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Commemorating 30 Years

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EDITORIAL OFFICE

Health and Human Rights Journal
François-Xavier Bagnoud Center for Health and Human Rights
Harvard School of Public Health
651 Huntington Avenue, 7th Floor
Boston, MA 02115, USA
Tel: (1) 617.432.0656
Fax: (1) 617.432.4310
Website: http://www.hhrjournal.org
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EDITORIAL

Thirty Years of Scholarship and Debate: Advancing the Right to Health

JOSEPH J. AMON AND CARMEL WILLIAMS

Last year marked the 75th anniversary of the Universal Declaration of Human Rights. As anniversaries go, it was kind of a quiet one, with global conflicts and crises calling into question whether human rights are mere aspirations or truly fundamental—and useful—tools for advancing human dignity and equality.

The idea of a right to health, however, predates the Universal Declaration of Human Rights, having been included two years earlier in the 1946 Constitution of the World Health Organization (WHO), whose preamble says that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition," and today the right is now included in over 115 national constitutions.[1]

Almost immediately, however, the right to health was contested, caught up in Cold War tensions between civil and political rights versus economic and social ones, and WHO, after a change in leadership, stepped away from its promotion of a right to health—and, more broadly, social medicine—toward a more technocratic and biomedical orientation.[2]

Reflecting these lingering tensions some 45 years later in the first issue of *Health and Human Rights*, Jonathan Mann, the journal's founding editor, wrote:

> *We have created this new journal,* Health and Human Rights*, to inform and expand the space within which ideas about the intersection between health and human rights can venture forth into the world, to be cited and criticized, debated and discussed, torn down and built up.*[3]

This "new beginning," now 30 years old, and this goal, continue to drive the journal forward.

In the spirit of informing and expanding debate and understanding of the intersection between health and human rights, we asked a number of authors of early articles published by the journal to look back and reflect on the issues raised and what progress—or regress—has occurred since their publication. We also invited members of our Executive Editorial Committee to contribute their views on any paper from the first volume to consider how far we have come or otherwise.

Each of these contributions tells part of the story of the development of the journal and of the field more generally—and often, as is the case with the contributions by Sofia Gruskin and Stephen Marks, of

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Joseph J. Amon, PhD, MSPH, is director of the Office of Global Health and a clinical professor at Drexel University Dornsife School of Public Health, Philadelphia, United States, and editor-in-chief of *Health and Human Rights*.

Carmel Williams, PhD, is executive editor of *Health and Human Rights*.

personal journeys alongside the development of a journal and a discipline.[4]

Sofia Gruskin's contribution reflects on the foundational article from the first issue that she coauthored with Jonathan Mann, Lawrence Gostin, Troyen Brennan, Zita Lazzarini, and Harvey V. Fineberg, entitled simply "Health and Human Rights."[5] She highlights how the ground has since shifted from discussions of "why link health and human rights" to "how to do it? What does it mean to do so in practice?"[6] On rereading the foundational article, Gruskin finds that it not only is a piece of history but remains a living document.

Stephen Marks attended the first two health and human rights conferences organized and reported on by the journal and found his life transformed by them.[7] The enthusiasm of conference participants resulted in the completion of five tasks set at the first conference, one of which contributed to the launch of *Health and Human Rights*. He concludes that "ideas do change the world, and the linkage of human rights and health work is one of those ideas."[8]

Lawrence Gostin and Eric Friedman reexamine Gostin and Mann's article on health and human rights impact assessment, also from the first issue, which combines a personal history and historical perspective of the influence of the global HIV/AIDS pandemic on the emerging health and human rights field.[9] The impact assessment approach described in the original article laid out a view of health and human rights as a pragmatic tool, speaking in a language and a "checklist" orientation familiar to public health practitioners, emphasizing such steps as evaluating policy effectiveness and assessing the necessity for coerciveness. Thirty years later, they believe that impact assessments remain necessary but could be even more forceful with increased emphasis on equity, participation, and accountability.

Sharifah Sekalala and Kene Esom also reflect on HIV, and risks that arise from overlooking structural inequalities and the indivisibility of all human rights. They focus on Mark Heywood and Morna Cornell's paper "Human Rights and AIDS in South Africa: From Right Margin to Left Margin," which examined South Africa's apartheid struggle and asserted that despite efforts to develop a bold national HIV/AIDS policy, the failure to integrate social and economic rights would render its response ineffective.[10] Sekalala and Esom note the remarkable progress South Africa has made in the fight against HIV/AIDS, but they highlight that deep inequalities remain and that the absence of a human rights-based response with the rights of structurally marginalized groups at the center leaves South Africa grappling to address other health challenges and pandemics.

Finally, the current United Nations (UN) Special Rapporteur on the right to health, Tlaleng Mofokeng, examines Lynn Freedman's 1995 article "Reflections on Emerging Frameworks of Health and Human Rights."[11] Like many of the articles in the first volume of the journal, Freedman emphasized how the "analytical tools of public health can be used in conjunction with emerging theories of human rights" to advance women's reproductive health and rights.[12] Mofokeng expounds on Freedman's belief in using advocacy as an inherently subversive tool to challenge sociopolitical norms that both produce and sustain ill health. She explains that in her UN mandate, she uses anti-racist, anti-colonial analyses and employs intersectional frameworks to advocate for substantive equality to fulfill health rights.

Collectively, these commentaries speak both to progress and to ongoing struggles in the effort to expand understanding and realization of the right to health. Thirty years on, there are still those who stubbornly debate that health (and other social and economic rights) does not deserve a full seat at the rights table alongside civil and political rights.[13] They argue that negative rights—restrictions on governments' actions—which relate to, for example, the prohibition of torture, arbitrary detention, and other civil and political rights abuses, are fundamentally different from positive rights, which promote the progressive realization of rights such as the rights to health, education, and shelter.

Since the founding of the journal, health and human rights scholars and activists have challenged this contention. In each issue, articles have pointed to the indivisibility of civil, political, economic, social, and cultural rights. Irrespective of which specific health issue an author is addressing, achieving progress in preventing or treating it requires the understanding that all human rights must be respected. Scholars published in the journal were examining the "underlying" determinants of health long before they became more mainstream with WHO's world report in 2008 on the social determinants of health.[14] Over the past 30 years, the journal has published multiple articles on the environment, tuberculosis, compulsory drug dependency treatment, COVID-19, reproductive rights, disability rights, and more that have illustrated how both sets of rights influence health. In each case, recognizing this indivisibility strengthens efforts to uphold the right to health and protect vulnerable and marginalized communities.

For example, in the second volume, published in 1997, Alistair Iles wrote that "linkages between health and the environment are increasingly recognized, but human rights law still does not provide an adequate framework for dealing with those connections."[15] Today, there is a UN Special Rapporteur on human rights and the environment, who, along with organizations such as the Center for International Environmental Law and Human Rights Watch, recognizes the deep connections between human rights and health and the importance of addressing all civil, political, economic, and social rights in their research and advocacy.[16] Ten years ago, the journal assembled a special section on climate justice and the right to health, linking it to issues related to children's rights, racism, and social justice, and in 2021 there were two special sections on both the climate crisis and ecological justice, which examined not just the indivisibility of human rights but also humanity and its interdependence with nature.[17]

Articles on multidrug-resistant tuberculosis in the journal have addressed permissible and impermissible rights restrictions—including quarantine—as well as the importance, from a rights perspective and from a public health perspective, of community-based alternatives.[18] These analyses, which insist on the indivisibility of all human rights, have proved equally important during the Ebola and COVID-19 outbreaks.[19] Similarly, articles on compulsory drug detention, and on drug policy generally, including with regard to access to palliative care, have highlighted the inescapable indivisibility of all human rights.[20]

Yet the challenges outlined by Mann in another editorial, "Human Rights and the New Public Health," remain.[21] In that editorial, Mann anticipated that public health professionals will resist a reframing of public health to recognize human rights as fundamental determinants of health, both because of a lack of familiarity with human rights and an unease with engaging beyond narrow, biomedical approaches.[22]

Nonetheless, the journal's archives show increasing confidence among contributors in developing human rights-based approaches and analyses. The term itself first appeared in the title of an article in the journal in 1998, "Human Rights Approaches to an Expanded Response to Address Women's Vulnerability to HIV/AIDS," which sought to identify effective strategies to address multiple components of vulnerability in addition to providing adequate health services.[23] Thereafter, "rights-based approaches" became more frequent, and in her final article as editor in 2006, Gruskin wrote, "Human rights are now understood to offer a framework for action and for programming, even as they provide a compelling argument for government responsibility—both to provide health services and to alter the conditions that create, exacerbate, and perpetuate poverty, deprivation, marginalization, and discrimination."[24]

In 2008, with Paul Farmer as the new editor-in-chief, a section explored what rights-based approaches mean, with the frequently cited Leslie London paper "What Is a Human Rights-Based Approach to Health and Does It Matter?" and Alicia Ely Yamin's "Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care."[25] In 2015, guest editors Paul Hunt, Yamin, and Flavia Bustreo presented an entire issue on evidence showing the impact of human rights-based approaches to health.[26]

But in practice, the record is mixed. Organizations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria have recognized the importance of rights-based approaches to remove barriers to access, uptake, and retention in prevention and treatment programs.[27] WHO highlights rights violations related to the detention of hospital patients for being unable to pay their bill; violence against women, including abuses during childbirth and pregnancy and female genital mutilation; "conversion" therapy; and the denial of sexuality education, among other abuses, as critical to address in order to achieve a right to health for all.[28] WHO also promotes rights-based approaches to health services, recently seen in its QualityRights training materials for people working in mental health and in its guidance on mental health services.[29]

Other global health donors and actors are more reticent in recognizing the importance of rights and the need to overturn harmful laws, policies, and practices that impede the realization of the right to health. They may prefer to talk more broadly about "equity" than "rights," failing to recognize linkages between the two—or intentionally avoiding the discussion of rights and questions of obligation.[30] The concept of accountability can also be a challenge for UN agencies, donors, and other global health actors to accept—both in holding themselves accountable and in holding governments to account.[31]

The journal's archives, covering 30 years of articles, present an extraordinary range of topics. The journal has provided a platform for scholars, health and legal practitioners, and activists to address health concerns that especially affect marginalized and disadvantaged communities, along with the underlying inequalities and discrimination that leave communities so vulnerable to ill health and multiple rights violations. As Mofokeng expresses in her commentary, "We have to be committed to ending the systems of oppression that create those situations. This can be done only through an unwavering commitment to social justice, reproductive justice, economic justice, and racial justice. And the tools we have to get to justice are human rights."[32]

We invite you to contribute commentaries with your own reflections on the current state of the right to health and how far—or how little—we have advanced since our early volumes on the recognition of the right to health; on the integration of the right to health among bilateral and multilateral donor agencies; and on how the right to health is operationalized by community-based organizations worldwide. As always, we welcome critical and lively debate—or as Mann suggested, tearing down and building up.[33]

