalty dilemmas are conflicts between health care professionals' obligations toward their patients and third-party interests. These conflicts are more common and starker in custodial settings, such as jails and prisons, military detention facilities, immigration detention centers, and involuntary psychiatric institutions. Despite encountering patients in custody, health care professionals (HCPs) in community settings have limited knowledge and training. In this narrative review, we examined dual loyalty conflicts faced by HCPs working in custodial settings and then applied the identified themes to community-based hospitals where HCPs care for patients in custody. We searched databases for original papers relating to patients in custody and dual loyalties and then abstracted key themes, findings, and characteristics of the conflicts. There are five categories of competing loyalties that give rise to dual loyalty conflicts: institutional and organizational entities, legal and regulatory guidelines, ethical and moral responsibilities, social and public responsibilities, and other individuals. Themes include the inappropriate withholding or delaying of care, the provision of intervention despite patient refusal, the violation of patients' rights to privacy, cruel non-clinical interventions (e.g., torture), and the failure to document or report information accurately. Mitigation strategies in the literature emphasize expanding human rights education, improving patient communication around possible conflicts, and raising clinician awareness of institutional policies. Common in the care of patients in custodial settings worldwide, dual loyalty conflicts can impact patient care. However, pursuing mitigation strategies can lessen their impact.

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Competing interests: None declared.

Case study

A hospitalist at a large urban medical center is caring for a 52-year-old incarcerated man transferred from the county jail with sepsis due to an infected diabetic foot ulcer. Two uniformed correctional officers are permanently stationed outside his hospital room, restricting his movement and monitoring his interactions with staff. When the hospitalist attempts to conduct a private physical examination, one of the officers insists on remaining in the room, citing security protocols. The patient looks visibly distressed and withdraws from further discussion. The hospitalist asks the officer if he can remove the patient's ankle shackles to enable a complete assessment. The officer declines, again citing security protocols. Later, the hospitalist documents incomplete findings in the medical record, noting limited access to the patient for an adequate assessment. In the afternoon, a prison administrator calls the hospitalist, requesting updates on the patient's condition and estimated discharge date. A hospital administrator asks whether the hospitalist could expedite discharge to the jail infirmary due to limited bed space in the hospital.

Introduction

Dual loyalty dilemmas arise when health care professionals (HCPs), defined as anyone involved in the care of a patient, experience conflicts between their ethical obligations toward their patients and competing responsibilities to third parties.[1] These conflicts are particularly pronounced in custodial settings, such as military combat zones, military or government detention facilities, immigration detention centers, involuntary psychiatric institutions, and jails or prisons. The existing literature has extensively described dual loyalty conflicts among HCPs working directly within these custodial settings. However, there is limited application of dual loyalty frameworks to community HCPs caring for patients in custody in traditional, non-custodial hospital settings. On-site medical services at correctional facilities are typically limited to primary care, and incarcerated patients requiring emergent or specialty care are transferred to community hospitals. In the United States, more than 730,000 incarcerated adults receive care in community hospitals annually, often under the custodial supervision of correctional officers and with institutional policies that may inadvertently contribute to dual loyalty conflicts.[2] Community HCPs often lack formal training to address the unique challenges that arise when balancing the needs of patients in custody against institutional or legal demands.[3] Unfortunately, there are few clinical guidelines surrounding the care of in-custody patients in traditional, non-custodial hospitals.[4]

This paper adopts a two-part approach. First, we present the results of a narrative review of dual loyalty conflicts faced by HCPs working in custodial settings. Second, we apply the identified themes to a related but underexamined context: community-based hospitals where HCPs care for patients in custody. Although structurally distinct, both settings feature hierarchical structures of authority, security oversight, and limitations in patients' freedom that give rise to similar dual loyalty conflicts. Finally, we propose mitigation strategies tailored to the unique nature of dual loyalty conflicts experienced by community HCPs in non-custodial, traditional hospitals.

Some dual loyalty scenarios, such as those that involve favoring third-party competing interests in the interest of distributive justice, are considered ethically supportable and arise from duties to promote fairness across populations. However, this paper focuses on dual loyalty conflicts that emerge from external pressures that may compromise patient care. These frameworks share a structural similarity of focusing on competing obligations. However, there is a distinction in the moral stakes. While distributive justice reflects principled ethical prioritization, many custodial dual loyalty conflicts result from external demands contradicting principles of patient-centered care.

Methods

Search strategy

A qualitative literature review was conducted to identify and categorize instances of dual loyalty conflicts among HCPs practicing within custodial settings. We searched PubMed, Web of Science, and Embase for peer-reviewed, English-language, original studies published up to February 20, 2024. We used free-text terms such as “dual loyalties,” “physician,” “jail,” “prison,” and “correctional facilities.”

Inclusion and exclusion criteria

Search results were uploaded into Covidence for deduplication and screening. Two independent reviewers evaluated each article for inclusion in the analysis, with discrepancies resolved by consensus via discussion with a third reviewer.

Articles were included if they (1) described dual loyalty conflicts where HCPs faced tensions between patient care obligations and third-party interests, (2) focused on HCPs practicing directly in custodial settings, including military combat zones, government or military detention centers, immigration enforcement facilities, inpatient psychiatric units, and jails or prisons, and (3) provided empirical data, case studies, or normative ethical analyses of dual loyalty conflicts.

Articles were excluded from analysis if they (1) focused on dual loyalty conflicts in health care without discussing custodial settings or (2) addressed health care in custodial settings without specific references to dual loyalty conflicts.

Data extraction

A structured, four-tiered data extraction framework was developed to systematically identify and categorize data. This framework enabled consistent coding and thematic synthesis across diverse sources that included empirical studies, case reports, ethical analyses, legal discussions, and policy documents. The framework included identifying the following within included papers: (1) competing objects of loyalty that are not the patient and patient’s interests, (2) contexts in which dual loyalty conflicts occurred with examples, (3) themes describing the nature of dual loyalty conflicts, and (4) mitigation strategies for dual loyalty conflicts. Dual loyalty conflicts were explicitly described as dual loyalty conflicts by article authors or inferred by reviewers based on discussion of conflicting obligations. Each article was coded for content across these four dimensions by two independent reviewers, with key excerpts extracted verbatim where applicable. Discrepancies were resolved by consensus via discussion with a third reviewer.

Thematic analysis and categorization

The extracted data underwent inductive and thematic analysis. Two independent reviewers coded studies, with discrepancies resolved through consensus discussion. To ensure consistency, codes were iteratively refined, consolidating overlapping themes. Coded excerpts were cross-checked with existing ethical and legal frameworks, including international human rights law, professional medical ethics guidelines, and institutional policies. Extracted themes were organized into a narrative synthesis.

While our literature review is limited to studies addressing custodial contexts, we incorporate additional references into the discussion to contextualize the application of these findings to non-custodial settings. These references were not included in the formal review process but serve to bridge thematic insights into clinical environments where HCPs may encounter patients in custody in traditional, non-custodial hospitals.

Results

Our initial search returned 639 studies, of which 63 met inclusion criteria and were abstracted for analysis. These studies provided insights into the competing objects of loyalty influencing HCPs, contexts of dual loyalty conflicts, thematic categories of dual loyalty dilemmas faced by HCPs in custodial settings, and proposed mitigation strategies for dual loyalty conflicts.

Competing objects of HCP loyalty in dual loyalty conflicts in custodial settings

HCPs practicing in custodial settings face obligations to many competing objects, including institutional and organizational entities;

legal and regulatory guidelines; ethical, moral, and professional responsibilities; social and public responsibilities; and individual people. As shown in Table 1, institutions such as hospitals, military organizations, and immigration agencies shape medical decision-making through policies and administrative pressures. Legal requirements, such as mandatory reporting laws and national security considerations, may also create dual loyalty conflicts. Professional commitments, personal morals, and broader societal responsibilities, such as public safety and resource allocation, also complicate dual loyalty dynamics.

Contexts and examples of dual loyalty conflicts in custodial settings

Across the literature, five common custodial contexts emerged in which HCPs experience dual loyalty conflicts: military combat zones, military and government detention, immigration deten-

Table 1. Competing objects of HCP loyalty in dual loyalty conflicts within custodial settings

Objects of loyalty	Examples
Institutional and organizational entities	• Managed care plans • Insurance companies • Clinical leadership • Prison administration • Universities and medical schools • Military • Immigration agencies • Corporations • The government • “The state” • Health quality and performance metrics
Legal and regulatory guidelines	• Mandatory reporting requirements • National security • Local, state, and federal law • International human rights law • Military law • Criminal legal system • Fear of liability • Professional licensing and credentialing bodies
Ethical, moral, and professional commitments	• Principle of justice within medical ethics (clinician may feel like or need to conserve or allocate scarce health care resources for the benefit of the community and other patients rather than the patient before them) • Specific doctrines or treatises (e.g., Hippocratic Oath, Geneva Conventions) • Preservation of life • Professional identity • Personal morals and beliefs • Religious and cultural beliefs
Social and public responsibilities	• Public health • Public safety • One’s own country • National security • Community values • Resource utilization • Advancement of medical knowledge • Medical education
Individual people	• Family members • Employers • Colleagues • Supervisors • Correctional staff • One’s physical safety • One’s personal interests

tion, inpatient psychiatric facilities, and jails and prisons. Within each of these contexts, specific examples illustrate the complexity of the dual loyalty dilemmas, as outlined in Table 2. For example, in military settings, HCPs may prioritize their own soldiers over enemy combatants. In detention settings, HCPs have historically participated in practices such as force-feeding hunger strikers, disclosing confidential medical information to authorities, or even evaluating detainees' fitness for torture. Immigration enforcement introduces unique dual loyalty dilemmas, such as conducting forensic age assessments or evaluating detainees for deportation despite inadequate medical evaluations. In psychiatric facilities and prisons, conflicts arise in cases involving disclosure of patient information, forensic evaluations, and participation in punitive measures, such as solitary confinement or competency restoration for execution.