References

1. J. Morsink, *The Universal Declaration of Human Rights: Origins, Drafting and Intent* (Philadelphia: University of Pennsylvania Press, 1999); Office of the United Nations High Commissioner for Human Rights and World Health Organization, *The Right to Health: Fact Sheet No. 31* (June 2008), https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf.
2. B. M. Meier, "Global Health Governance and the Contentious Politics of Human Rights: Mainstreaming the Right to Health for Public Health Advancement," *Stanford Journal of International Law* 46/1 (2010); P. Alston, "The United Nations' Specialized Agencies and Implementation of the International Covenant on Economic, Social and Cultural Rights," *Columbia Journal of Transnational Law* 18 (1979).
3. J. Mann, "A New Journal: A New Beginning," *Health and Human Rights Journal* 1/1 (1994).
4. S. Marks, "A Personal Commentary on the Two Conferences on Health and Human Rights," *Health and Human Rights Journal* 26/1 (2024); S. Gruskin, "Health and Human Rights: What Relevance Now?," *Health and Human Rights Journal* 26/1 (2024).
5. J. Mann, L. O. Gostin, S. Gruskin, et al., "Health and Human Rights," *Health and Human Rights Journal* 1/1 (1994).
6. Gruskin (see note 4).
7. "Conference Report: First International Conference on Health and Human Rights," *Health and Human Rights Journal* 1/2 (1994); J. M. Mann and S. Gruskin, "The 2nd International Conference on Health and Human Rights: Bridge to the Future," *Health and Human Rights Journal* 2/3 (1997).
8. Marks (see note 4).
9. L. O. Gostin and E. A. Friedman, "The Health and Human Rights Impact Assessment: The Preeminent Value of Equity," *Health and Human Rights Journal* 26/1 (2024).
10. M. Heywood and M. Cornell, "Human Rights and AIDS in South Africa: From Right Margin to Left Margin," *Health and Human Rights Journal* 2/4 (1998)
11. L. P. Freedman, "Reflections on Emerging Frameworks of Health and Human Rights," *Health and Human*

Rights Journal 1/3 (1995).

12. T. Mofokeng, "Freedom Dreaming: On Emerging Frameworks of Health and Human Rights," *Health and Human Rights Journal* 26/1 (2024).

13. A. Neier, "Differentiating Fundamental Rights and Economic Goals," in B. Fassbender and K. Traisbach (eds), *The Limits of Human Rights* (Oxford: Oxford University Press, 2019).

14. Commission on the Social Determinants of Health, *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health* (Geneva: World Health Organization, 2008).

15. A. T. Iles, "Health and the Environment: A Human Rights Agenda for the Future," *Health and Human Rights Journal* 2/2 (1997).

16. See, for example, UN Special Rapporteur on Human Rights and the Environment, "Thematic Reports," https://srenvironment.org/thematic-reports; Human Rights Watch, "'They Destroyed Everything': Mining and Human Rights in Malawi" (September 27, 2016), https://www.hrw.org/report/2016/09/27/they-destroyed-everything/mining-and-human-rights-malawi; Center for International Environmental Law, "Chilean Communities' Responses and Recommendations to Accountability Mechanisms of Development Banks Regarding the Alto Maipo Hydroelectric Project (June 2023)" (June 28, 2023), https://www.ciel.org/reports/chilean-communities-responses-and-recommendations-to-accountability-mechanisms-of-development-banks-regarding-the-alto-maipo-hydroelectric-project-june-2023/.

17. See *Health and Human Rights Journal* 16/1 (2014), Climate Justice and the Right to Health: A Special Issue; *Health and Human Rights Journal* 23/2 (2021), Special Section: Ecological Justice and the Right to Health and Health Rights and the Urgency of the Climate Crisis.

18. J. J. Amon, F. Girard, and S. Keshavjee. "Limitations on Human Rights in the Context of Drug-Resistant Tuberculosis: A Reply to Boggio et al.," *Health and Human Rights Journal* (October 7, 2009), https://www.hhrjournal.org/2009/10/limitations-on-human-rights-in-the-context-of-drug-resistant-tuberculosis-a-reply-to-boggio-et-al/.

19. Human Rights Watch, "West Africa: Respect Rights in Ebola Response" (September 15, 2014), https://www.hrw.org/news/2014/09/15/west-africa-respect-rights-ebola-response; N. Sun, E. Christie, L. Cabal, and J. J. Amon, "Human Rights in Pandemics: Criminal and Punitive Approaches to COVID-19," *BMJ Global Health* 7/2 (2022).

20. R. Elliott, J. Csete, E. Wood, and T. Kerr, "Harm Reduction, HIV/AIDS, and the Human Rights Challenge to Global Drug Control Policy," in M. Gordin, D. Tarantola, G Annas, and S. Gruskin (eds), *Health and Human Rights in a Changing World* (New York: Routledge, 2013); M. Golichenko and A. Sarang, "Atmospheric Pressure: Russian Drug Policy as a Driver for Violations of the UN Convention against Torture and the International Covenant on Economic, Social and Cultural Rights," *Health and Human Rights Journal* 15/1 (2013); D. Lohman and J. J. Amon, "Evaluating a Human Rights-Based Advocacy Approach to Expanding Access to Pain Medicines and Palliative Care: Global Advocacy and Case Studies from India, Kenya, and Ukraine," *Health and Human Rights Journal* 17/2 (2015).

21. J. Mann, "Human Rights and the New Public Health," *Health and Human Rights Journal* 1/3 (1995).

22. Ibid.

23. D. Whelan, "Human Rights Approaches to an Expanded Response to Address Women's Vulnerability to HIV/AIDS," *Health and Human Rights Journal* 3/1 (1998).

24. S. Gruskin, "Rights-Based Approaches to Health: Something for Everyone," *Health and Human Rights Journal* 9/2 (2006).

25. L. London, "What Is a Human Rights-Based Approach to Health and Does It Matter?," *Health and Human Rights Journal* 10/1 (2008); A. E. Yamin, "Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care," *Health and Human Rights Journal* 10/1 (2008).

26. P. Hunt, A. E. Yamin, and F. Bustreo, "Editorial: Making the Case: What Is the Evidence of Impact of Applying Human Rights-Based Approaches to Health?," *Health and Human Rights Journal* 17/2 (2015).

27. K. Hinman, N. Sun, and J. J. Amon, "Ensuring Access to Justice: The Need for Community Paralegals to End AIDS by 2030," *Journal of the International AIDS Society* 26/8 (2023).

28. See, for example, World Health Organization, "Right to Health: Standing against Rights Abuses" (March 17, 2022), https://www.who.int/news-room/facts-in-pictures/detail/right-to-health.

29. World Health Organization, *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches* (Geneva: World Health Organization, 2021); see also World Health Organization, "QualityRights Materials for Training, Guidance and Transformation," https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools.

30. P. Braveman, "Social Conditions, Health Equity, and Human Rights," *Health and Human Rights Journal* 12/2 (2010).

31. G. Gray, "The Center for Justice and Accountability," *Health and Human Rights Journal* 4/1 (1999); M. Akashah and S. P. Marks, "Accountability for the Health Consequences of Human Rights Violations: Methodological Issues in Determining Compensation," *Health and Human Rights Journal* 9/2 (2006); S. Mayhew, M. Douthwaite, and M. Hammer, "Balancing Protection and Pragmatism: A Framework for NGO Accountability in Rights-Based Approaches,"

Health and Human Rights Journal 9/2 (2006); A. E. Yamin, "Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health," *Health and Human Rights Journal* 10/2 (2008); V. Maru, "Allies Unknown: Social Accountability and Legal Empowerment," *Health and Human Rights Journal* 12/1 (2010).

32. Mofokeng (see note 12).
33. Mann (1994, see note 3).

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COMMENTARY

Health and Human Rights: What Relevance Now?

SOFIA GRUSKIN

It is both an honor and terrifying to be asked to revisit an article we wrote 30 years ago for *Health and Human Rights*—one often touted as having been central to launching the health and human rights movement, but also written at a time when we didn't have the words to describe and concretize the linkages and had limited empirical evidence of what we were seeking to conceptualize and create.[1]

We often say in more recent times that the question is no longer *why* link health and human rights but *how* to do it. What does it mean to do so in practice? And for many of us—authors of the original paper and friends and colleagues around the world—we have dedicated much of our professional lives to doing just that: putting into place the evidence and the building blocks that can make a difference in their own right but that can also demonstrate the added value of these linkages to outcomes and human well-being more generally. Historically, it must be remembered that at the time, our interests were more modest—we sought to show simply *why* link health and human rights and what can be seen differently by considering them as connected.

It is also worth remembering the realities of the field at the time this was written—a time when these two communities (those working in public health and those working in the legal/human rights field) did not generally work together. This was true within the United States, where I live, but just as much in South Africa and in Brazil, two countries where I had close colleagues working on these issues, but all of us working in silos, and most often without collaboration. And I would assume that this was true wherever else these nascent efforts existed at the time as well. Technical languages were different between the two communities, but there was also a lack of trust. Folks on the public health side were concerned that, as was said to me at that time by a very high-ranking public health official, "I don't need these human rights people who know nothing about health coming in and telling me how to do my job." And on the flip side, the human rights community was deeply skeptical of government authority; it was accustomed to calling out abuses and not trusting that governments genuinely considered the rights impacts of their policies on the humans who were affected. This was in the real world so to speak, but the same issues existed also in terms

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Sofia Gruskin, JD, MIA, is a distinguished professor of population, public health sciences and law; professor at the Keck School of Medicine and Gould School of Law; division chief of the Division of Disease Prevention, Policy and Global Health; and director of the Institute on Inequalities in Global Health, University of Southern California, Los Angeles, CA, United States.

Please address correspondence to the author. Email: gruskin@med.usc.edu.

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of how teaching and training were done.

One may ask what efforts existed at the time to help students understand and see past their disciplines and their differences to work together on solving health-related human rights concerns, drawing on the strengths of each discipline. The reader will not be surprised to hear that this just did not exist, neither in rhetoric nor in reality. Consequently, when, under Jonathan Mann's leadership, we determined that training was needed and that part of this would require organizing a first-ever course on health and human rights, which could then in turn be replicated and adapted by others, the first question was, what sort of syllabus and readings could be provided to an initial cohort of students and what sorts of exercises would we put in place? And as the junior person on the team, I was tasked with finding materials from others who had made similar efforts, in the hopes of not reinventing the wheel. We assumed that a wobbly wheel could be found, but a wheel nonetheless. And while there were lots of engaging examples addressing survivors of torture, and in the fields of HIV and of women's health, to name a few, there was no conceptual framework categorizing and explaining what had been found or done programmatically that sought to link health and human rights. Finding nothing really suitable, we therefore set out to create a publication that could lay out such a framework and serve as a basic introduction that would be equally available and accessible to those students engaged in public health as those engaged in human rights, but written in such a way that it could also be used in academic and programmatic circles to facilitate general understanding of these linkages. And ultimately, we hoped, through this conceptual framework, to create a paradigm that could help facilitate work at this intersection going forward.

Moving to the substance, in revisiting this article I was relieved to see that while the first sections laying out the basics of public health and of human rights certainly require an update, there was nothing immediately embarrassing or fully irrelevant to the present moment. Phew. Again, much to add and contextualize, but so far so good. I have far more to say about how I think now about the utility of each of the three relationships presented in the original paper, alongside what I would consider the framing and explanations we offered for each. Again, nothing wrong, just a bit of history. Jonathan always liked for things to be in threes—for example, he taught me when I was making an intervention to always say that I have three points (not two or four but three), even if I didn't, because that's how folks hear things. It was thus clear that if we were to set out a conceptual framework, this would have to be done in threes. These, then, were the three relationships: (1) the impact of health policies, programs, and practices on human rights; (2) the health impacts resulting from violations of human rights; and (3) the inextricable linkage between health and human rights.

Sadly, while I think there is much to be said in support of the first two relationships, the third does feel now a bit like it was necessary more for the symmetry it offered than for the additional thinking it contained. Yes, health and human rights are inextricably linked, and the promotion or violation of rights in one area will impact the other; but in truth, I no longer think that there is a need to set out this third relationship. Indeed, I have noted over time how in my own work, and in the work of others, rarely is this third relationship elaborated in any way.

With respect to the first two relationships, then, while I mean this neither as a strength nor a weakness, it is important now to see them simply as analytical and descriptive—as a way to portray something that has occurred as opposed to setting out a program of action that can be used to move actions forward. I would also note that while I consider the two relationships to be solid, some friendly modifications in how they are discussed and used have proven useful over time:

- A key point that was implicit in what we laid out, but which has been made much clearer in the decades that follow, is the critical importance of framing these relationships around the notion of who are the duty bearers and who are the rights holders. In both cases, we are well served by being much more explicit about the fact that we are talking about the actions of state actors and their impacts on individuals and populations. Whether positive or negative, the focus therefore must be on these actors and the interactions between them. These bidirectional relationships do not happen in the abstract but are the result of the actions of states.

- Importantly, and relatedly, these actions and their impacts do not take place in a vacuum, even if this is how they were set out in this initial publication. Recognition of, and engagement with, the economic, social, cultural, political, and legal environment within these relationships and actions take place is central to any thinking or work on the health and human rights linkage if this framework is truly to remain a useful analytical model.

In this highly charged political moment, I am relieved to see, at least in my opinion, that the value of this article persists. History is important, and I believe in this complex time that we would be better served not to invent a new wheel but to build and improve on what we have, what we know, and what has been tested. I encourage the reader to review the original article, with its very humble beginnings in mind. Finally, to be honest, this remains an article that, despite whatever additional critiques I and others may now offer, I continue to provide in all my courses that touch on the health and rights intersection. I hope it can remain useful to others over the next 30 years, not only as a piece of history but as a living document.

References

1. J. Mann, L. Gostin, S. Gruskin, et al., "Health and Human Rights," *Health and Human Rights Journal* 1/1 (1994).

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COMMENTARY

A Personal Commentary on the Two Conferences on Health and Human Rights

STEPHEN P. MARKS

This 30th anniversary of *Health and Human Rights* (*HHR*) is an extraordinary moment to think back on how far we have come. The enormous debt we all owe to Jonathan Mann will no doubt be expressed by all contributors to this commemoration. I was privileged to participate in the first two health and human rights conferences in 1994 and 1996 and to have been profoundly influenced by them in both my intellectual development and my professional career. I no doubt owe the invitation to the first conference to Sofia Gruskin, my former teaching assistant, who had taken up a position at the newly created FXB Center for Health and Human Rights (founded thanks to the vision and generosity of Albina du Boisrouvray) and contributed her background in international human rights to the launch of the Center and the organization of the conferences. Jonathan's inspiring vision that emerged from his experience dealing with the HIV/AIDS pandemic was expressed so eloquently in this passage of his report for the Hastings Center:

> *Modern human rights, precisely because they were initially developed entirely outside the health domain and seek to articulate the societal preconditions for human well-being, seem a far more useful framework, vocabulary, and form of guidance for public health efforts to analyze and respond directly to the societal determinants of health than any inherited from the biomedical or public health traditions.*[1]

It is truly extraordinary for me as a participant to look back at who was there and the spirit that prevailed in our deliberation and outcome documents. The First International Conference on Health and Human Rights (September 1994) was an elaborate event, involving 72 individuals from the health and human rights fields from 23 countries and 21 "affiliated organizations," including local, national, and international health and human rights groups. It concluded with the adoption of a document enumerating five tasks, along with "actions and follow-up … for each."[2] Rereading that list, I realize how the five tasks exemplify the clear purposefulness of our deliberations and the keen desire to launch a multipronged effort to translate the

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Stephen P. Marks, docteur d'état, dipl. IHEI, is dean of the Jindal School of Public Health and Human Development at O. P. Jindal Global University, Sonipat, India, and François-Xavier Bagnoud Professor of Health and Human Rights Emeritus at Harvard T.H. Chan School of Public Health, Boston, United States.

Please address correspondence to the author. Email: spmarks@jgu.edu.in

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conceptual linking of health and human rights into a set of meaningful actions.

Expanding and facilitating communication among health and human rights workers and organizations (task 1) has made enormous progress since 1994. Of course *HHR* and its free, online, open-access availability, as well as the World Health Organization website on human rights (https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health), contribute to that communication. This task was further promoted when the American Public Health Association adopted six "Principles on Public Health and Human Rights" in November 2000 as just one example of engaging health practitioners to work with scholars and activists.[3]

Collecting and publishing examples and suggestions of actions linking health and human rights (task 2) is of course also what *HHR* and similar publications—such as the *International Journal of Human Rights in Healthcare*, the *International Journal for Equity in Health*, and the *International Journal of Social Determinants of Health and Health Services*— have done.

The education of health workers by disseminating a registry of courses and programs, developing model curricula, and publishing articles (task 3) has also expanded. Not surprisingly, Sofia Gruskin, who was instrumental in organizing both conferences, created a database of health and human rights syllabi as part of her creative initiatives as director of the Program on Global Health and Human Rights and the USC Institute on Inequalities in Global Health. I had the pleasure of working with her when she created, in 1997, the Program on International Health and Human Rights at the FXB Center and admire deeply how she has contributed to the shared vision from the conferences at Harvard (including as editor of *HHR*) and her current leadership at USC. Another example of task 3 achievement is the continuing efforts of the International Federation of Health and Human Rights Organisations, which "supports the mobilization of health professionals for human rights through: 1) advocacy on social media, and 2) information, education and communication activities."[4] It is currently developing a *Right to Health Toolkit*, which is designed for health care workers.[5]

Task 4 was quite ambitious, as it covered "advocacy, education and research on specific health and human rights issues" through six actions, such as forming interest groups, engaging with the international human rights system, developing methodologies, and negotiating and funding strategies. It even identified the need to address "emerging areas such as environmental health and rights," which has become a priority area in human rights, reflected in the mandate of the United Nations Special Rapporteur since 2012 and a United Nations declaration on the human right to a clean, healthy and sustainable environment in 2022.[6]

The final task was to organize a second international conference on the topic within two years, and that is precisely what happened in October 1996, fulfilling the aspiration to expand participation by bringing together 500 participants.[7] I was honored to present to the conference my thoughts on "Common Strategies for Health and Human Rights: From Theory to Practice."[8] Little did I know that my explorations on that topic would change my life.

Acknowledging the mobilizing force of these two conferences is not a polite expression of support for this journal. It is an honest assessment of the impact the conferences had on the intellectual framing of health and human rights, on the professional careers of many participants, on institutional growth in this field, and on related national and international policies. But it is also deeply personal for me. Indeed, I came to the two conferences from my position as director of United Nations studies at the School of International and Public Affairs and lecturer at the Law School at Columbia University, being deeply anchored in the field of international law and organizations. By participating in follow-up events that Jonathan, Daniel Tarantola, and Sofia Gruskin organized at the FXB Center, I realized the value of engaging the mutually reinforcing character of the health and human rights paradigms. The two conferences motivated me to see a future in professional engagement in implementing the action plan adopted at the first conference and considerably expanded upon in the second. As I noted at the time, "It is truly extraordinary that five hundred people have come to explore a theme that, a few short years ago, might have appeared esoteric and marginal."[9]

After Jonathan's tragic death in 1998, I advised the Harvard School of Public Health that his successor should follow the same formula of success—namely, a medically trained person with considerable experience in public health and an interest in integrating human rights into public health teaching, research, and advocacy. My recommendation was rejected, and the position of FXB Center director was offered to me, quite surprisingly. I was fortunate to work with the outstanding staff Jonathan had assembled and to take inspiration from giants in the field, such as Larry Gostin, Anthony Fauci, Jack Geiger, Nahid Toubia, and Mathilde Krim, and leading human rights scholars and practitioners, also committed to this vision, such as Virginia Leary, Michael Kirby, Paul Farmer, Jennifer Leaning, Alicia Ely Yamin, and Paul Hunt, to name a few.

"Transformative" is an overused and abused term in modern parlance, but I feel confident applying it to the effort made by the two conferences. Indeed, Jonathan wrote, "Only with the passage of several years will this newborn's relationship to the intellectual and pragmatic work of the world become evident."[10] Frankly, my life was transformed, literally. Not only did I move to Harvard and spend 23 years as the FXB Professor of Health and Human Rights (six years as the FXB Center's director), but my teaching and research shifted to the precise set of tasks identified in the 1994 and 1996 conferences. Starting with a 1999 study on the public health and human rights implications of economic sanctions, I published on the health and human rights approach in the Carnegie Council's *Human Rights Dialogue* magazine, the *Journal of Law, Medicine and Ethics*, the *American Journal of Public Health*, and the *Proceedings of the American Society of International Law.*[11] This new focus of my scholarship led me to explore a range of fascinating intersections of health and human rights, such as genetic manipulation and cloning, tobacco control, medical experimentation, access to medicines, the right to health, the right to benefit from advances in science and technology, and mental health.[12] I beg the reader not to misinterpret this enumeration of publications; my sole purpose is to illustrate the direct connection between my participation in the two conferences and my subsequent scholarship.

My professional life was profoundly changed, and that continues to this day in my current functions as founding dean of the Jindal School of Public Health and Human Development in India. With newly recruited faculty and students dedicated to the values articulated at the conferences, I feel proud to be continuing to heed the call to action I expressed at the 1996 conference "that we will not remain bystanders while millions upon millions of children, women, and men continue to live in ignorance, poverty, and deprivation of their fundamental dignity and integrity. Ideas," I concluded, "do change the world, and the linkage of human rights and health work is one of those ideas."[13]

References

1. J. Mann, "Medicine and Public Health, Ethics and Human Rights," *Hastings Center Report* 27/3 (1997), reprinted in J. Mann, S. Gruskin, M. A. Grodin, and G. J. Annas (eds), *Health and Human Rights: A Reader* (New York: Routledge, 1999), p. 444.

2. *Conference Report: First International Conference on Health and Human Rights* (September 22–24, 1994, Harvard University), https://www.hhrjournal.org/wp-content/uploads/sites/2469/2020/08/4-First-International-Conference.pdf.