Themes of dual loyalty conflicts in custodial settings

From these diverse contexts in which HCPs work directly in custodial settings, we identified five overarching themes of dual loyalty conflicts, as summarized in Table 3. These themes are as follows:

1. **Withholding or delaying care inappropriately**

   DL conflicts may lead HCPs to delay or withhold treatment, particularly in military combat

Table 2. Contexts and examples of HCPs' dual loyalty conflicts in caring for patients in custody

Context	Settings	Examples
Military combat zones	• Australian Defence Force[1] • Dutch military in Srebrenica[2] • French Operation Barkhane in the Sahel[3] • Israeli Defense Forces in Palestine[4]	• Prioritizing care for own soldiers over enemy's soldiers[5] • Delaying care to foreign civilians in favor of own soldiers[6] • Providing inadequate care to enemy soldiers[7] • Delaying ambulance transportation of civilians and enemy soldiers[8] • Delaying or withholding care from civilians or captured enemy soldiers[9]
Military or government detention	• Israeli Prison Service and Israeli Defense Force detention of Palestinians[10] • Global War on Terrorism - United States Abu Ghraib prison in Iraq[11] - United States Guantanamo Bay detention facility[12] - United Kingdom Operation Herrick in Afghanistan[13] - Canadian operations in Afghanistan[14] - French Operation Barkhane in Sahel[15] • Arab Spring in Bahrain and Syria[16] • South African Apartheid[17] • Nazi Germany[18] • Sadaam Hussein's Baathist regime[19] • Augusto Pinochet's regime in Chile[20] • Uruguayan dictatorship[21] • Former Soviet Union[22] • China and the Falun Gong movement[23] • Turkish detention centers[24]	• Participating in torture, including evaluation of victims' fitness[25] • Failing to report witnessed abuse[26] • Force-feeding individuals engaged in hunger strikes[27] • Forcibly dialyzing a detained patient[28] • Inadequately completing or falsifying medical records[29] • Failing to ensure appropriate discharges and continuity of care[30] • Disclosing medical information to third parties without consent (e.g., to facilitate interrogation)[31] • Providing inadequate care for chronic conditions (e.g., hypertension)[32] • Providing inadequate screening or treatment for indicated conditions (e.g., hepatitis C)[33] • Withholding indicated care from patients (e.g., blood transfusions)[34] • Killing patients via medication overdoses[35]
Immigration enforcement	• United States Immigration and Customs Enforcement (e.g., Mexico border)[36] • Australian Immigration Detention Centers (e.g., Nauru)[37] • German Office for Migrants and Refugees[38]	• Assessing age of detainees via dental radiographs[39] • Force-feeding individuals engaged in hunger strikes[40] • Resource limitations or third parties preventing HCPs from providing needed care[41] • Assessing fitness to travel for deportation[42] • Complying with the manacling and guarding of immigration detainees in hospitals[43] • Misdiagnosing self-harm behaviors as manipulative or personality-driven[44] • Participating in torture[45] • Disclosing medical information to third parties without consent (e.g., to facilitate deportation proceedings)[46] • Failing to report witnessed abuse[47]

*Examples marked with an asterisk are considered in many circumstances to be an ethically or legally appropriate prioritization of third-party interests. In taking care of patients in custody, public health and public safety may be favored over individual patient priorities.

and detention. HCPs may prioritize their own soldiers over enemy combatants or civilians, provide inadequate care, withhold necessary treatments, or delay decisions due to resource constraints. In jails and prisons, concerns about medication misuse may limit appropriate prescribing by HCPs. These dual loyalty dilemmas force HCPs to balance competing priorities between national interests, orders from superiors, loyalty to colleagues or soldiers, security needs, and just allocation of resources.

2. **Providing interventions against patient wishes**

The primary forced intervention highlighted in the literature is force-feeding individuals on hunger strikes. In these situations, HCPs must balance respecting patients' autonomy and minimizing harm through traumatic force-feeding with institutional priorities of preventing in-custody deaths due to starvation.

3. **Violating a patient's right to confidentiality and privacy**

HCPs may inappropriately disclose medical information without patient consent or for non-clinical purposes, such as deportation proceedings or interrogations. In these situations, HCPs must balance respecting patients' rights to privacy and confidentiality, maintaining trust in the patient-physician relationship, upholding societal justice as defined by third parties, promoting institutional security and public safety, and adhering to legal and institutional disclosure policies.

TABLE 2. *continued*

Context	Settings	Examples
Inpatient psychiatric care	• Court-mandated mental health treatment in Switzerland[48] • Patient-physician confidentiality (and exceptions) in the United States[49]	• *Obtaining and disclosing medical information from forensic evaluations (e.g., determining competency to stand trial or receive death penalty, evaluating criminal responsibility)[50] • Failing to report witnessed abuse[51] • *Disclosing a patient's medical information to ensure safety of third parties (e.g., *Tarasoff* warnings)[52] • Presenting identifiable clinical information in an academic forum[53]
Jail and prison settings	• United States[54] • United Kingdom[55] • Ireland[56]	• Assisting in body searches or obtaining body fluids for analysis[57] • Assessing fitness for punishment (e.g., solitary confinement)[58] • Altering assessment of patient injuries based on security staff reports of "what actually happened"[59] • Disclosing medical information to security staff for reasons unrelated to provision of care[60] • Supervising trainees to a lesser degree in caring for incarcerated patients[61] • Allowing trainees to perform invasive exams due to perceived inability of patients to decline (e.g., rectal exams)[62] • Inappropriately limiting treatment due to concerns about medication diversion[63] • Force-feeding individuals engaged in hunger strikes[64] • Limiting guideline-based treatments (e.g., for asthma)[65] • Limiting guideline-based diagnostics and screening (e.g., for hepatitis C)[66] • Participating in execution, including restoration of competence for execution[67] • *Testing for communicable diseases without consent (e.g., HIV, tuberculosis, hepatitis C)[68] • Delaying medical decision-making due to difficulty in contacting family members[69]

4. **Engaging in unnecessary or cruel interventions**

   HCPs have participated in unnecessary and cruel interventions that not only transgress clinical obligations but also contribute to human rights violations. Examples include torture, inappropriate medical evaluations (e.g., age assessments via dental radiographs and fitness for deportation or punishment), punitive measures (e.g., body searches or solitary confinement), and executions. These cases challenge HCPs' loyalty to colleagues, institutional policies, state-based third parties, legal systems, and national security.

5. **Falsifying or omitting medical documentation**

   HCPs may withhold reports of abuse, misdiagnose self-harm behaviors, or alter injury assessments based on non-medical staff reports. In these situations, HCPs face dual loyalty conflicts stemming from their professional obligation to protect patients from harm, legal or institutional reporting requirements, institutional pressure to conceal abuse or avoid negative publicity, and perceived obligations to protect public safety.

Mitigation strategies for HCPs experiencing dual loyalty conflicts in custodial settings

The reviewed literature also identified a range of strategies to mitigate dual loyalty conflicts, including education, transparent communication between HCPs and patients, and institutional policy development, as detailed in Table 4. Educational interventions include integrating human rights principles into medical school curricula and providing specific training on dual loyalty conflicts. At the individual HCP level, strategies focus on careful documentation, transparent communication with patients about conflicting loyalties, and proactive advocacy efforts. Institutions have sought to mitigate dual loyalty conflicts by ensuring separation between HCPs and third-party influences, establishing whistleblower protections, and adopting mechanisms for independent oversight. Developing quality improvement frameworks and peer support systems can empower individual HCPs to inform organizational policy and seek support when needed.[5]

Discussion

The findings from our literature review demon-

TABLE 3. Thematically organized examples of dual loyalty conflicts from all custodial contexts

Theme	Examples
Withholding or delaying care inappropriately	• Withholding or delaying screening and treatment of chronic conditions • Blocking emergency medical transportation • Providing inadequate care due to external limitations (e.g., resource limitations, triage decisions, state or institutional policies, concern for medication diversion) • Delaying care due to difficulty identifying and contacting surrogate decision-makers • Providing limited supervision for trainees • Failing to ensure appropriate discharges and continuity of care
Providing a clinical intervention that has been refused by the patient	• Forcibly performing invasive medical interventions (e.g., force-feeding individuals engaged in hunger strikes, forced dialysis) • Performing non-indicated interventions or exams solely for training or at the request of the correctional facility
Violating a patient's right to confidentiality and privacy	• Disclosing medical information without consent • Disclosing medical information for non-clinical reasons (e.g., interrogation, deportation, security) • Disclosing more than the minimal amount of medical information needed to correctional staff • Presenting identifiable clinical information in an academic forum
Providing an unnecessary intervention that is cruel or transgresses clinical obligations	• Participating in torture • Conducting inappropriate medical evaluations (e.g., fitness for deportation or punishment) • Assisting in punitive measures (e.g., body searches, solitary confinement) • Participating in executions
Failing to accurately report or document relevant information	• Failing to accurately report or document clinical information (e.g., misdiagnosing self-harm behaviors, altering injury assessments) • Failing to report witnessed abuse

strate the diverse contexts and recurring themes of dual loyalty conflicts experienced by HCPs taking care of patients directly in custodial contexts. While these insights offer independently valuable lessons, dual loyalty conflicts also often manifest distinctly in non-custodial, traditional hospitals where community HCPs encounter patients in custody. These HCPs encounter patients in custody less frequently in their day-to-day practice and often without the benefit of formal training or institutional guidance. This lack of clarity may heighten clinicians' deference to correctional officers or institutional authority, especially when security protocols are unfamiliar or may seem to supersede clinical norms. However, both custodial settings and non-custodial, traditional hospitals are characterized by hierarchical structures, an emphasis on security, and care for patients with limitations on their freedom. In the discussion of our findings, we extend the themes identified in our narrative review of custodial settings to assess how analogous dual loyalty dilemmas arise in non-custodial hospitals. In this process, we hope to provide a framework for understanding the challenges faced by HCPs in non-custodial settings and for identifying tailored mitigation strategies.