3. See C. E. Easley, S. P. Marks, and R. E. Morgan, "The Challenge and Place of International Human Rights in Public Health," *American Journal of Public Health* 91/12 (2001).

4. IFHHRO, "About Us," https://www.ifhhro.org/about-us/.

5. IFHHRO, "Right to Health Toolkit," https://www.ifhhro.org/home/dignity-by-the-bedside-project/.

6. Human Rights Council, Human Rights and the Environment, UN Doc. A/HRC/RES/19/10 (2012); United Nations General Assembly, The Human Right to a Clean, Healthy and Sustainable Environment, UN Doc. A/RES/76/300 (2022). See Office of the United Nations High Commissioner for Human Rights, United Nations Environment Programme, and United Nations Development Programme, *What Is the Right to a Healthy Environment? Information Note* (2023), https://www.undp.org/sites/g/files/

zskgke326/files/2023-01/UNDP-UNEP-UNHCHR-What-is-the-Right-to-a-Healthy-Environment.pdf.

7. J. M. Mann and S. Gruskin, "The 2nd International Conference on Health and Human Rights: Bridge to the Future," *Health and Human Rights Journal* 2/3 (1997).

8. S. P. Marks, "Common Strategies for Health and Human Rights: From Theory to Practice," *Health and Human Rights Journal* 2/3 (1997).

9. Ibid., p. 95.

10. J. Mann, "A New Journal: A New Beginning," *Health and Human Rights Journal* 1/1 (1994), p. 1.

11. S. P. Marks, "Economic Sanctions as Human Rights Violations: Reconciling Political and Public Health Imperatives," *American Journal of Public Health* 89/10 (1999); S. P. Marks, "The New Partnership of Health and Human Rights," *Human Rights Dialogue* (Spring/Summer 2001); S. P. Marks, "Jonathan Mann's Legacy to the 21st Century: The Human Rights Imperative for Public Health," *Journal of Law, Medicine and Ethics* 29/2 (2001); Easley et al. (see note 3); S. P. Marks, "Health and Human Rights: The Expanding International Agenda," *Proceedings of the Annual Meeting (American Society of International Law)* 95 (2001); S. P. Marks, "The Evolving Field of Health and Human Rights: Issues and Methods," *Journal of Law, Medicine and Ethics* 30/4 (2002).

12. S. P. Marks, "Tying Prometheus Down: The International Law of Human Genetic Manipulation," *Chicago Journal of International Law* 3/1 (2002); S. P. Marks, "Human Rights Assumptions of Restrictive and Permissive Approaches to Human Reproductive Cloning," *Health and Human Rights Journal* 6/1 (2002); C. Dresler and S. P. Marks, "The Emerging Human Right to Tobacco Control," *Human Rights Quarterly* 28/3 (2006); S. Marks, "Human Rights-Based Approach to Tobacco Control," invited commentary in *Tobacco Control* 21/2 (2012); S. Marks, "Medical Experimentation," in *Encyclopedia of Genocide and Crimes Against Humanity* (New York: Macmillan Reference, 2004); S. P. Marks, "Access to Essential Medicines as a Component of the Right to Health," in A. Clapham and M. Robinson (eds), *Realizing the Right to Health* (Zurich: Rüfer and Rub, 2009); S. Marks and A. Lee Benedict, "Access to Medical Products, Vaccines and Medical Technologies," in J. M. Zuniga, S. P. Marks and L. O. Gostin (eds), *Advancing the Human Right to Health* (Oxford: Oxford University Press, 2013); S. P. Marks, "Normative Expansion of the Right to Health and the Proliferation of Human Rights," *George Washington International Law Review* 16 (2016); S. P. Marks, "Out of Obscurity: The Right to Benefit from Advances in Science and Technology and its Implications for Global Health," in *Proceedings of the 3rd Conference on Law, Science, and Technology: Health and Science: Human Rights and Legal Issues* (Taipei: Academia Sinica, 2012); S. P. Marks, L. Verdeli, and S. Willis, "Mental Health and Human Rights: International Standards and Clinical Practice," in N. S. Rubin and R. l. Flores (eds), *Cambridge Handbook of Psychology and Human Rights* (Cambridge: Cambridge University Press, 2020).

13. See Marks (1997, see note 8), p. 104.

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COMMENTARY

The Health and Human Rights Impact Assessment: The Preeminent Value of Equity

LAWRENCE O. GOSTIN AND ERIC A. FRIEDMAN

The year was 1994. Contracting HIV was a death sentence. Triple therapy was still two years away in the United States. Efforts to achieve antiretroviral treatment at scale in Sub-Saharan Africa would not begin for nearly another decade. In the United States, AIDS was still heavily associated with men who have sex with men, and later also users of injection drugs. People living with HIV faced stigma, discrimination, and even animus. In the mid-1980s, Ryan White, a young boy from Indiana living with AIDS, insisted, "Mom, I want to go to school."[1] But he was excluded.

It was also a very different era for health and human rights. It would be six years before the Committee on Economic, Social and Cultural Rights (ESCR Committee) would issue General Comment 14 on the right to health. At the time, there was a widespread belief that public health and human rights were in deep, sometimes irresolvable, conflict. On issues ranging from mandatory HIV testing to named reporting to partner notification, public health would trump human rights. The debate was rarely informed by whether public health interventions were actually effective.

In February 1987, I (LOG) met a young American public health professional named Jonathan Mann in Geneva. The World Health Organization's Global Programme on AIDS comprised only Jon and a Swiss secretary. By the time Jon left Geneva, it had become the largest program in the World Health Organization's history. Jon had become widely renowned for founding the health and human rights movement, grounded on the idea that human rights and public health were not in tension but were synergistic.

By 1994, Jon and I had become close friends and he joined me at the Harvard School of Public Health. Standing at a chalkboard in the basement of Longwood Avenue, we drafted the outlines of a health and human rights impact assessment to guide the creation and evaluation of public health policies.

Lawrence O. Gostin is co-faculty director of the O'Neill Institute for National and Global Health Law, the founding O'Neill Chair in Global Health Law, and director of the WHO Collaborating Center on Global Health Law at Georgetown University Law Center, Washington, DC, United States.

Eric A. Friedman is a global health justice scholar at the O'Neill Institute for National and Global Health Law, Georgetown University Law Center, Washington, DC, United States.

Please address correspondence to Lawrence O. Gostin. Email: gostin@law.georgetown.edu.

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That was the genesis of our article in the inaugural issue of *Health and Human Rights*.[2] The impact assessment would be informed by evidence of a policy's effectiveness, its real-world consequences, the extent of its human rights burdens, the public health gain (if any), and whether the policy is narrowly tailored to achieve a compelling public health purpose. The impact assessment would serve as an analytical tool to ensure that data, ethics, and human dignity—rather than fears and stereotypes—inform public health policy. The impact assessment we developed had seven steps:

> Step I: Clarify the public health purpose.
> Step II: Evaluate likely policy effectiveness.
> Step III: Determine whether the public health policy is well targeted.
> Step IV: Examine the policy for possible human rights burdens.
> Step V: Determine whether the policy is the least restrictive alternative that can achieve the public health objective.
> Step VI: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on the "significant risk" standard.
> Step VII: If a coercive measure is truly necessary to avert a significant risk, guarantee fair procedures for persons affected.

Our article followed the very first paper in the journal, simply entitled "Health and Human Rights."[3] That paper focused on the synergies between health and human rights—how respecting, protecting, and fulfilling human rights is essential for public health. It foreshadowed a value that animates the health and human rights movement, and what public health emergencies—from HIV/AIDS to COVID-19—have made inescapably clear: that equity must be at the heart of health and human rights. Justice demands it.

Here, we examine the centrality of health equity to human rights, and how and why equity has risen on the global health agenda—and has become firmly embedded in health and human rights impact assessments. How to now unleash the full potential of these assessments?

Equity and the nondiscrimination principle

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.

The full power of the International Covenant on Economic, Social and Cultural Rights' prohibition on discrimination requires recognizing the breadth of its delineated grounds for prohibited discrimination. This breadth became clear in 2009, when the ESCR Committee issued its authoritative General Comment 20. Crucially, the general comment clarifies that the nondiscrimination obligation bars not only facially discriminatory measures but also discrimination that is substantive and indirect (i.e., that disproportionately burdens a population), with positive obligations for states to adopt measures to redress discrimination that exists in practice. And it offers a comprehensive list of grounds for applying the treaty's nondiscrimination principle, going beyond those expressly named in the covenant, including disability, economic or social situation (e.g., poverty), and nationality, among others. Several treaties further detail discrimination against particular populations, prominently women, racial and ethnic groups, and people with disabilities. These treaties encompass nondiscrimination with respect to the right to health, as well as other rights closely linked to people's ability to achieve the highest attainable standard of health, such as the rights to housing, education, and employment.

The rise of equality on the global health agenda

Thirty years ago, the global health community was focused primarily on reducing the enormous burdens in low- and middle-income countries of readily—and largely inexpensively—preventable death and disease, such as maternal and child mortality. In the aggregate, the quarter century from

1990 to 2015 was indeed one of significant health improvements. The global maternal mortality rate fell by 44%.[4] The child (under five) mortality rate fell by over half (53%), as did the proportion of the world's population experiencing hunger (falling about 54%).[5] Yet as the total burden of disease continued to fall, the inequities grew ever more glaring. Global health was improving, but *global health with justice*, not so much.

In India, the mortality rate of women in the lowest wealth quintile is four times that of women in the top wealth quintile (most recent data as of 2017).[6] Globally, children under five were twice as likely to die when in the poorest wealth quintile compared those in the richest wealth quintile in 1990—and still in 2015.[7] Life expectancy disparities within countries, even within cities, can exceed 20 years.[8] Billions of people remain without access to essential health services, medicines, water, or sanitation.

Globally, while the life expectancy gap has narrowed, a child born in a low-income country has a life expectancy 18 years shorter than a child born in a high-income country (2021 data).[9] In 2017, the maternal mortality ratio was 40 times greater in high-income countries than in low-income countries.[10] Little could make clearer the divergence between health improvements and equitable health improvements than the record-breaking speed at which scientists developed highly effective COVID-19 vaccines contrasted with the global disparities in vaccine access. Painfully obvious, too—helping further bring health equity into the public consciousness—was the extra toll of COVID-19 on traditionally marginalized populations, such as Indigenous peoples, who experienced infection and death rates far exceeding those of their countries' overall population.

One issue had, by the turn of the century, already begun to turn the world's eye to equity—the tremendous disparities in HIV treatment between wealthy countries and those in Sub-Saharan Africa, where HIV/AIDS posed practically an existential risk. The power of the AIDS movement, the level of inequality, and the particularly glaring nature of it—pills that made the difference between life and death, available to the rich but not the poor—catalyzed major initiatives to make treatment available to people everywhere.

Beyond the issue of access to antiretroviral treatment, the emergence of the AIDS movement, as well as the growth of health rights advocacy organizations, has been transformative. The AIDS movement forced governments—their own and development partners'—to see people who were marginalized, such as LGBTQ+ people, users of injecting drugs, and sex workers. Other equity-focused social movements have also taken off around the world, such as movements on behalf of and led by women and girls, and people with disabilities.