Withholding or delaying care inappropriately

As described in Table 3, withholding or delaying care is a common theme of dual loyalty conflicts in custodial settings. In non-custodial hospitals, dual

TABLE 4. Mitigation strategies for dual loyalty conflicts encountered by HCPs caring for patients in custody

Focus area	Mitigation strategy	Examples
Education	Adjusting graduate and undergraduate medical education structure[1]	• Prioritizing socially minded applicants[2] • Mandatory training in ethics, law, and human rights (e.g., all medical schools in South Africa)[3] • Continuing medical education involving human rights[4] • Instructing trainees in clinical settings with a high prevalence of dual loyalty conflicts[5]
	Explicit education on dual loyalties[6]	• Addressing the hidden curriculum of diagnostic skepticism, misplaced deference to third parties, and violation of incarcerated patients' rights[7] • Providing education and training for health professionals on the dual loyalty challenges they may face in custodial settings[8]
	Changing teaching methods to focus on human rights framework[9]	• Emphasis that human rights cannot be deprioritized except under very limited circumstances[10]
	Courses in ethics and professional development[11]	• Professional development and training in reflective listening[12]
Individual HCPs	Carefully documenting encounters and maintaining confidentiality[13]	• Documenting evidence that might underpin civil advocacy • Documenting the rationale for breaking confidentiality and the decision-making process[14] • Requesting that correctional staff not be within earshot during history-taking[15]
	Reporting abuse and human rights violations[16]	• Using an independent medical authority[17] • Setting up internal channels[18]
	Transparently communicating with patients about dual loyalty conflicts[19]	• Involving the patient in the decision-making process and explaining the conflicting loyalties to the patient[20] • Balancing transparency and unchecked information-sharing[21] • Addressing the importance of clear communication in early therapy sessions[22] • Communicating the limits of confidentiality with the patient[23] • Respecting patient's pace and perceived coercion[24] • Allowing patients to read (but not edit) documentation prior to submitting it to authorities[25]
	Advocacy[26]	• Boycotting employment with institutions known to perpetuate human rights violations[27] • Letter writing, lobbying, protests, campaigns, and marches[28] • Providing witness testimony in official inquiries[29] • Developing position statements and conducting research[30]

loyalty conflicts in caring for patients in custody can lead HCPs to delay or withhold care due to security concerns resulting from competing loyalties, as outlined in Table 1. For example, institutional pressures from hospital administrators or correctional facilities may result in patients in custody receiving fewer diagnostic tests and treatments than other patients while they are in non-custodial hospitals.[6] These delays mirror examples from custodial settings (Table 2), where prioritization of institutional needs over patient care often hinders timely treatment. Security measures in non-custodial hospitals, such as concealing patients' locations or treatment plans to mitigate real or perceived safety risks, further extend these delays.[7]

Community HCPs caring for patients in custody also face barriers to effective discharge planning and continuity of care. Security protocols frequently restrict communication by community HCPs with patients in custody about their pending discharge, and follow-up care can be neglected due to difficulties coordinating with correctional facilities.[8] Security protocols may limit communication with patients' surrogate decision-makers, and adapting follow-up plans to the limited resources available in correctional facilities further complicates safe discharge planning.[9]

Community HCPs often lack guidance on decision-making authority for incapacitated patients in custody, leading to delays in care. Examples from Table 2, such as prioritizing institutional demands over patient autonomy in detention centers, further demonstrate the ingrained systemic barriers that perpetuate these delays. Community HCPs have reported collaborating with correctional staff to make decisions for unrepresented patients, bypassing legal surrogate decision-making processes and violating patients' decisional rights.[10] This type of violation also occurs within jails and prisons, as noted in Table 2.

Providing interventions against patient wishes

In custodial settings, HCPs may be compelled to perform interventions against patients' wishes, such as force-feeding or non-indicated procedures (Table 2). Similar conflicts arise in non-custodial hospitals, where community HCPs may incorrectly believe that patients in custody cannot legally refuse recommended treatments.[11] These perceptions by HCPs are often influenced by loyalties to

TABLE 4. *continued*

Focus area	Mitigation strategy	Examples
Organizational and institutional	Separating HCP employers and third parties[31]	• Completely separating health care personnel and prison administration[32]
	Implementing reporting mechanisms and whistleblower protections[33]	• Requiring reporting by institutions on how they are meeting their own and international standards[34]
	Evaluations by independent entities[35]	• Civilian oversight (e.g., HCPs skilled in ethical issues and human rights)[41] • Peer review (e.g., independent psychiatrists review psychiatrists working in carceral setting)[42] • Military ethics tribunals[43] • Establishing peer review structures such as case conferences, grand rounds, and journal clubs in high-risk settings[44]
	Professional guidelines on dual loyalty conflicts[45]	• Encouraging medical associations to formally endorse recommendations of the International Dual Loyalty Working Group[46] • Guidelines minimizing judgment required of individual physicians[47]
	Quality improvement framework for breaches[48]	• Integrating mechanisms for documentation into electronic health record to review for lapses[49]
	Supporting HCPs via peer support and mentorship[50]	• Support from senior medical officers to ensure that military HCPs are not professionally isolated and have access to necessary resources and expertise[51] • Forming peer networks and support networks among HCPs[52]
Regulatory	Accountability for violations of human rights[53]	• Instituting systems in licensing bodies to discipline members for human rights transgressions[54]

institutional policies or legal frameworks, as can be seen in Table 1. This misconception is evident when correctional staff inappropriately attempt to make unilateral decisions about withdrawing life-sustaining treatment for patients in custody.[12] However, like the general public, patients in custody retain the right to refuse medical interventions, except in cases involving high-risk communicable diseases, forensic testing, or involuntary treatment for severe agitation that poses risks to themselves or others.[13] Overriding an incarcerated patient's refusal typically requires a court order.

Violating a patient's right to confidentiality and privacy

As noted in Table 3, breaches of patient confidentiality and privacy are pervasive in all custodial settings, often driven by institutional and legal mandates. These violations are equally problematic in non-custodial hospitals, where community HCPs' competing loyalties to correctional authorities or fear of legal repercussions (see Table 1) may lead to inadvertent disclosures of medical information to correctional staff.[14] A multi-site study found that less than half of surveyed community HCPs knew how to access policies regarding care for patients in custody, highlighting a significant knowledge gap.[15] In another study, nearly half of surveyed HCPs reported not asking correctional staff to leave the room during patient histories or physical exams, and 42% reported sharing care plans with correctional staff without a clear justification.[16] These patterns can be clearly seen in both custodial and non-custodial settings, representing a central theme of dual loyalty conflicts.

Engaging in unnecessary or cruel interventions

Cruel or unnecessary interventions, such as shackling, are another recurring theme in dual loyalty conflicts identified in Table 3. The routine use of shackling for patients in non-custodial hospitals reflects similar practices by HCPs in multiple custodial settings (see Table 2). Shackling can lead to worse health outcomes by directly interfering with medical interventions, causing psychological distress, and amplifying patients' feelings of isolation and fear.[17] Shackling has been documented even in situations where security is clearly not a concern.[18] In a single-program survey, over 65% of general surgery residents reported caring for incarcerated patients who were sedated and intubated but remained shackled.[19] However, HCPs often face significant administrative and logistical hurdles in obtaining permission to remove shackles, again demonstrating the strength of various third-party interests in dual loyalty conflicts as listed in Table 1.

Falsifying or omitting medical documentation

Inaccurate or incomplete medical documentation occurs across both custodial and non-custodial settings. Community HCPs often struggle to transfer medical records between custodial and non-custodial hospitals to ensure continuity of care.[20] On a broader scale, the absence of incarcerated patients' data in national health care databases hinders efforts to monitor and address health disparities in this population, as current and formerly incarcerated individuals are often missing from datasets.[21] These documentation challenges mirror those in custodial settings, where HCPs may be pressured to alter records or misreport clinical findings to avoid exposing human rights violations (see Table 2).

Mitigation strategies

Effective strategies to mitigate dual loyalty conflicts in non-custodial hospitals are those that address the precipitants of the conflicts themselves, namely resource limitations, policy misunderstandings, and challenges in collaborating with correctional institutions.[22] Our literature review highlights three key focus areas for mitigation strategies for dual loyalty conflicts in custodial contexts, as described in Table 4. Within these focus areas, three specific mitigation strategies may be particularly relevant for community HCPs treating patients in custody in non-custodial, traditional hospitals: emphasizing human rights education, transparently discussing existing dual loyalty conflicts with patients in custody, and understanding the policies at one's own hospitals and correctional facilities.

Medical education in the United States typically emphasizes bioethical analysis to address ethical conflicts. In this framework, ethical principles such as respect for autonomy, beneficence, non-maleficence, and justice are balanced, often with limited guidance on how or when to prioritize one over another.[23] While these principles can guide patient-centered care, they do not inherently resolve the unique tensions that can arise in dual loyalty conflicts. Thus, this framework may leave HCPs ill-equipped to manage situations where loyalties diverge between patients and other entities. While few United States medical schools have human rights curricula, all South African medical schools require such training.[24] A human rights-based approach to dual loyalty conflicts may better equip community HCPs to manage third-party demands that compromise patient care, as human rights are considered absolute and cannot be negotiated or de-prioritized.[25] One institution in the United States has implemented a human rights curriculum covering human rights frameworks, abuse documentation, and clinical skills for working with affected patients.[26] Human rights training integrated into all levels of medical education and training could better prepare community HCPs to manage dual loyalty dilemmas in non-custodial, traditional hospitals. Partnerships between correctional facilities and academic medical centers (e.g., University of Texas Medical Branch in Galveston) highlight opportunities for collaboration.[27]

Community HCPs can mitigate dual loyalty conflicts by clearly communicating the limits of confidentiality and the nature of dual loyalty conflicts with patients in custody. The literature on inpatient psychiatry offers guidance on these disclosures, which are particularly important in non-custodial, traditional hospitals since patients in custody may be unaware of HCPs' affiliations with correctional institutions. Effective communication involves clearly stating boundaries, explaining reporting obligations, and ensuring that patients understand potential breaches due to legal mandates or institutional pressures.[28] HCPs should specify which types of information will remain confidential and should reassure patients that their health needs are prioritized despite possible coercive pressures from the correctional institution.[29] Given patients' potential distrust in community HCPs due to uncertainty about their affiliations, building trust at the patient's preferred pace is essential.[30] This transparent approach has been shown to strengthen patients' trust in their HCPs.[31]

Finally, community HCPs can more effectively advocate for their patients if they understand policies regarding shackling, privacy, confidentiality, discharge disclosures, refusal of care, follow-up, and communication with patients' family members at their non-custodial hospitals and at the custodial facilities from which their patients are admitted.[32] These efforts not only improve care within non-custodial hospitals but also set the stage for broader collaboration between HCPs and correctional facilities.

Case study outcome

The hospitalist realizes that she is encountering multiple dual loyalty dilemmas. After discussion with the department chair and hospital legal team, a hospital policy regarding care of incarcerated patients is identified. It clearly states that patients in custody must be within view of correctional officers, but the officers are not required to remain in the room during sensitive history-taking and exams unless a specific security concern is cited. The hospital policy does not comment on shackling, so the hospital administrative team and correctional leadership develop a new agreement that shackles can be moved to a different extremity to allow HCPs to conduct necessary physical exams. The hospital administrative team works with the hospital legal team to develop a policy outlining which information, including protected health information, can be disclosed to specific correctional staff. The hospitalist organizes a series of reflection groups and discussion sessions to raise awareness of dual loyalty dilemmas among HCPs.

Conclusion

The recurring themes of dual loyalty conflicts identified in custodial settings—withholding or delaying care inappropriately, providing interventions against patient wishes, violating a patient's right to confidentiality and privacy, engaging in unnecessary or cruel interventions, and falsifying or omitting medical documentation—mirror the experiences of community HCPs caring for patients in custody within non-custodial hospitals. These parallels offer a framework for developing mitigation strategies that address the unique challenges faced by community HCPs caring for patients in custody in non-custodial hospital settings.

Future efforts to mitigate dual loyalty conflicts for HCPs in non-custodial settings should focus on developing, implementing, and evaluating these strategies across diverse health care contexts to ensure that community HCPs are equipped to advocate effectively for their patients. Policy makers, correctional facilities, and health care institutions must collaborate to address dual loyalty conflicts experienced by community HCPs caring for patients in custody to improve health care outcomes for this vulnerable population. Addressing dual loyalty conflicts comprehensively will not only safeguard patient rights but also contribute to systemic reforms that reduce health care disparities and promote equity for patients in custody.

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PERSPECTIVE

Health Care Justice: Improving Emergency Response to Sexual Violence Against Deaf Women

CAROLINA TANNENBAUM-BARUCHI AND ORLI GRINSTEIN-COHEN

People with disabilities often face discrimination and barriers when seeking medical treatment.[1] They may experience violations of their basic rights in health care settings, including denial of care, lack of informed consent, or inadequate accommodations, resulting in disparities in the quality of care received compared to individuals without disabilities.[2] Sexual violence represents a widespread societal issue with severe immediate and long-term physical and mental health consequences.[3] While growing evidence indicates that men and boys also experience sexual violence, global prevalence data remain limited.[4] Sexual violence is recognized as a human rights violation and a global public health crisis by the World Health Organization.[5] Emergency rooms (ERs) represent critical points of access to both health care and justice for survivors. Previous research has documented significant communication challenges for deaf patients in ERs, which becomes even more critical in cases of sexual violence, where clear communication is essential for both medical care and legal documentation.[6] However, for deaf women, who face heightened vulnerability to sexual violence, fundamental barriers to ER care constitute violations of their rights to health, dignity, and equal access to emergency services as guaranteed under the Convention on the Rights of Persons with Disabilities.[7]

The World Health Organization estimates that one in three women worldwide experiences sexual violence during their lifetime, while UNICEF reports that more than 370 million women and girls globally have been subjected to rape or sexual assault during childhood, underscoring the magnitude of this human rights violation.[8] People with disabilities are disproportionately affected by violent crime generally, with women with disabilities being twice as likely to experience sexual violence compared to those without disabilities.[9] Additionally, women with disabilities face higher rates of physical force during sexual violence and are more likely to experience violence over extended periods.[10] Contributing factors include greater

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Competing interests: None declared.

social isolation, exposure to diverse perpetrators, dependency related to disability, difficulty identifying disability-related abuse, and cultural or societal barriers.[11]

This elevated risk is particularly pronounced during childhood, with children with disabilities being 3.14 times more likely to be sexually abused than their peers without disabilities $[x^2 (1, N = 40{,}211) = 330.92, p < .001]$.[12] This pattern extends across disability types: Danish population data reveal significantly higher sexual victimization risks for children with attention-deficit/hyperactivity disorder, speech impairments, and intellectual disabilities, with comorbid conditions further increasing vulnerability.[13] Notably, meta-analytic findings across multiple countries, including in North America, Western Europe, Africa, Asia, Australia, and Israel, show that people with sensory disabilities, such as deaf women, carry the highest risk $(OR = 7.57, p < .001, k = 12)$ compared to those with intellectual deficits $(OR = 1.81, p < .011, k = 24)$, physical disability $(OR = 1.71, p = .007, k = 16)$, or mixed types of disability $(OR = 1.76, p < .001, k = 28)$.[14] Despite these high rates, only approximately 15% of assault survivors seek emergency care, with rates even lower among those with disabilities due to accessibility barriers.[15]

Recent research documents how barriers related to gender, disability, language, and cultural factors can further increase vulnerability and impede access to support services after assault.[16] Deaf women and girls face overlapping challenges that significantly increase their risk of sexual violence.[17] This elevated risk is documented across diverse settings. Among the general adult population, deaf women are approximately 1.5 times more likely to experience sexual violence than hearing women.[18] In terms of childhood experiences, nearly 50% of deaf girls report experiencing sexual abuse before adulthood.[19] Among clinical populations, 56% of deaf women accessing outpatient mental health treatment report lifetime physical abuse.[20] Among the higher-education population, 69% of deaf female undergraduates disclose experiencing at least one sexual assault, with 56% encountering multiple forms of assault—rates that far exceed the 25% sexual assault prevalence found among hearing women.[21]

Deaf violence survivors face unique forms of communication abuse, including perpetrators damaging hearing aids, confiscating communication devices, refusing to repeat information, and deliberately misrepresenting situations when serving as informal interpreters with service providers.[22] Research further reveals the severity of underreporting among deaf survivors specifically, with 49% never reporting their abuse at all and 11% attempting to report but not being believed.[23]

Studies examining relationship dynamics have found that deaf women in relationships with hearing partners experience reduced ability to negotiate during conflicts due to hearing privilege imbalances.[24] While deaf-deaf relationships show more equal power dynamics and better negotiation, they still report concerning rates of sexual coercion, potentially due to limited awareness about intimate partner violence within the Deaf community.[25] However, the close-knit nature of Deaf communities can create additional barriers to help-seeking. Survivors report concerns about confidentiality and fear that disclosing abuse will damage their standing in the community, particularly if the perpetrator is well regarded.[26] Furthermore, many deaf women depend on family members or caregivers, who may be the perpetrators, for communication assistance.[27] Economic vulnerability significantly compounds safety barriers for deaf women experiencing intimate partner violence. Deaf women face disproportionate unemployment and underemployment, with one study documenting rates exceeding 80% among survivors of intimate partner violence. The same study found that systemic barriers to vocational training and higher education exacerbate this marginalization, with approximately three-quarters of deaf survivors reporting educational attainment at or below the high school level.[28]

This heightened vulnerability is compounded by structural factors: deaf children often lack access to comprehensive sex education in sign language, limiting their understanding of consent and personal boundaries.[29] During an interview, a deaf woman participant expressed how tactile communication, fundamental to Deaf culture, can create vulnerability: "Being deaf means we're always touching to communicate. We touch someone to get their attention—it's just normal for us. When we're kids, we don't know which touches are okay and which aren't."[30] This observation illuminates how the necessity of touch-based communication in Deaf culture may inadvertently complicate children's ability to recognize and report inappropriate touching. Sometimes, educational institutions themselves can be sites of risk, with approximately 51% of deaf abuse survivors reporting abuse in connection with school settings.[31]

Despite nearly five decades of civil rights legislation in the United States intended to ensure equitable health care access, people with disabilities continue to experience significant disparities in health service delivery, highlighting the persistent gap between legal protections and practical implementation.[32] For deaf women seeking emergency care, this gap manifests through multiple systemic failures: insufficient qualified interpreters, inadequate Deaf cultural competency training, and absent accessible reporting mechanisms. Consequently, deaf women encounter significant communication challenges with providers and limited access to qualified sign language interpreters during medical encounters, directly compromising their ability to receive appropriate emergency care.[33] These barriers result in measurable delays; patients who utilize American Sign Language experience prolonged emergency department stays, a 9% increase—equivalent to 30 additional minutes—compared to English-speaking patients.[34] Such delays fundamentally compromise time-critical sexual assault care protocols, potentially jeopardizing forensic evidence collection and prophylactic interventions.

Current health care approaches perpetuate these problems by emphasizing targeted interventions rather than addressing fundamental structural inequities. Health care providers often resort to inadequate communication methods such as handwritten notes, lip-reading attempts, or vocal modifications rather than implementing appropriate communication accommodations.[35] This medicalized framework positions deaf women as passive recipients instead of active participants in their health care decisions, contradicting core principles of disability rights and patient autonomy.[36]

Global evidence-based prevention and response programs for deaf survivors remain critically scarce. Recent research in developed nations reveals significant gaps between recognizing deaf individuals' vulnerability to sexual violence and implementing culturally appropriate intervention protocols, particularly in time-sensitive emergency settings.[37]

Evolving emergency care standards for sexual assault survivors provide important context for addressing deaf women's specific needs. Shifting societal attitudes toward sexual assault have transformed emergency department protocols, increasing utilization rates and establishing trauma-informed care standards.[38] Emergency departments now offer survivors comprehensive services addressing both physical and mental health needs, including crisis counseling, treatment for sexually transmitted infections, emergency contraception, and care for HIV exposure prevention and forensic examinations.[39] Many emergency departments now utilize sexual assault nurse examiners (SANE)—nurses specialized in supporting sexual violence survivors. SANE programs are instrumental in supporting psychological recovery, delivering comprehensive care, gathering forensic evidence, and improving legal outcomes and community responses.[40] However, these advances in standard emergency care protocols often fail to address the unique communication and cultural needs of deaf survivors, highlighting the critical importance of specialized interventions.

Addressing these gaps requires evidence-based interventions to enhance emergency care for deaf survivors. Essential reforms include establishing standardized visual communication protocols featuring anatomical diagrams, procedural explanations, and validated emotional assessment scales.[41] Cost-effective environmental modifications—optimized lighting for lip-reading and sign language communication, alongside unobstructed sight lines in examination rooms—provide high-impact improvements.[42] Additional structural improvements include enhanced documentation protocols prioritizing patients' communication preferences during triage and implementing interpreter-specific confidentiality guidelines.[43] While emergency departments can utilize video remote interpreting as an interim solution, developing partnerships with local deaf advocacy organizations remains vital for establishing on-call support networks and mental health referral pathways.[44] Robust privacy safeguards are essential, particularly in smaller communities where health care providers may have personal connections to survivors.[45] Health care facilities must also designate staff for specialized sign language and Deaf cultural competency training through digital platforms.[46] Integration with local deaf organizations should establish comprehensive services encompassing training for health care workers, interpreters, law enforcement, and support providers.[47] Such comprehensive services should align with European policy frameworks that require systematic staff training and standardized communication protocols.[48]

Sexual violence against deaf women constitutes a critical intersection of human rights and health care justice, demanding urgent global intervention. Deaf survivors face significant barriers to emergency care that fundamentally violate their rights to health equity and dignified treatment.[49] While basic health care accessibility exists through disability legislation, comprehensive, culturally competent protocols remain essential, including mandatory interpreter services and specialized provider training.[50] Pilot interventions' successes demonstrate the feasibility of systematic emergency care delivery, making health care transformation a fundamental human rights imperative requiring immediate action.[51] Future research should systematically assess health care systems' fulfillment of human rights obligations, evaluating emergency provider training requirements and institutional support mechanisms for ensuring equitable, accessible emergency care.