Health-related civil society organizations have taken up the mantle of advocacy, not only service delivery. Equity is central to their agendas. These, in turn, have increasingly influenced the global health agenda.

Also advancing attention to health equity has been the evolution of global health assistance. The prevailing model of global health assistance had been one of charity—funding provided and essential vaccines and medicines donated as acts of generosity. But people in lower-income countries, especially in Sub-Saharan Africa, have always known that charity comes too little and too late. By the early 2000s, that model began to change (at least nominally) with the language of partnership. "Donors" became "development partners," and "recipients" were "host countries." Modern thinking rejects a charitable model of rights, seeing assistance as an obligation. These changes, though, failed to bring anything near equity to access to vaccines and other essentials during the COVID-19 pandemic. The idea of high manufacturing capacities in low- and middle-income countries has now taken hold, requiring intellectual property waivers, investment in national and regional capacities, and technology transfer.

We see the growing influence of health equity, from universal access to HIV treatment to the centrality of equality in the 2030 Agenda for Sustainable Development, which pledges that "no one will be left behind" and includes goals directly addressing equality.[11] COVID-19's inequities ensured that equality would be a core theme of the Principles and Guidelines on Human Rights and Public Health Emergencies, which include equitable international distribution of scarce resources during public health emergencies.[12] The equity focus has even extended to extraterritorial obligations related to economic, social, and cultural rights, as the Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights include prioritizing the rights of marginalized and disadvantaged groups.[13]

And for all the shortcomings of COVAX, it was an unprecedented effort to ensure COVID-19 vaccines for people wherever they lived. It enabled many millions of people in low- and middle-income countries to receive COVID-19 vaccines earlier than they would have otherwise.

There is little more unjust than the happenstance of people's lives—factors beyond their control—shaping their opportunities to live long, healthy lives and to flourish.[14] To disadvantage people in this way is like stealing from them both life itself and the ability to write the stories of their lives.

Realizing the promise of the impact assessment for rights and equity

Equity, as well as the participation of affected communities, has become central to the health and human rights impact assessments that have built on our article in the founding issue of *Health and Human Rights* and are now frequently used, even as many do not take an explicit rights approach. Most assessments evaluate the potential health effects of a policy, program, or action and recommend how to maximize positive and minimize negative health effects.

Some assessments are framed around human rights and also incorporate other elements of the right to health, including accountability mechanisms and comparisons of the health effects of the policy or project to the AAAQ (availability, accessibility, acceptability, and quality) framework. Impact assessments should also include right to health education and capacity-building for both rights holders and duty bearers.[15]

The ESCR Committee and United Nations Special Rapporteurs on health and education have already encouraged the use of impact assessments.[16] The Special Rapporteur on the right to food has said that authorities "should systematically perform *ex ante* impact assessments on the right to food when engaging in large-scale infrastructural projects, such as dams," with community participation.[17]

It's past time to go a step further and recognize health and human rights impact assessments as an immediate right to health obligation. The International Covenant on Economic, Social and Cultural Rights' progressive realization stipulation was intended to recognize that countries face resource constraints. Yet there are many ways to advance health rights with relatively low resource demands; for the most vital health rights, particularly those with limited resource implications—like impact assessments—state duties should be immediate. General Comment 14 already recognizes that core aspects of the right to health, including nondiscrimination and the equitable distribution of health resources, are immediate. The ESCR Committee should extend these core obligations to include health and human rights impact assessments. This obligation should include the right of affected populations to receive government (or business) feedback on the assessments, which is critical for accountability. Feedback should include how and why a government (or business) did, or did not, follow the impact assessment's recommendations. And this feedback should justify how the ultimate policy or proposal is consistent with human rights obligations.

The United Nations General Assembly and Human Rights Council could also recognize health impact assessments as required under the right to health. The World Health Assembly could urge states to establish legal frameworks on regular government and business use of impact assessments.

All of these bodies should also provide guidance to governments and nongovernmental organizations on fulfilling their duties. Such guidance should encompass common core standards centered in equity. This would include inclusive participation in conducting assessments together with matrices to measure equitable outcomes. The guidance could also offer a framework or threshold for determining when health and human rights impact assessments should be required (e.g., for laws, policies, programs, and projects that have the potential to substantially affect health rights).

Civil society organizations need not wait for further global, or regional, action on health and human rights impact assessments in order to press their governments to include robust impact assessments in their policy and legal frameworks. Our original impact assessment proposal called for a new paradigm for HIV/AIDS policies and laws. Success in institutionalizing even more forceful impact assessments, emphasizing equity, participation, and accountability, could be transformative.

References

1. Ryan White HIV/AIDS Program, US Department of Health and Human Services, "Who Was Ryan White?," https://ryanwhite.hrsa.gov/about/ryan-white.
2. L. Gostin and J. M. Mann, "Towards the Development of a Human Rights Impact Assessment for the Formulation and Evaluation of Public Health Policies," *Health and Human Rights Journal* 1/1 (1994).
3. J. Mann, L. Gostin, S. Gruskin, et al., "Health and Human Rights," *Health and Human Rights Journal* 1/1 (1994).
4. World Health Organization, "Maternal Deaths Fell 44% Since 1990 — UN," https://www.who.int/news/item/12-11-2015-maternal-deaths-fell-44-since-1990-un.
5. UN Inter-agency Group for Child Mortality Estimation, *Level and Trends in Child Mortality: 2015 Report* (New York: UNICEF, 2015); World Health Organization, "Progress on Sanitation and Drinking-Water Update 2015: Key Facts," https://www.who.int/docs/default-source/wash-documents/wash-coverage/jmp/jmp2015-key-facts.pdf.
6. M. Hamal, M. Dieleman, V. De Brouwere, and T. de Cock Buning, "How Do Accountability Problems Lead to Maternal Health Inequities? A Review of Qualitative Literature from Indian Public Sector," *Public Health Reviews* 39/9 (2018).
7. F. Chao, D. You, J. Pettersen, et al., "National and Regional Under-5 Mortality Rate by Economic Status for Low-Income and Middle-Income Countries: A Systematic Assessment," *Lancet Global Health* 6/5 (2018).
8. NYU Langone Health, "Large Life Expectancy Gaps in U.S. Cities Linked to Racial & Ethnic Segregation by Neighborhood" (June 5, 2019), https://nyulangone.org/news/large-life-expectancy-gaps-us-cities-linked-racial-ethnic-segregation-neighborhood.
9. World Bank, "Life Expectancy at Birth Total Years," https://data.worldbank.org/indicator/SP.DYN.LE00.IN.
10. Our World in Data, "Maternal Mortality," https://ourworldindata.org/maternal-mortality.
11. United Nations General Assembly, Transforming Our World: The 2030 Agenda for Sustainable Development, UN Doc. A/RES/70/1 (2015).
12. Global Health Law Consortium and International Commission of Jurists, *Principles and Guidelines on Human Rights and Public Health Emergencies* (2023), https://www.ohchr.org/sites/default/files/documents/new-york/events/hr75-future-generations/PGs-on-Human-Rights-and-Public-Health-Emergencies-26-June-2023.pdf.
13. Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights (2011).
14. L. O. Gostin and E. A. Friedman, "Imagining Global Health with Justice: Transformative Ideas for Health and Well-Being While Leaving No One Behind," *Georgetown Law Journal* 108/6 (2020), p. 1556.
15. G. MacNaughton, "Human Rights Impact Assessment: A Method for Healthy Policymaking," *Health and Human Rights Journal* 17/1 (2015).
16. Ibid.
17. World Bank, *Study on Human Rights Impact Assessments: A Review of the Literature, Differences with Other Forms of Assessments and Relevance for Development* (Washington, DC: World Bank, 2013), p. 5.

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Drexel University Dornsife School of Public Health
FXB Center for Health & Human Rights at Harvard University

COMMENTARY

Law, Human Rights, and Pandemic Response: Reflecting on the South African HIV Response 25 Years Later

SHARIFAH SEKALALA AND KENE ESOM

Introduction

The 1998 article "Human Rights and AIDS in South Africa: From Right Margin to Left Margin" by Mark Heywood and Morna Cornell examined South Africa's response to HIV five years into the epidemic and how the country's liberation struggle against apartheid shaped its initial response to the epidemic.[1] The authors argued that the government's delay in rolling out a comprehensive HIV treatment program, its lack of integration of human rights principles into HIV/AIDS policies, and its failure to address structural inequalities had serious consequences for the country's ability to combat the epidemic effectively. They noted that the readiness of governments in low- and middle-income countries to dispense with their socioeconomic rights obligations is the biggest obstacle to the HIV response. They predicted that a failure to integrate social and economic rights, especially in light of the deep structural inequalities that plagued South Africa, would render its HIV response ineffective.[2]

Reflecting on these predictions 25 years later, we argue that Heywood and Cornell were right to be concerned with the focus on economic prosperity at the expense of deeper structural social and economic rights.

The South African HIV response 25 years later

There has been significant progress in South Africa in the fight against HIV/AIDS in the last two decades. The South African courts rose to the challenge of integrating rights, especially socioeconomic rights,

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Sharifah Sekalala, PhD, is a professor of global health law at the University of Warwick, UK and is a member of the Health and Human Rights Executive Editorial Committee.

Kene Esom, LLM, is a postgraduate researcher at the School of Law, University of Warwick, UK.

Please address correspondence to Sharifah Sekalala. Email: sharifah.sekalala@warwick.ac.uk.

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into the HIV response through several landmark decisions that contributed to an enabling legal and policy environment. The courts affirmed human rights in the context of HIV, including through decisions on nondiscrimination in employment based on HIV status, protection from public disclosure of one's HIV status, and the right of people living with HIV to serve in the military.[3] The courts have also intervened in other rights-related issues that evidence shows are important for the HIV response, including guaranteeing women's right to landed property, addressing gender-based violence, decriminalizing consensual same-sex sexual conduct, and securing access to HIV prevention and treatment for people in prison.[4] The most notable HIV-related decision of the South African Constitutional Court is *Minister of Health v. Treatment Action Campaign (TAC)*, in which the court ordered the government to make nevirapine, an antiretroviral drug for HIV-positive pregnant women, available across the country and to devise a plan for its wider distribution, thus affirming the constitutional right to access health care services.[5] This decision probably saved thousands of lives and underscored the judiciary's commitment to uphold socioeconomic rights, setting a significant precedent for future health care-related litigation.