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STUDENT ESSAY

Nongovernmental Organizations: Advocates of Adolescents' Sexual and Reproductive Health Rights in Kenya

IRENE TUDELA TOMÀS

Abstract

Through a one-country case study, this essay analyzes nongovernmental organizations' (NGOs) institutional work, ranging from legal to grassroots actions, to enforce adolescents' sexual and reproductive health rights in Kenya. Within the rapidly shifting landscape in international aid and despite the difficulties of achieving internationally agreed rights and Sustainable Development Goals, NGOs continue to position themselves as key advocates for adolescents' rights. NGOs' multilevel institutional work has three main roles: legal advocacy and litigation, evidence generation and policy monitoring, and rights awareness-raising. This Kenyan analysis highlights NGOs' actions, successes, and challenges in advocating for adolescents' sexual and reproductive rights, providing valuable insights for similar settings within the region.

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Competing interests: None declared.

Introduction

Adolescents and youth make up 25% of the global population, most of whom live in low- and middle-income countries.[1] Keeping youth safe and healthy is an urgent priority that includes ensuring the attainment of their sexual and reproductive health rights (SRHR), as reflected in target 3.7 of the Sustainable Development Goals on universal access to sexual and reproductive healthcare services.[2]

Substantial progress has been made in adolescents' SRHR in the last few decades, but significant gaps remain. Issues such as harmful practices, sexual and gender-based violence, and pervasive social norms hinder the progress in many low- and middle-income countries, including Kenya.[3] The last Kenya Demographic and Health Survey showed that female genital mutilation (FGM), a practice performed during childhood, has a prevalence of 15% among women aged 15 to 49, increasing to 56.3% among women without formal education.[4] Fifteen percent of adolescent women were or had already been pregnant, and 34.5% of unmarried women aged 15-19 years had unmet need for family planning, leading to mistimed pregnancies and unsafe abortions.[5]

Both formal and informal norms play a role in the attainment of human rights. Many sub-Saharan African countries present complex and contradictory laws, policies, and strategies relating to adolescents' sexual and reproductive health (SRH), creating barriers to the realization of these SRHR.[6] In contrast, Kenya has developed progressive adolescents' SRH policies.[7] However, the informal norms around SRH present challenges in Kenya that reflect the reality common in low- and middle-income countries.[8] The influence of the community and cultural norms on adolescents' lived realities is substantial.

In a field with many actors, strategies, and agendas, nongovernmental organizations (NGOs) play a key role as advocates for adolescents' SRHR. Their institutional work addresses many levels in society, from national government forums through to rural communities. This essay aims to illustrate the range of NGOs' advocacy work in Kenya, especially at a time when international aid is facing major challenges.[9] Using this one-country case study, the essay highlights the successes and challenges of NGOs advocating for adolescents' SRHR in Kenya, and is relevant to other countries in the sub-Saharan region.[10]

Adolescents' right to sexual and reproductive health

International law in Kenya

The International Covenant on Economic, Social and Cultural Rights (ICESCR) laid the foundational "right to the highest attainable standard of health" in article 12 in 1966, and in 2016, General Comment No. 22 expanded on SRH.[11]

Following ICESCR, treaties such as the Convention on the Elimination of Discrimination Against Women (CEDAW) (1979), the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol, 2003), the UN Convention on the Rights of the Child (1989) and the African Charter on the Rights and Welfare of the Child (1990) have protected the right to health of youth.[12] Kenya has ratified each of those treaties and has, therefore, obligations to fulfill adolescents' rights.[13]

As Kenya uses the monist approach to international law, all ratified international treaties and conventions become automatically part of Kenyan law, without the need for separate domestic legislation.[14] Consequently, all the abovementioned international treaties are enforceable in Kenyan courts.[15] Judges can cite and rely on those treaties and NGOs can invoke international law to challenge laws or policies that contradict those international obligations. Conclusions or declarations of the committees appointed to monitor implementation of these treaties can, as soft law, guide interpretation in court. Although not binding, conclusions are commonly used by pro-rights actors within the legal and judicial context to press the Kenyan state to comply with its international obligations.[16]

The legal and judicial national context

International obligations have been partially reflected in the Kenyan 2010 Constitution. Article

43 on the right to the highest attainable standard of health, including SRH, is stated in ICESCR and is the foundation for individuals' rights to health.[17] Article 26 in the constitution on the right to life from conception, and section (4) on abortion are significant when reflecting on women's SRHR.[18] Article 26 creates a general prohibition against abortion but recognizes grounds for exemption if "in the opinion of a trained health professional, there is need for emergency treatment, or the life or health of the mother is in danger." This article, subject to much controversy, (partially) supports women's reproductive health rights when permitting abortion in case of mental or physical danger for the woman.

In addition, article 55 on the rights of youth and article 53 on the rights of the child specifically protect adolescents' rights. Finally, article 27 on the right to equality and nondiscrimination is key to protecting vulnerable groups, such as teenage girls, and is used in that regard by pro-rights actors in court.

These articles in the Kenyan Constitution lay the foundation for Kenyan SRH legislation, policies, and guidelines. A major formal achievement is *The Prohibition of FGM Act*, a national agreement on the eradication of this harmful practice.[19] Other national and legally relevant elements include the Sexual Offences Act No. 3 (2006), the Sexual Offences (Medical Treatment) Regulations of 2012 and the National Guidelines on Management of Sexual Violence (2014).[20] These laws establish the provision of free medical treatment for victims of sexual offenses and the right to terminate a pregnancy if it is a result of rape but their interpretation by judges has been proven problematic.[21]

However, there are also laws posing barriers to the fulfillment of SRHR. The Kenyan Penal Code criminalizes the procurement of unsafe abortion under sections 158 to 160.[22] Although section 240 allows trained health professionals to provide safe abortion services in some circumstances, interpretation of the section is unclear and law enforcement officers (including the Attorney General) have used section 158 of the Penal Code to initiate prosecution against medical providers.[23]

The policy context in Kenya

Since the International Conference on Population and Development in Cairo in 1994, where governments embraced the idea of SRHR, Sub-Saharan Africa has made substantial progress toward the attainment of youth SRHR. Kenya has been a leader and developed the first adolescents' SRH policy in the region.[24] The Adolescent Reproductive Health and Development Policy of 2003 was grounded in fundamental human rights and freedoms and "adapted to the cultural and religious beliefs of the country."[25] The policy priority areas were addressing the high numbers of unsafe abortion and harmful practices (FGM and others), the continuous practical denial of reproductive rights recognized in Kenyan law, and the need to improve reproductive health information and services.[26] The policy document also identified NGOs as key stakeholders for success, as "watchdogs to ensure this policy is implemented at all levels of society."[27]

A 2013 Implementation Assessment Report showed the policy had achieved favorable results on the main indicators, but it acknowledged substantial implementation challenges remained.[28] To overcome these challenges and align with international agreements, a new Adolescent Sexual and Reproductive Policy was released in 2015, including the term "sexual" for the first time.[29]

Progressive norms can be linked to the positive trend in the official indicators. The use of family planning has improved from an unmet need of 27% in 2003 to an unmet need of 14% in 2022. Despite the general reduction, adolescents are the group facing the major unmet need in the last report of 2022, with 21.6% of them still not having their contraceptive needs met.[30] Notwithstanding that in certain counties FGM remains a majoritarian practice, the overall percentage of women undergoing FGM has dropped from 32.2% in 2003 to 15% in 2022.[31] NGOs also report positive results, from successful abortion litigation cases to promising attitudinal changes regarding FGM in underserved communities with high prevalence of FGM.[32]

Although formal progressive norms may seem well established, they can suddenly be replaced with regressive rules. For example, in 2022, the National Adolescent Sexual and Reproductive Health Policy was superseded by the National Reproductive Health Policy 2022-2032, which now serves as the primary reference document until a new adolescent specific policy is agreed.[33] The new policy is facing criticism because it requires parental consent for adolescents to access SRH services which places additional barriers for termination of pregnancy. The policy promotes sexual abstinence until the age of 21.[34] NGOs have sought court orders barring the implementation of the policy and seeking its review to ensure it aligns with constitutionally established rights.[35]

Therefore, the Kenyan legal and policy context has shown progressive SRHR achievements but there are challenges in maintaining this progress in formal norms, which can also affect measured indicators.

The institutional work of NGOs as rights advocates

The challenges of implementing formal norms

Institutions around SRH encompass not just formal rules and procedures—laws and policies—but also societal moral templates that guide people's actions.[36] Kenyan formal institutions are relatively well-defined, but informal institutions prevail and cause difficulties, especially in the community context where daily informal influence takes place linked to the relationships among family members, neighbors, school, and religious village leaders. An analysis of informal institutions is, therefore, important to understand the challenges in the attainment of adolescents' rights.

NGOs' roles within the distributed agency

Formal and informal institutions are two intertwined elements of the complex societal arena, where many actors—from politicians to family members—advocate for their own interests.[37] In Kenya, multiple actors use influential tactics to create, maintain, or disrupt institutions surrounding SRHR. From government representatives to parents in rural villages, many stakeholders have an influence on the attainment of adolescents' rights.

The agency, that is, the power or the capacity of influence in this arena, is not owned by one actor but distributed among the many stakeholders that play a role in the achievement of youth SRHR. Adolescents are minors with limited agency and autonomy and as a result, their SRHR attainment depends on the actions of a wide range of individuals, often with different interests and opinions. NGOs are, therefore, navigating a complex arena with a clear distributed agency, a fact that poses additional difficulties to their advocacy work.

Among all those actors, NGOs focused on SRHR can be defined as a multi-level pro-rights advocate in general terms, with some exceptions. This essay argues that NGOs are a plural actor—an actor formed by many organizations that share a common final goal, but using different means and different arenas to advocate for it.[38] Because of their plurality, NGOs can influence both formal and informal institutions, working toward the common goal of promoting the attainment of SRHR.

It has been during the last three decades that NGOs have moved from exclusive service provision to a more comprehensive role that includes rights advocacy.[39] Today, in Kenya NGOs have three main roles when approaching the common goal of advocating for adolescents' SRHR in their SRHR work:

Legal advocacy and litigation role: aimed at influencing the interpretation of the SRHR that are set in the Kenyan Constitution and international treaties. The goal of NGOs is to obtain a better alignment of the national framework with the international formal one.

Evidence generation and monitoring role: aimed at generating evidence on the implementation of SRHR law and policy and evaluating the interaction between formal and informal norms.

In-field education and awareness-raising role: aimed at modifying informal institutions by increasing knowledge in the community. NGOs promote rights awareness and work to disrupt harmful beliefs and regressive norms, facilitating an alignment between the formal norms and individuals' realities.

NGOs' work on formal institutions: Legal advocacy and litigation role

NGOs with a legal advocacy and litigation role use both cooperation and confrontation to influence the judiciary and legislative power in the country. Their cooperation strategy includes releasing factsheets to the public, sending letters to international monitoring bodies, and organizing cross-country gatherings at international summits.

Their litigation work provides a confrontational strategy. NGOs choose possible landmark cases that can set progressive legal precedents at the national level and, in this way, effectively enforce adolescents' SRHR. Examples include the Center for Reproductive Rights (CRR) and the Kenya Legal and Ethical Issues Network (KELIN), NGOs that work to maintain and create institutions around safe abortion, combining collaboration and confrontation with positive results.

For example, in 2014, a 14-year-old girl became pregnant as a result of rape and, after being unable to access a safe abortion procedure, she had her pregnancy terminated by an unqualified provider and died from complications. CRR filed the Petition 266 of 2015 and the High Court at Nairobi, acknowledging article 26(4) of the Constitution, concluded that there had been a violation of the adolescent's right to access safe abortion, because of the threat to her mental health imposed by the rape.[40] The court further elaborated on state obligations under CEDAW and the Maputo Protocol. Kenya had made a reservation to Maputo Protocol article 14(2) regarding state obligations to protect women by authorizing medical abortion in cases of sexual assault and where the mental or physical health of the mother was in danger.[41] However, the court concluded that this reservation was not consistent with article 26(4) of the Constitution which states that abortion is permitted in case the life or health of the mother is in danger.[42] This case was a major victory for rape survivors, clarifying that abortion is permitted for victims of sexual violence.[43]

Earlier, in 2010, CRR and Reproductive Health Network Kenya filed the case *PAK and Salim Mohammed v. Attorney General et al.* before the High Court of Malindi. In this case, a pregnant teenage girl experienced pregnancy complications and went to a clinic where a healthcare professional performed a safe abortion procedure. Police officers stormed in the clinic and detained both the minor and the healthcare professional, charging them with receiving and procuring an abortion, contrary to the Penal Code.[44] In the ruling, the court quashed the criminal charges and proceedings and asked the legislature to draft a law that recognized a right to abortion in consonance with article 26(4) of the Constitution, declaring that "criminalizing abortion under the penal code without Constitutional statutory framework is an impairment to the enjoyment of women's reproductive rights."[45]

These two cases are currently at the Court of Appeal and both will most likely be presented before the Supreme Court due to the constitutional issues raised.[46] Notwithstanding this uncertainty, Kenya was the first African Court to pronounce abortion as a fundamental right in its ruling on Petition 266 of 2015.[47]

But NGOs' institutional work goes beyond maintenance and creation of new institutions and includes the disruption of existing regressive norms. In the case of Petition 27 of 2022, the National Reproductive Health Policy 2022-2032 has been challenged by KELIN before the High Court of Kenya at Kiambu.[48] KELIN claimed a procedural violation of the policy, arguing that there was a lack of effective and meaningful public participation in the development of the policy. KELIN also claimed a substantive violation of women's and adolescents' SRH, as the policy violates the right to health and the right to life provided in the Kenyan Constitution by establishing a requirement of parental consent for adolescents to access reproductive health services until the age of 21.[49] The procedural violation argued by the petitioners did not succeed. However, in the ruling delivered on 2 October 2025, the Court declared that paragraph 12 of clause 3.4.1 is inconsistent with the right to life and the right to termination of pregnancy as set in the Constitution, which can be called a partial victory.[50]

This analysis shows that NGOs, together with judicial actors, are pushing for the realization of adolescents' rights as per international and national law. However, anti-abortion groups have also successfully pursued their agenda in some cases.[51] Therefore, progressive formal institutions cannot be considered secure and the work to maintain and improve those norms must continue.

NGOs' work on implementation: Evidence-generation and monitoring role

Despite divergent opinions in Kenya regarding access to sexual and reproductive education, services, or commodities among youth, issues such as teenage pregnancy or HIV infection are widely recognized societal challenges that need to be confronted.[52] Kenya launched progressive policies to promote adolescents' SRH in 2003 and 2015, as well as programs to improve adolescents' public health.[53] However, implementation of these policies remains a challenge.[54]

NGOs help to address these issues through their evidence generation and monitoring role, which deepens an understanding of adolescents' circumstances and helps identify solutions. An example of this is the Solutions for Supporting Healthy Adolescents and Rights Protection (SHARP) project. Led by Health Action International and their collaborators, the project collects and presents evidence on adolescents' access to contraception and youth-friendly health centers based on information from the public, private, and faith-based sectors.[55] Their results identified an unmet need for contraception in 34.5% of sexually active unmarried adolescents, due to both lack of availability and high cost.[56] Similar results were found regarding access to youth-friendly health centers, with barriers in the availability, accessibility, and affordability of the commodities as well as in privacy. Half the private health facilities share information with adolescents' parents or with their school and faith leaders.[57] The SHARP project concluded that the main challenges were effectively disseminating policies and guidelines, allocating adequate budgets, developing and delivering trainings to healthcare workers, and strengthening monitoring.[58]

Abolishing FGM is a practical challenge which NGO knowledge generation can help address. As the Evidence to End FGM Research Programme showed, there is a correlation between belonging to certain ethnic or religious groups and undergoing the procedure, which reflects the weight of moral templates and religious beliefs. Informal norms are in conflict with the formal (legal) prohibition of FGM.[59] Tackling informal norms may be the key to success.

NGOs' work at the grassroots level: Awareness-raising role

NGOs operating at the community level are moving away from an exclusive service-provision role and are introducing health rights in their strategies and discourse, aiming to align social beliefs with formally framed rights. Global organizations such as Doctors without Borders have embraced education and awareness-raising roles. In their Adolescents and Youth Population Project in Mombasa, they focus on educating youth and reducing stigma.[60]

A more recently founded NGO, Save a Girl Save a Generation, was established with the aim of promoting health as a human right.[61] In their Kuelekea Mabadaliko Program, a multidisciplinary team of healthcare professionals, social workers, and legal professionals inform and educate women on SRHR, focusing on FGM.[62] This program provides information and education twice a year to vulnerable women in communities where FGM practices are highly prevalent. The program is designed for target communities, where low literacy levels and strong social norms prevail. Their targeted approach is showing positive results, with an increase in the number of participants.[63] Their program is directed to women who have undergone an FGM procedure, aiming at transforming them into allies against FGM in their own community. Participants later participate in public events and advocate against FGM to protect their female children from suffering the same harmful practice they underwent.[64]

These two examples show how grassroot-focused NGOs have introduced health rights in their strategy and speech, aiming to align social beliefs with formally framed rights.

Recommendations and conclusion

The progress that has occurred around adolescents' SRHR in the last decades in Kenya cannot be denied. In terms of formal norms, successful laws and policy plans have been set.[65] In terms of outcomes, the Kenya Demographic and Health Surveys show a decreasing trend in major national concerns such as FGM prevalence or the unmet need of family planning.[66] However, informal norms pose barriers to both political prioritization and policy implementation. Most African leaders have adhered to other development priorities.[67] While NGOs have, to some extent, influenced leaders to keep SRH on the policy agenda, national funding and efforts have proven insufficient. Conflicting power dynamics between different stakeholders at the national level—religious organizations, NGOs, political parties—pose obstacles when operationalizing international human rights and agreements.[68]

The legal cases explained above show the importance and success of NGOs' work as human rights advocates and their influence in Kenya, a pioneer country in terms of policies and laws within the region.[69] Pervasive social norms influence society at all levels, including African leaders; and that leads to a lack of priority and funding regarding SRH. In this process of moving from formal norms to implementation, NGOs have proven important allies, as they use their influential power to keep SRHR on the policy agenda and in the national budget.[70]

NGOs are key advocates of adolescents' rights. While community members and politicians lack consensus on a cohesive public positioning on SRHR and adolescents lack the political power to force high-level decision makers to act, NGOs persevere in promoting the international treaties at multiple levels in Kenya.[71] As outlined in the three categories of work, their role goes beyond formal legal advocacy and litigation into evidence-generation, education, and awareness-raising activities. Their holistic institutional work, plurality of strategies and progressive approach is much needed in an environment where anti-rights movements seem to be gaining agency, and where rooted pervasive informal institutions remain a challenge to progress.[72]

The contribution of NGOs has been crucial to promote and defend international treaties and SRHR in Kenya, while fostering national leaders' support toward rights-based law, policies, and implementation. The Kenyan government has obligations to fulfill the SRHR of its adolescent population and the work of NGOs can help them meet these obligations.

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Health and Human Rights

STUDENT ESSAY

Energizing Health: Electricity Access and the Right to Health in Nigeria

OSHOKHA CALEB ILEGOGIE

Abstract

In this essay, I explore the link between energy access, especially electricity, and human rights, particularly the right to health in Nigeria. Despite its plentiful natural resources, including vast reserves of oil, gas, and sustainable bioenergy sources, Nigeria faces an energy crisis that constrains health care delivery, particularly in rural areas where health facilities lack reliable access to electricity. I analyze Nigeria's recently enacted Electricity Act, assessing its potential to address systemic energy challenges that hinder the realization of the right to health. I balance a doctrinal reading of the act with a rights-based analysis of its capacity to enhance equitable access to energy, recognizing electricity access as a social determinant of health. I further highlight the importance of policy and legal measures to alleviate Nigeria's energy crisis and improve health care access for millions disproportionately affected by the lack of clean and reliable energy. Crucially, the analysis also examines the governance and implementation gaps, such as regulatory coordination, that might prevent the act from ensuring energy is a tool to help fulfill the right to health.