Despite the initial slow rollout of the national program, which is thought to have resulted in over 330,00 deaths, South Africa currently has the largest HIV treatment program in the world, with about 5.7 million people on treatment out of the estimated 7.8 million people living with HIV, and an estimated overall annual price tag of US$25 billion.[6] The country has witnessed a 57% reduction in new HIV infections and a 70% reduction in AIDS-related deaths between 2010 and 2022.[7]

Socioeconomic rights ideals versus deepening socioeconomic inequality

Pro-rights decisions of courts and good laws and policies alone are insufficient to guarantee the enjoyment of socioeconomic rights and successful epidemic responses. South Africa's Constitutional Court has noted that the Constitution requires the government to take "other measures" to "respond to the people's basic social and economic needs."[8] Heywood and Cornel argued that the government's economic priorities and financial investments have not reflected the ambition of the socioeconomic rights guaranteed by the South African Constitution.[9]

South Africa still has intractable socioeconomic challenges that continue to blight the hope of universal health care. The country is considered the most unequal in the world, with the top 10% of its people holding 80.6% of financial assets.[10] Thirty percent of people in South Africa live below the World Bank's absolute poverty threshold of US$1.90 per day.[11] This socioeconomic disparity is reflected in other areas, including employment opportunities, health, and access to decent shelter. Unemployment stands at 32.1%, with youth (ages 15–34) unemployment at 42.2%.[12]

South Africa has a dual-model health care system of stretched, overcrowded, low-quality free public facilities on which the majority of the population relies, and expensive high-quality private facilities accessible mostly through private medical insurance.[13] With only 16% of the population covered by medical insurance, health outcomes are dire for most.[14] The right to shelter guaranteed by South Africa has yet to translate into adequate, affordable housing for most. About 13% of South Africans are estimated to live in shacks and informal settlements.[15] Despite these challenges, South Africa's status as one of the most advanced economies in the region makes it a preferred destination for labor migrants, asylum seekers, and refugees from other African countries.[16] This has undoubtedly placed an additional burden on the country's public services. Government officials stoke the embers of xenophobia by blaming African migrants for poor service delivery and employment opportunities.[17] The media's amplification of these narratives has resulted in several violent attacks on foreign migrants in South Africa, with the government seemingly unable to address them.[18] Although the South African Constitution guarantees asylum seekers and refugees the right to access medical services, bureaucratic inefficiency has left many asylum seekers undocumented and unable to access health care.[19]

Pandemic preparedness and response: Lessons from COVID-19 and HIV

The COVID-19 pandemic exposed the fault lines of inequality in both rich and poor countries worldwide, and South Africa was no exception.[20] South Africa had the highest number of COVID-19 cases in Africa, with an estimated four million cases and over 100,000 deaths.[21] Food prices soared, and almost 70% of people in the country reported that they could not work due to the strict lockdowns imposed by the government. Protests and violence broke out across South Africa, with the looting of shops occurring across the major cities.[22] Xenophobic attacks were common, with many Zimbabwean migrants scapegoated and wrongly accused of spreading COVID-19.[23]

The South African government declared a national state of disaster using disaster management powers designed to allow it to mobilize resources, coordinate responses, and implement special measures for effectively addressing crises.[24] Under a state of disaster, certain rights may be limited but not derogated through the promulgation of regulations. While the lockdowns may have been necessary, their effect on certain groups, especially those living in informal settlements and workers in the informal sector, was disproportionate. The conditions of the informal settlements made it virtually impossible to observe social distancing, self-isolation, or frequent handwashing.[25] Additionally, the lockdowns meant that those who worked in informal jobs as domestic workers, gardeners, roadside vendors, or restaurant employees were out of work, without savings, food, or a social safety net to absorb the impact of the pandemic.[26] The courts highlighted this structural vulnerability in *De Beer N.O and Others v. Minister of Cooperative Governance and Traditional Affairs*, which held that some of the government's lockdown regulations were unconstitutional. The ruling referred to the millions of informal workers who had lost their livelihoods and to the communities that watched children go hungry, stripped of their rights to dignity and equality.[27]

COVID-19, just like HIV, revealed that although pandemic responses may be rooted in biomedical responses, social relations and socioeconomic realities undermine the effectiveness of the response.[28] Sadly, the lessons of effective community engagement and public education campaigns that contributed to the success of the HIV response were not deployed to the same extent for COVID-19. Furthermore, evidence from the HIV response shows that the excessive use of criminal law has the effect of increasing stigma around the virus and discrimination and human rights abuses against people living with the virus, as well as driving people suspected of having the virus underground.[29] South Africa was one of the few countries that did not criminalize HIV nondisclosure, exposure, and transmission as part of its response, instead opting for an approach that incentivized voluntary testing and treatment. Unfortunately, for its COVID-19 response, the government chose to lean heavily on criminal law, issuing fines and prison sentences to those who broke lockdown restrictions.[30] The absence of a human rights-based approach and effective community engagement may have contributed to hesitancy when vaccines eventually became available. Surveys consistently showed that vaccine hesitancy in South Africa was associated with age, race, education, geography, and employment status.[31]

Another issue that further complicated the human rights dimensions of the COVID-19 pandemic response was the use of new technologies and digital health surveillance of the population, including global positioning systems, cell phone apps, and facial recognition to control the spread of COVID-19. To its credit, the government piloted and discarded a few applications and technologies following concerns over data privacy and the surveillance of people without due consent and the involvement of the private sector.[32]

Conclusion

In May 2023, the World Health Organization declared the COVID-19 pandemic over, with much relief. As the pandemic recedes from South African memories, priorities shift to more economic ones, such as establishing mRNA hubs. There is a danger of forgetting the deep structural inequalities that this pandemic highlighted. Although health interventions often rely on working toward clearly discernible ends of pandemics, official announcements of the end of a pandemic or a public health crisis risk undermining governments' commitments to and investments in addressing deep socioeconomic challenges in societies such as South Africa as part of their obligations concerning the right to health and pandemic preparedness. The COVID-19 pandemic might be over, and South Africa is making steady progress toward achieving global targets of HIV epidemic control. However, the country still needs to grapple with other health challenges, such as tuberculosis, noncommunicable diseases (including diabetes and high blood pressure), and whichever global pandemic may be lurking around the corner. South Africa must double up efforts to "take additional measures" necessary to effect the South African Bill of Rights promises.[33] A human rights approach, as Heywood and Cornel spelled out—which puts the rights of structurally marginalized groups at the center—is the only way that states like South Africa can create enduring and sustainable responses to pandemics.

References

1. M. Heywood and M. Cornell, "Human Rights and AIDS in South Africa: From Right Margin to Left Margin," *Health and Human Rights Journal* 2/4 (1998).

2. Ibid.

3. *Hoffman v. South African Airways*, CCT 17/2000 ZACC 17 (2000); *NM and others v. Smith and Others* CCT 69/2005 ZACC 6 (2017); *Dwenga and Others v. Surgeon-General of the South African Military Health Services and Others* (40844/2013) [2014] ZAGPPHC 727.

4. *Rahube v. Rahube* (CCT 319/2017) [2018] ZACC 42; *Carmichele v. Minister of Safety and Security* (CCT 48/00) [2001] ZACC 22; *National Coalition for Gay and Lesbian Equality and Another v. Minister of Justice and Others* (CCT11/98) [1998] ZACC 15; *Van Biljon and others v. Minister of Correctional Services and Others* 1997 (4) SA 441 (C).

5. *Minister of Health and Others v. Treatment Action Campaign and Others* (No 2) (CCT8/02) [2002] ZACC 15.

6. P. Chigwedere, G. Seage, S. Gruskin, and T. Lee, "Estimating the Lost Benefits of Antiretroviral Drug Use in South Africa," *Journal of Acquired Immune Deficiency Syndromes* 49/4 (2008); Catherine Tomlinson, "Analysis: Amid Budget Constraints, Tough Choices for SA's HIV Response," *Spotlight* (November 29, 2023), www.spotlightnsp.co.za/2023/11/29/analysis-amid-budget-constraints-tough-choices-for-sas-hiv-response/.

7. UNAIDS, *UNAIDS Data 2023* (Geneva: UNAIDS, 2023), p. 155.

8. See the judgment of J. O'Regan of the South African Constitutional Court in *Mazibuko and Others v. City of Johannesburg and Others* (CCT 39/2009) on the right to water.

9. M. Heywood, "Economic Policy and the Socio-Economic Rights in the South African Constitution, 1996 – 2021: Why Don't They Talk to Each Other," *Constitutional Court Review* 11/1 (2021).

10. World Bank, *Inequality in Southern Africa: An Assessment of the Southern African Customs Union* (Washington, DC: World Bank, 2022).

11. Statista, "Number of People Living in Extreme Poverty in South Africa from 2016 to 2030," https://www.statista.com/statistics/1263290/number-of-people-living-in-extreme-poverty-in-south-africa/.

12. Statistics South Africa, *Quarterly Labour Force Survey: Quarter 4:2023* (Pretoria: Statistics South Africa, 2023).

13. P. Morudu and U. Kollamparambil, "Health Shocks, Medical Insurance and Household Vulnerability: Evidence from South Africa," *PLoS One* 15/2 (2020).

14. T. Gordon, F. Booysen, and J. Mbonigaba, "Socio-economic Inequalities in the Multiple Dimensions of Access to Healthcare: The Case of South Africa," *BMC Public Health* 20 (2020).

15. Borgen Project, "Addressing Homelessness in South Africa" (April 30, 2023), https://borgenproject.org/homelessness-in-south-africa/.

16. F. C. Mukumbang, A. N. Ambe, and B. O. Adebiyi. "Unspoken Inequality: How COVID-19 Has Exacerbated Existing Vulnerabilities of Asylum-Seekers, Refugees, and Undocumented Migrants in South Africa," *International Journal for Equity in Health* 19/1 (2020).

17. T. Myeni, "S African Minister Suggests Foreigners Are to Blame for No Jobs," *Aljazeera* (June 16, 2022), https://www.aljazeera.com/news/2022/6/16/s-africa-minister-suggests-foreigners-to-blame-for-no-jobs.

18. K. S. Tarisayi and S. Manik, "An Unabating Challenge: Media Portrayal of Xenophobia in South Africa," *Cogent Arts and Humanities* 7/1 (2020).

19. Ibid.

20. S. O'Malley, D. Parkinson, W. Leonard, et al., "Issues Paper: Gender Justice in Disaster Conference 2021," *Australian Journal of Emergency Management* (2021), https://knowledge.aidr.org.au/resources/ajem-january-2022-issues-paper-gender-justice-in-disaster-conference-2021/.

21. See South African Corona Virus Online Portal,

https://sacoronavirus.co.za/covid-19-daily-cases/.

22. R. Warah, "COVID-19 Has Exposed South Africa's Glaring and Enduring Inequalities," *One* (August 2, 2021), https://www.one.org/africa/stories/covid19-exposed-south-africa-inequalities/.

23. E. Hove, "Twitter and the Politics of Representation in South Africa and Zimbabwe's Xenophobic Narratives During the COVID-19 Pandemic," *Acta Academica* 54/2 (2022).

24. S. 27 Disaster Management Act, 2002 (Act No. 57 of 2002).

25. M. Nyashanu, P. Simbanegavi, and L. Gibson, "Exploring the Impact of COVID-19 Pandemic Lockdown on Informal Settlements in Tshwane Gauteng Province, South Africa," *Global Public Health* 15/10 (2020).

26. Ibid.

27. *De Beer N.O and Others v Minister of Cooperative Governance and Traditional Affairs* (21542/2020) [2021] ZAGPPHC 67.