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Competing interests: None declared.

Introduction

The challenges of energy poverty, energy insecurity, and limited electricity availability pose significant concerns for the enjoyment of fundamental rights and freedoms. Of particular importance is the impact of energy access on the right to health, especially its entitlements. Increasingly, researchers and policymakers are recognizing these links and directing greater attention to the broader implications of energy access for human rights.[1] One crucial issue examined in this paper is the extent to which access to energy shapes the realization of the right to health in Nigeria, with a specific focus on the entitlements that flow from the right to health.

The right to health, which guarantees entitlement to the highest attainable standard of physical and mental well-being, is a principle firmly enshrined in multiple international and regional human rights instruments.[2] Despite its strong normative foundation, the right to health was long regarded as controversial, owing to debates surrounding its precise scope and content, as well as its categorization within the broader framework of human rights.[3] Although contemporary legal scholarship increasingly underscores the indivisibility and interdependence of human rights (civil and political rights and socioeconomic and cultural rights), the practical reality in Nigeria demonstrates a significant gap, with socioeconomic rights such as the right to health remaining weakly protected and poorly enforced in comparison to civil and political rights.[4] In this context, the right to health requires states to take deliberate and proactive measures to secure access to health care services and to address the underlying social determinants of health, ensuring that they are available, accessible, acceptable, and of adequate quality (AAAQ).[5]

A key illustration of this gap is seen in the domain of energy access. Energy poverty must be understood as encompassing more than economic hardship, low energy efficiency, and the absence of infrastructure necessary for accessing energy.[6] It leads to other deprivations such as reliance on polluting fuels. In Nigeria, energy poverty is characterized not only by affordability challenges but also by the absence of physical access to energy systems altogether. Energy poverty therefore undermines essential aspects of human development, including health.[7]

The broad scope of the right to health extends beyond medical care to the social and infrastructure conditions essential for well-being. Reliable electricity is not merely a developmental goal, but it is necessary to fulfill health entitlements because it powers medical equipment, preserves medicines, supports safe childbirth, and enables disease surveillance.[8] Its role also extends to ensuring clean water and sanitation, regulating indoor temperatures in extreme heat or cold, enabling safe food preparation, and sustaining livelihoods.[9] Where electricity is absent or unreliable, health and wider socioeconomic rights are undermined, transforming energy poverty from a developmental challenge into a breach of human rights obligations.[10]

Adjacent to this problem is the issue of energy insecurity, which refers to the inability of individuals and households to have their basic energy needs met reliably.[11] Energy insecurity reflects a broad spectrum of vulnerability, capturing economic limitations as well as the physical, behavioral, and infrastructural dimensions of inadequate energy supply.[12] But prevailing policy responses in Nigeria tend to focus narrowly on economic factors, such as subsidies or electricity costs relief, while neglecting the long-term health and socioeconomic impacts of unreliable or insufficient energy access.[13]

Short-term policy responses, although politically convenient, fail to address the structural causes of energy deprivation in Nigeria, such as inadequate infrastructure, outdated transmission grids, and entrenched governance challenges.[14] Consequently, households remain trapped in cycles of energy poverty and insecurity, with limited prospects for sustainable improvement.

It is against this backdrop that Nigeria's recent enactment of the Electricity Act 2023 represents a significant policy shift.[15] The act seeks to restructure the electricity sector by promoting decentralized generation, incentivizing investment in renewable energy, and granting state governments greater regulatory authority over electricity supply.[16]

I situate the Electricity Act within the broader discourse on the right to health and energy access in Nigeria. In the paper, I first examine the extent to which the act provides a framework for addressing structural deficits in energy provision, before analyzing its implications for the fulfillment of health entitlements under international and domestic human rights law. In doing so, I evaluate whether the act can serve as a tool of economic development and as a juridical mechanism for progressively realizing the right to health through improved energy access.

The interplay between the right to health and energy access

The right to health is connected to broader struggles for social justice, which aim to address structural inequalities and improve conditions of life for all, particularly vulnerable and marginalized populations.[17] The WHO *Ottawa Charter for Health Promotion* states that health is a resource for everyday life, not merely the objective of living, pushing back against an older, narrow view of health as the end goal of human life, now recognizing health as a social and personal resource that supports living as an instrumental good, rather than the final purpose of human existence.[18]

In Nigeria, the right to health is situated within a layered constellation of legal and policy instruments. The 1999 Constitution, while limiting the right to health to the non-justiciable provisions of Chapter II, nonetheless directs the state to safeguard "the health, safety and welfare of all persons in employment" and to ensure the provision of "adequate medical and health facilities for all persons."[19]

Although Nigerian courts have consistently held that the provisions in Chapter II are aspirational, this position was firmly established in the case of *Archbishop Okogie & Ors v. Attorney-General of Lagos State (1981)*, where the Court of Appeal held that the rights under Chapter II of the Constitution are non-justiciable due to the contents of section 6(6)(c), which prevents the courts from enforcing the rights in Chapter II.[20] However, this does not absolve the government of responsibility for these rights. Rather, it means that although the state is expected to pursue the policy objectives set out in Chapter II, including those relating to health, education, and housing, individuals cannot compel their judicial enforcement. However, the Nigerian Supreme Court has clarified in *Attorney-General of Ondo State v. Attorney-General of the Federation* that the Nigerian National Assembly may enact legislation to give concrete and enforceable effect to these otherwise aspirational objectives.[21] Such legislation includes the National Health Act 2014, which obliges federal and state governments to address the social determinants of health and to guarantee Nigerians a basic minimum package of health services.[22] I contend here that the Electricity Act 2023 should also be read in the same manner. By mandating universal, sustainable energy access, it addresses an essential determinant of health and thus serves as a legislative means for achieving the constitutional objectives outlined in Chapter II of the Constitution.[23] In practice, however, chronic underfunding and poor regulatory enforcement have meant that access to health services remains uneven, and the right to health is more aspirational than tangible for many Nigerians.[24]

Understanding that the right to health encompasses state obligations to promote public health through service provision and the creation of enabling conditions underscores the need for intergovernmental collaboration across federal, state, and local levels. This responsibility extends beyond traditional health care interventions to include access to the infrastructure essential for realizing health rights, most notably electricity.[25] Reliable access to electricity is foundational for running health facilities, powering diagnostic tools, preserving vaccines, ensuring safe childbirth, and enabling emergency care.[26]

However, despite its importance, energy access is often underrepresented in mainstream health policy debates, with insufficient attention paid to the positive role of clean, stable, and affordable electricity in realizing health rights. Thus, this energy-health nexus requires greater integration in policy and legal discourse in Nigeria, where the lack of reliable electricity continues to obstruct access to the most basic health services. Recognizing electricity access as a core social determinant of health is essential to fully implementing the right to health in practice in Nigeria. In this sense, government accountability is not confined to health service delivery but extends to ensuring equitable access to the essential determinants of health, including electricity.

The centrality of electricity access to health rights in Nigeria

The significant policy shift in electricity regulation in Nigeria, evidenced by the Electricity Act (2023), is laudable because energy poverty and energy insecurity are not unique to Nigeria but reflect a persistent challenge across many low- and middle-income countries where access to adequate, affordable, and reliable energy services remains elusive. Sub-Saharan Africa, for instance, accounts for approximately 80% of the global population without access to electricity.[27] Alarmingly, nearly 60% of health care facilities across the region lack reliable access to electricity, severely limiting access to essential medical technologies and life-saving interventions. Nigeria illustrates this crisis. Over 90 million people (more than 40% of its population) mainly in rural areas, lack access to the national electricity grid. Even those who are connected face limited and unreliable electricity supply, with a few electricity companies controlling distribution. This leaves consumers with limited options, unable to otherwise obtain adequate, affordable, reliable, safe, or environmentally sustainable energy services. These structural energy shortages severely hinder the provision and access to health services, leading to poor health outcomes.[28]

Despite being one of Africa's largest economies, Nigeria's national electricity grid is one of the least reliable on the continent, with electricity demand consistently outstripping supply. Recent data from the Nigerian Independent System Operator (the agency responsible for managing the national electricity grid) show that the daily peak demand for electricity in Nigeria is about 20 gigawatts (GW), compared to the installed electricity generation capacity of 13 GW, yet the highest electricity generation output ever recorded is just 5.8 GW.[29] The demand for electricity refers to the total electricity needed to meet the need of households, industries, and public services across the country, including health facilities.

The persistent shortfall has serious consequences for the health sector, where unreliable power disrupts cold-chain vaccine storage, emergency care, and infection control measures in primary health care centers (PHCs).[30] As a result, many facilities are forced to rely on costly, polluting backup generators to bridge the electricity gap, further straining already stretched health budgets. Only 43% of Nigeria's PHCs are connected to the national grid, and of these, 57% receive an average of just five hours of electricity per day.[31] This chronic shortfall forces many facilities to limit services, making it impossible to provide consistent 24-hour care. The consequences are most acute during nighttime emergencies, when health care workers have to rely on low-quality lighting such as paraffin lamps or use fuel-powered generators, which emit toxic fumes and further compromise both health and safety.[32]

The public health consequences of these energy constraints are dire. Nigeria records one of the highest maternal and neonatal mortality rates in the world, and poor electricity access in PHCs has contributed significantly to this outcome.[33] Many premature and newborn infants require life-sustaining equipment like incubators, which require a stable electricity supply. Nigeria's overall neonatal mortality rate is currently estimated at about 37 per 1,000 live births, with nearly half of these deaths occurring within the first two days of life, when newborns are most vulnerable and require intensive monitoring, warmth, and emergency interventions.[34] Many of neonatal deaths occur in facilities with an inadequate power supply, which undermines the effectiveness of critical neonatal care.