28. S. Xun and S. L. Gilman, *I Know Who Caused COVID-19: Pandemics and Xenophobia* (London: Reaktion Books, 2021).

29. Global Commission on HIV and the Law, *Risks, Health and Rights: Supplement* (Global Commission on HIV and the Law, 2018); C. Staunton, C. Swanepoel, and M. Labuschaigne, "Between a Rock and a Hard Place: COVID-19 and South Africa's Response," *Journal of Law and the Biosciences* 7/1 (2020).

30. Staunton et al. (see note 29).

31. S. Cooper, H. van Rooyen, and C. S. Wiysonge, "COVID-19 Vaccine Hesitancy in South Africa: How Can We Maximise Uptake of COVID-19 Vaccines?," *Expert Review of Vaccines* 20/8 (2021).

32. J. Klaaren and B. Ray, "South Africa's Technologies Enhancing Contact Tracing for COVID-19: A Human Rights and Techno-Politics Assessment," *South African Journal on Human Rights* 37/4 (2021).

33. See the judgment of J. O'Regan of the South African Constitutional Court in *Mazibuko and Others v. City of Johannesburg and Others* (CCT 39/2009).

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COMMENTARY

Freedom Dreaming: On "Emerging Frameworks of Health and Human Rights"

TLALENG MOFOKENG

Lynn P. Freedman conceptualized human rights as being rooted in a rejection of the imposition of the will of any one person or group over another. In her paper "Reflections on Emerging Frameworks of Health and Human Rights," published in this journal 30 years ago, she connects health and human rights by viewing both through the lens of advocacy—an activity she views as inherently subversive in how it requires the active challenging of sociopolitical norms that both produce and sustain ill health.[1]

Advocacy is a core component of the work of human rights activists, but what role does advocacy play in the fields of public health and medicine? How do we do the work of dismantling the systems of power that continue to protect the rights of some at the expense of others?

The reproductive justice movement has grown significantly in the three decades since Freedman's article was published. Reproductive justice understands that individual autonomy is in reality not determined by individual predisposition; therefore, the reproductive justice movement seeks to center the experiences of people who have been pushed to the margins and to uncover and dismantle the systems and structures that inhibit and prohibit access to the conditions necessary for equal opportunity to a life of dignity in relation to sexual and reproductive rights.

Key to the foundational framework of the reproductive justice movement is the idea of intersectionality—a demand for continuous analysis of the power asymmetries that produce certain conditions of privilege and systemic exclusion. Factors such as racism, ethnic and caste systems, marital status, migration status, socioeconomic status, sexual orientation, and gender identity and expression are examples of how one's locality determines who is seen as credible and entitled to pronounce on matters such as fertility control, access to contraception, abortion care, and the right to make decisions about one's own body. The freedoms and entitlements as defined under the right to health embrace autonomy as a central principle. However, far too often, state power is executed in ways that erase international human rights laws and accountability mechanisms both within countries and through foreign policy when states provide health aid.

Tlaleng Mofokeng, MD, is the United Nations Special Rapporteur on the right to health and a member of the *Health and Human Rights* Executive Editorial Committee.

Please address correspondence to the author. Email: drtpmofokeng@gmail.com.

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These realities play out in subnational, national, and international economic and political theaters, with powerful actors such as elite philanthro-capitalists—each with different priority areas—often not speaking to the reality of the people they seek to help.

The emboldened rise of those who oppose the human right to autonomy—the so-called pro-life movement—has resulted in constant assaults on reproductive rights, such as, in the United States, the withdrawal of funding for nonprofits that provide reproductive health care, the "heartbeat" abortion ban, and the mifepristone case. But perhaps the greatest retrogression to the reproductive justice movement yet has been the political environment that enabled the overturning of *Roe v. Wade* in the 2022 *Dobbs v. Jackson Women's Health Organization* decision. These actions are a form of structural violence, as they are enforced and endorsed by the state through the courts and have a disproportionate impact on people from certain races and income levels.

Freedman, 30 years ago, saw the goal of the reproductive rights movement to be to change "whose point of view, whose values, whose experience, [and] whose choices" control reproduction, viewing the battleground of reproduction as a tool of political projects and a weapon of the war of identity politics. Nowhere is this more obvious than in the decades-long crusade to overturn *Roe v. Wade*.

Access to safe and legal abortion is essential not only for approaching gender equality but for erasing racial and ethnic inequities. Restrictions on abortion lead to preventable mortality and morbidity, particularly among those who lack access to quality health care. The *Dobbs* decision disproportionately harms poor, non-white women and non-binary individuals.[2] It also sets a dangerous precedent for human rights protections, signaling a regression in the recognition of fundamental rights and freedoms, and emboldens efforts to erode protections for people pushed to the margins, including LGBTQ+ people, people with disabilities, and racially minoritized groups. In the wake of *Dobbs*, other cases have followed that have pointed to the sociopolitical stakes of major policy actors. In the US state of Alabama, for example, the state supreme court ruled that embryos can be considered people under the law, kicking up a national debate about the ruling's implications for fertility treatments such as in vitro fertilization.[3] This has left many representatives of the conservative right scrambling to find a way to protect the in vitro fertilization procedure, one that has historically been accessed by those of financial means.[4] This necessitates an interrogation of whose rights are being prioritized over whose, and of the ways in which reproduction continues to be a political battleground.

Joseph Amon, in his editorial for the December 2023 issue of *Health and Human Rights*, writes that "certain rights are emphasized while others are ignored or even denied."[5] This is evident not only in the arena of reproductive rights but more broadly in the context of ongoing human rights violations in international conflicts. The conflict between Israel and Palestine is a key example and has had long-lasting implications for human rights. The ongoing fighting in Gaza has drawn international concern due not only to the direct violence being inflicted on innocent civilians but to the severe restrictions on the movement of people and goods. Food, water, and shelter have all been made inaccessible, as have essential services such as schools and medical establishments, violating the most basic human rights, including the right to life, the right to freedom of movement, the right to adequate housing, the right to health, the right to education, and the right to work.

The health care system in Gaza also faces significant challenges, having reached crisis shortages of supplies and personnel. Such violence can be understood only in the framework of the uneven application of human rights. Again, whose rights matter? Discourse about Palestinians has historically treated Palestinians as almost subhuman or even non-human, effectively making the human rights paradigm inapplicable to them. This stripping of Palestinian human rights happens not only in discourse but in state-sanctioned and state-sponsored violence. This prompts us as people in the health and medical fields to ask ourselves, What systems and structures do we have to act, meaningfully, as a field? The international community as a whole, including nation-states and civil society organizations, must work together to uphold international humanitarian law and human rights standards and to alleviate the suffering of innocent civilians in Gaza.

South Africa offers us an opportunity to learn from the violence on autonomy in the context of an apartheid regime and efforts toward resolution after its dissolution. Apartheid, the institutionalized regime of racial segregation and discrimination that lasted from 1948 to 1994, remains one of the most egregious violations of human rights in modern history. Founded on the ideology of white supremacy, apartheid systematically dehumanized Black South Africans and enforced harsh racial segregation laws, institutionalizing discrimination in all aspects of life, including housing, education, health care, employment, and public amenities. The apartheid state sponsored the forced removal of millions of Black South Africans from their homes and communities and implemented a series of laws, such as the Group Areas Act and the Native Land Act, aimed at forcibly relocating them to designated areas known as "homelands" or "townships," which made up only 13% of the country's land yet housed 80% of its population.[6] These forced removals resulted in the destruction of vibrant communities, the loss of livelihoods, and the dispossession of ancestral lands, perpetuating lasting cycles of poverty and marginalization.

Pass laws and the Suppression of Communism Act sought to control Black South Africans' movement and activities by requiring them to carry identification documents—known as "passes"—at all times, violating their right to freedom of movement. These South Africans were not allowed to participate in the country's political life, and they were prohibited from performing mass gatherings. Brutal tactics, including arbitrary arrests, torture, and extrajudicial killings, were used to suppress dissent and maintain the status quo. Although apartheid officially ended in 1994, its legacy continues to reverberate in the sociopolitical fabric of the country, and we can learn from South Africa's efforts at justice and redress.

The country's Truth and Reconciliation Commission (TRC), established in 1995, was built to gather evidence and uncover information from both victims and perpetrators, rather than prosecuting individuals for past crimes. The TRC faced a number of challenges, including a lack of political support among all parties to the conflict, and noncooperation from the highest level of military command. In addition, the TRC's key weakness was its failure to examine the policies and political economy of apartheid. Therefore, the impact of Apartheid's policies was not sufficiently examined. Perpetrators, or the "trigger pullers," were the focal point of accountability efforts, while those who benefited from apartheid evaded responsibility through the TRC's efforts.

In a world where justice evades and multiple crises continue to rage, we are reminded that the slogan "leave no one behind" rings hollow for millions around the world. These millions of people who suffered from colonialism and racism are still reeling under the crushing weight of what is their daily lives, and they have a right to remedies and reparations.

In the context of a global system of governance predicated on deeply unequal hierarchies, the importance of human life has been based on a person's race, gender, sexuality, ability, religion, age, and wealth, to name a few. In fulfilling my mandate as United Nations Special Rapporteur on the right to health, I use an anti-racist, anti-colonial analysis and employ intersectional frameworks to advocate for substantive equality to achieve health equity and the highest attainable standard of the enjoyment of the right to physical and mental health for all.

Inspired by Lynn P. Freedman in my work as a medical doctor, I see clearly the intersection of medicine and law, viewing my practice of medicine in itself as a way of defending the human rights of those affected by structural inequalities and those experiencing intersectional and multiple forms of discrimination.

I believe that intersectionality is the bridge to justice. We are not inherently vulnerable—situations of injustice are what make us vulnerable. To correct that, we have to be committed to ending the systems of oppression that create those situations. This can be done only through an unwavering commitment to social justice, reproductive justice, economic justice, and racial justice. And the tools we have to get to justice are human rights.

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References

1. L. P. Freedman, "Reflections on Emerging Frameworks of Health and Human Rights," *Health and Human Rights Journal* 1/4 (1995).

2. Global Justice Center, *Pregnancy Justice, Human Rights Watch, et al., Human Rights Crisis: Abortion in the United States after Dobbs* (2023).

3. J. Sharfstein, "The Alabama Supreme Court's Ruling on Frozen Embryos," Johns Hopkins Bloomberg School of Public Health (February 27, 2024), https://publichealth.jhu.edu/2024/the-alabama-supreme-courts-ruling-on-frozen-embryos.

4. I. Galic, O. Negris, C. Warren, et al., "Disparities in Access to Fertility Care: Who's In and Who's Out," *F&S Reports* 2/1 (2021).

5. J. J. Amon, "Realizing the Right to Health: A Long and Winding Road," *Health and Human Rights Journal* 25/2 (2023).

6. S. Rugege, "Land Reform in South Africa: An Overview," *International Journal of Legal Information* 32/2 (2004).

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Interpreting International Humanitarian Law to Guarantee Abortion and Other Sexual and Reproductive Health Services in Armed Conflict

CHRISTINA ZAMPAS, REBECCA BROWN, AND ONYEMA AFULUKWE

Abstract

The provision of basic sexual and reproductive health services in humanitarian settings, including armed conflict, is extremely limited, causing preventable mortalities and morbidities and violating human rights. Over 50% of all maternal deaths occur in humanitarian and fragile settings. International humanitarian law falls short in guaranteeing access to the full range of sexual and reproductive health information and services for all persons. Guaranteeing access to sexual and reproductive health services under international humanitarian law can increase access to services, improving the health and well-being of civilians in conflict zones. This paper sets forth ways in which international human rights law on sexual and reproductive health and rights should be incorporated into the forthcoming International Committee of the Red Cross Commentary on Geneva Convention IV, regarding the protection of civilians, to ensure services in the context of armed conflict.