Electricity access also underpins broader health infrastructure by enabling diagnostic tools, oxygen and dialysis machines, vaccine storage, and drug manufacturing and distribution. Without electricity, even basic laboratory services and equipment sterilization are not possible.[35]

Beyond clinical settings, electricity also shapes broader public health outcomes through its impact on the social determinants of health. Households without access to electricity often rely on charcoal and firewood for cooking, which contributes to indoor air pollution and respiratory illnesses.[36] In contrast, access to clean energy promotes safer food preparation and storage and it supports health education through improved access to media and communication technologies. Electricity access also improves home sanitation, environmental hygiene, and physical safety, especially for women and children.[37]

The interdependence between health and energy access has been recognized by international agencies. The United Nations' Sustainable Energy for All (SE4All) initiative, along with Sustainable Development Goals (SDGs) 3 and 7, affirm the importance of clean, affordable, and reliable energy access for ensuring health and well-being.[38] SDG 3 commits to ensuring healthy lives and promoting well-being for all, while SDG 7 calls for universal access to modern energy services by 2030. The synergy between these goals reinforces the urgency of treating electricity access not just as an infrastructure target, but as a critical enabler of the right to health.[39]

In this context, Nigeria's response to its energy crisis must transcend temporary palliatives and embrace a transformative energy policy. Addressing health-related energy gaps demands a shift away from dependence on fossil fuels and toward sustainable, low-carbon alternatives.[40] This shift is feasible in Nigeria given its vast untapped renewable energy potential with solar, wind, and bioenergy resources. Recognizing this, the Nigerian government has passed the Electricity Act 2023, a landmark statute that seeks to modernize the energy sector through decentralization, deregulation, and an emphasis on renewable generation. The act, alongside supporting policies, holds the promise of improving electricity access across the country, especially in rural and peri-urban areas where the energy-health nexus is most acute.

The Electricity Act creates pathways to health equity

Recent shifts in the global energy landscape have created new opportunities for Nigeria to address chronic electricity deficits by adopting sustainable, low-carbon energy solutions. Fossil fuels still supply over 80% of domestic energy needs, but Nigeria has begun transitioning toward a more diversified energy mix.[41]

The Electricity Act of 2023 repeals previous electricity laws and consolidates their provisions into a single, comprehensive framework for electricity regulation in Nigeria.[42] Central to the act is a commitment to promoting universal electricity access, improving sector efficiency, and increasing investment, especially in decentralized and renewable energy systems. It designates the Nigerian Electricity Regulatory Commission (NERC) as the regulatory authority, granting it the power to oversee licensing, generation, distribution, and tariff setting.[43] Importantly, the statute's goal to ensure "affordable, reliable and sustainable" energy may open the door for rights-based lawsuits if widespread power outages prevent access to essential health services.[44]

The introduction of the act closely followed the constitutional amendment of 17 March 2023, which revised section 14(b), part II of the second schedule to the 1999 Constitution, thereby granting State Houses of Assembly explicit authority to legislate on electricity matters within their jurisdictions.[45] This devolution of power enables state governments and local actors to establish mini-grids and embed renewable systems tailored to rural and peri-urban communities historically excluded from national grid coverage.[46] For health systems, this opens the door to electrifying PHCs, maternity wards, and cold-chain vaccine stores, facilities whose operations are contingent on a reliable energy supply.[47]

Beyond enhancing subnational regulatory autonomy, the act also embeds a renewable energy quota system, mandating that electricity producers integrate a minimum percentage of renewable energy into their output.[48] Eligible technologies under this provision include solar, wind, small hydro, biomass, hybrid systems, and cogeneration.[49] This quota-based approach not only fosters environmental sustainability but also aligns with Nigeria's obligation under article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) to ensure the availability and accessibility of the determinants of health, including energy.[50]

To incentivize private sector participation, the act streamlines the licensing process for renewable energy service providers, particularly those seeking to operate off-grid or mini-grid solutions in underserved regions.[51] It also introduces feed-in tariff mechanisms, guaranteeing stable pricing for renewable electricity fed into the grid.[52] These provisions are especially relevant for health infrastructure, as off-grid solar installations, for example, can provide uninterrupted power to run incubators, refrigeration for vaccines, oxygen concentrators, and other critical medical equipment in remote health facilities. Complementary tax incentives in the act encourage both capital investment and domestic energy generation within the renewables sector, offering an integrated policy strategy for boosting energy reliability and health resilience.

Collectively, these statutory reforms reveal a paradigm shift in Nigeria's energy governance, addressing the drivers of energy poverty such as centralized control, low generation capacity, and limited investment. If fully implemented, the act could significantly reduce electricity deficits that currently compromise Nigeria's health system, thereby operationalizing the state's positive obligation under both international and domestic legal frameworks to secure the underlying determinants of the right to health. By enabling decentralized, affordable, and sustainable electricity, the act not only promotes energy justice but also affirms the indivisibility of socioeconomic rights.

However, while the Electricity Act offers a promising legal foundation, its ambitious goals face implementation challenges.

Shortcomings of the Electricity Act 2023

The Electricity Act 2023 marks a significant step toward decentralized, renewable, and inclusive electricity supply in Nigeria and is commendable as a comprehensive tool to address the country's energy challenges. However, there are structural, regulatory, and financial gaps that could limit its transformative potential and weaken its alignment with the national renewable energy policy.

A primary limitation is the absence of an operational roadmap. The act and the federal government's Energy Transition Plan have ambitious targets, such as deploying 6.5 GW of off-grid renewables and expanding the central grid capacity to 42 GW by 2030, through a mix of gas, solar photovoltaic, and biomass sources. But the federal government has not issued a detailed implementation schedule, a funding model, nor outlined accountability mechanisms.[53] By neglecting to provide such details, the government undermines its own statutory commitments and weakens accountability for results. From a human rights perspective, states are obligated to adopt deliberate, concrete, and targeted measures to progressively realize health-related entitlements.[54] The lack of a clear roadmap risks rendering these plans aspirational only, jeopardizing potential improvements in energy access essential for sustaining health care systems and fulfilling human rights obligations.

A second major weakness is the lack of coordination between federal and state regulators. The act allows both the federal regulator (NERC) and individual state governments in Nigeria to oversee and develop their own electricity markets, issue licenses for generation, transmission, and distribution projects within their borders, as long as they have established their own state laws on electricity. This excludes captive generation, which is electricity produced by a person, company, or community solely for their own use, not for sale to the public or feeding into the national grid.[55] This provision in the act reflects a framework for implementing the recent constitutional amendment that decentralizes electricity generation, enabling states to improve access, competition, and efficiency by moving power generation closer to the point of use. However, because there is no system to coordinate these two levels of regulation, their powers often overlap, leading to confusion. For example, if a state-licensed mini-grid operator later connects to the national grid for backup power or to share excess electricity, it immediately falls under NERC's authority and needs an additional federal license to carry out either activity.[56] This creates inconsistent regulations, which pose a major obstacle for private investors and discourage private capital from entering the market.

One possible resolution would be for each state to develop an autonomous electricity framework, complete with independent generation and grid systems, thereby minimizing reliance on the national infrastructure. However, the capital-intensive nature of such projects makes them unrealistic for many states. A more practical solution would be the creation of joint licensing protocols between NERC and state regulatory authorities, with clearly defined boundaries of oversight.[57] Nonetheless, unless a constitutional or legislative fix is introduced, even this shared approach may still result in over-regulation and continued investor hesitation.

Another critical concern is the decrepit state of Nigeria's national grid, which frequently undermines service delivery even in areas nominally connected to power infrastructure. Between 2017 and 2023, the grid collapsed over 45 times.[58] In the first quarter of 2024 alone, six total blackouts were recorded, with causes ranging from infrastructure sabotage and vandalism to inadequate gas supply for thermal plants. This is especially paradoxical in a country with an abundance of natural gas.[59] Despite the abundance, electricity generation operates at only 30% of the national electricity grid's installed capacity (11,000 MW), largely due to a chronic failure to make gas available to power plants.[60]

Since the return to democratic governance in 1999, the federal government has spent over N11 trillion (approximately US$6.7 billion) on the electricity sector.[61] Yet it continues to generate a grossly inadequate amount of electricity for its population, exceeding 200 million individuals.[62] This failure is not due to insufficient investment, but to the government's ineffective expenditure, chronic mismanagement, and entrenched corruption, which have diverted public, private, and donor resources away from critical infrastructure.[63] By misallocating resources in this way, the Nigerian government breaches its obligation under article 2(1) of the ICESCR to employ the maximum of its available resources for the progressive realisation of socioeconomic rights, including the right to health.[64] Corruption and mismanagement, therefore, operate not merely as governance failures but as systemic violations that deprive people of reliable electricity, thereby undermining both constitutional guarantees and international human rights obligations.

Unless the government addresses structural and operational gaps, the Electricity Act 2023 will fail to meet its human rights obligations and remain an unrealized reform. The act's ability to advance the right to health depends not only on its legal provisions but also on effective implementation, regulatory accountability, and sustainable financing.

Conclusion

I have argued that access to electricity is not merely a developmental issue, but a fundamental entitlement intrinsically linked to the right to health. A rights-based approach, therefore, requires that energy policy is framed around core human rights principles such as participation, accountability, nondiscrimination, and transparency, so that individuals are treated not as passive recipients of services but as rights-holders with enforceable claims. In line with CESCR General Comment 14, the Nigerian state bears tripartite obligations to respect the right to health by preventing arbitrary or discriminatory electricity disconnections, to protect it by regulating private providers and ensuring equitable electricity distribution, and to fulfill it by progressively expanding reliable access to electricity, particularly for health facilities and vulnerable populations. Energy insecurity must therefore be recognized as a structural barrier to health and subject to judicial and regulatory scrutiny.

To meet these obligations, a multi-sectoral rights-based approach is required to integrate energy policy with public health, education, and social protection strategies. This approach must embed clear mechanisms of accountability and review to ensure that electricity provision supports essential services, reduces inequalities, and advances the progressive realization of health in Nigeria. The Electricity Act 2023 provides an important foundation for such reforms, with its emphasis on decentralization, renewable energy mandates, and expanded regulatory powers. Its success depends on effective implementation.

Key priorities include resolving regulatory duplication, modernizing electricity grid infrastructure, stabilizing subsidies, and promoting pro-poor electrification strategies such as subsidized connection costs and lifeline tariffs. Complementary measures, such as deploying solar mini-grids and microgrids in underserved areas, expanding pay-as-you-go solar home systems, supporting energy-efficient appliances, and enabling productive-use programs, can further reduce the energy burden while advancing economic empowerment. Public–private partnerships and community-led management of renewable energy infrastructure are also vital to ensuring sustainability and local community-led electrification solutions that improve social determinants in line with efforts to reduce extreme poverty and uphold human rights.[65]

Ultimately, overcoming energy poverty and insecurity requires a unified rights-based framework that places the right to health at its core. The AAAQ framework should guide implementation measures, ensuring that electricity provision is not only technically and financially viable but also equitable, health-enhancing, and accountable. By embedding these standards into the design and execution of the Electricity Act, Nigeria can transform it from an aspirational reform into a vehicle for delivering affordable, sustainable, and equitable energy access that directly advances the right to health.

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