Christina Zampas, JD, is a fellow at the International Reproductive and Sexual Health Law Program, Faculty of Law, University of Toronto, Canada.

Rebecca Brown, JD, is senior regional director of global advocacy at the Center for Reproductive Rights, New York, United States.

Onyema Afulukwe, LLB, LLM, is associate director for new initiatives and business development at the Center for Reproductive Rights, New York, United States.

Please address correspondence to Christina Zampas. Email: christina@zampas.org.

Competing interests: None declared.

Introduction

In the 1950s and 1960s, the International Committee of the Red Cross (ICRC) published a set of commentaries on the Geneva Conventions, giving practical guidance to support these treaties' implementation. These commentaries are considered a definitive source of interpretation of obligations under the Geneva Conventions. In 2011, the ICRC and a team of experts embarked on an effort to update the commentaries to reflect recent developments in law and practice and, hence, new interpretations of the conventions.[1] Currently, the ICRC has commissioned a Commentary on Geneva Convention IV, which covers the protection of civilians.

It is important to recall that customary international humanitarian law (IHL) provides that "the specific protection, health and assistance needs of women affected by armed conflict must be respected."[2] In order to achieve this and customary IHL's own recognition that it should be viewed in light of the "prominent place of women's rights in human rights law," the forthcoming Commentary on Geneva Convention IV must go further in applying the long-standing international human rights law (IHRL) protections in the area of sexual and reproductive health and rights without discrimination.[3] It is insufficient merely to recognize that the Geneva Conventions are outdated without more robustly tackling the health needs of persons long discriminated against and ignored, as well as the gendered biases that are embedded in IHL.

Updated commentaries on other Geneva Conventions reflect, to some degree, the progressive changes that have taken place in recent decades under domestic law and IHRL and in practice with regard to women and persons of diverse sexual orientation, gender identity and expression, and sex characteristics. However, the history of the subordination of these populations under international law requires continued commitment and vigilance to ensure a contemporary interpretation in IHL that incorporates continued developments in IHRL and domestic law, including in the area of sexual and reproductive health and rights.[4]

This paper begins with a brief overview of the factors that hinder access to sexual and reproductive health (SRH) services in humanitarian settings, including in armed conflict. We then explore how IHL provisions ensuring humane treatment and guaranteeing no adverse distinction should be read consistently with IHRL obligations on the right to be free from torture, cruel, and inhuman and degrading treatment and the right to nondiscrimination, respectively, in the area of sexual and reproductive health and rights. Next, we provide examples of how articles 16 and 27 in Geneva Convention IV, as well as common article 3, could be interpreted to include SRH services more comprehensively. Finally, we argue that the forthcoming commentary should interpret relevant provisions of Geneva Convention IV in line with developments in state practice on laws on abortion.

Background

The United Nations (UN) Office for the Coordination of Humanitarian Affairs has estimated that nearly 300 million people will need humanitarian assistance and protection in 2024, with more people being forcibly displaced now than at any other time since the beginning of this century.[5] Conflict, climate crisis, and economic factors are the main drivers of these emergency situations.[6] UNFPA emphasizes that during conflicts and emergencies, SRH needs are often unmet, with grave consequences.[7] Lack of access to delivery and emergency obstetric care poses life-threatening complications for those who are pregnant.[8] Loss of access to contraceptives exacerbates unintended pregnancy in already perilous conditions.[9] Women and girls continue to remain at increased risk of sexual violence, exploitation, and HIV infection, with all the mental, physical and social consequences.[10] Conflict settings have demonstrated consistently higher maternal mortality rates than non-conflict settings, as well as lower access to reproductive and maternal health services for marginalized populations, including poor, less educated, and rural populations.[11]

International and regional human rights law on torture and on nondiscrimination support more robust considerations of sexual and reproductive health and rights in IHL

Alongside IHL, IHRL applies during armed conflict.[12] Customary IHL recognizes that IHRL instruments, documents, and case law support, strengthen, and clarify analogous principles of IHL.[13]

Two sets of rights and principles where IHRL has been expressly used to clarify IHL—and which are important for ensuring greater access to SRH services—are (1) the right to be free from torture and other ill treatment (as enshrined in IHLR) and the principle of humane treatment (as enshrined in IHL); and (2) the right to nondiscrimination (as enshrined in IHRL) and the principle of no adverse distinction (as enshrined in IHL).

IHRL's right to be free from inhuman and degrading treatment in the area of sexual and reproductive health and rights should be reflected in IHL's obligation of humane treatment

Humane treatment is considered a norm of customary international law from which there can be no derogation.[14] It requires that all non-combatants, including civilians and the sick and wounded, be treated humanely in all circumstances and with respect for their person and honor, without any adverse distinction based on sex or other similar criterion.[15]

Customary IHL notes that "the detailed rules found in international humanitarian law and human rights law give expression to the meaning of 'humane treatment'" and that "this notion develops over time under the influence of changes in society."[16] These "changes in society" are reflected in the ICRC's 2016 and 2020 updated Commentaries on Geneva Conventions I and III, respectively, which note that "sensitivity to the individual's inherent status, capacities and needs, including how these differ among men and women due to social, economic, cultural and political structures in society, contributes to the understanding of humane treatment under Common Article 3."[17] In the commentaries, the ICRC helpfully references numerous health and sexual and reproductive rights issues—including involuntary sterilization and "gender-based humiliation such as shackling women detainees during childbirth"—as examples of violations of common article 3 that human rights bodies have found to violate IHRL's right to freedom from torture and other ill treatment.[18]

While these examples are important to include, the obligation of humane treatment under IHL should more robustly encompass the range of SRH services that are protected under the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment under IHRL.[19] While it is important not to create a framework of humane treatment that risks being narrow and inflexible, and thus incapable of responding to circumstances that arise in the contemporary world, the 2020 Commentary on Geneva Convention III's article 3 recognizes that some guidance is needed—otherwise, there is too much discretion that could lead to interpretations incompatible with ensuring humane treatment.[20] Providing examples in the forthcoming commentary on Geneva Convention IV that reflect long-standing protections of IHRL on access to SRH services, such as abortion, emergency contraception, and emergency obstetric care, would be critical to closing this gap.[21]

UN treaty bodies and Special Procedures. Over the past two decades, authoritative regional and UN treaty body and Special Procedure mandate holders have articulated the lack or denial of SRH services as violations of the right to be free from torture and cruel, inhuman, and degrading treatment.

The Committee against Torture, which monitors state compliance with the Convention against Torture, recognizes that "the contexts in which females are at risk [of torture or ill treatment and the consequences thereof] include … medical treatment, particularly involving reproductive decisions."[22]

For example, the committee has long found that denying or delaying safe abortion or post-abortion care may amount to torture or cruel, inhuman, or degrading treatment.[23] It has long expressed concern over complete bans on abortion and other restrictive abortion laws and practices, recognizing that they may constitute violations of articles 2 and 16 of the convention.[24] It has consistently found that the denial or delay of post-abortion care can violate obligations under the convention and has recommended ensuring access to post-abortion care, regardless of the law.[25]

The committee has also recognized how the denial of relevant services for survivors of sexual violence, including emergency contraception and abortion, exposes them to ongoing violations.[26]

Similarly, the Human Rights Committee, which monitors state compliance with the International Covenant on Civil and Political Rights, in the first-ever case on denial of access to abortion in the UN treaty body system and in every single subsequent case thereafter, has found that denial of abortion, regardless of its legal status, constitutes physical and mental suffering amounting to a violation of article 7.[27]

The committee reinforces this interpretation in its General Comment 36 on the right to life.[28]

Most recently, the Committee on the Rights of the Child, which monitors state compliance with the most widely ratified human rights treaty—the Convention on the Rights of the Child—in its first-ever decision related to the denial of abortion to a minor, found a violation of cruel, inhuman, and degrading treatment.[29]

The African, European, and inter-American human rights systems have also considered that the denial or delay of abortion and other SRH services is a violation of the right to be free from torture and other ill treatment under their respective treaties.[30]

The UN Special Rapporteur on torture has noted that "international human rights law increasingly recognizes that abuse and mistreatment of women seeking reproductive health services cause tremendous and lasting physical and emotional suffering," which can constitute cruel and degrading treatment.[31]

In September 2021, seven Special Procedure mandate holders, including the Special Rapporteur on torture, filed an amicus brief with the US Supreme Court in an abortion case that eventually overturned 50 years of abortion protection under the US Constitution. In this brief, they argued that IHRL protects abortion access and that prohibitions on such access breach numerous international human rights, including the right to be free from torture and cruel, inhuman, or degrading treatment, and asked the court to uphold existing constitutional protections on abortion and refuse the retrogression of rights.[32]

IHL's prohibition of adverse distinction should be interpreted consistently with IHRL's right to nondiscrimination

The prohibition of adverse distinction is found throughout the Geneva Conventions.[33] IHL's approach to the prohibition of adverse distinction is similar to IHRL's approach to the prohibition of discrimination.[34] State practice establishes this rule as a norm of customary international law.[35]

The ICRC's 2016 Commentary on Geneva Convention I notes that "sex is traditionally recognized as justifying, and in fact requiring, differential treatment."[36] It recognizes:

> *Grounds for non-adverse distinction could also be found in an awareness of how the social, economic, cultural or political context in a society forms roles or patterns with specific statuses, needs and capacities that differ among men and women of different ages and backgrounds. Taking such considerations into account is no violation of the prohibition of adverse distinction, but rather contributes to the realization of humane treatment of all persons protected under common Article 3.*[37]

This is an important recognition, particularly in the area of sexual and reproductive health and rights, given that many of the challenges concerning the availability and accessibility of SRH information and services exist because of discrimination on grounds of sex, gender, and sexual orientation, as well as related harmful gender stereotypes.

The fact that the IHL principle of no adverse distinction is similar to the human rights principle of nondiscrimination suggests that IHRL should provide guidance as to how this principle should be interpreted, including in the context of SRH services.[38]

State obligations on nondiscrimination under IHRL require ensuring access to SRH services. Fulfilling the right to nondiscrimination requires ensuring access to sexual and reproductive health care. UN treaty bodies have repeatedly articulated that the failure to provide such services, including contraception and abortion, is a form of discrimination against women.[39] As early as 1999, the Committee on the Elimination of Discrimination against Women (CEDAW Committee) articulated that "it is discriminatory for a State party to refuse to provide legally for the performance of certain reproductive health services for women."[40]

A year later, the Human Rights Committee also addressed restrictions on access to reproductive health services as forms of discrimination and inequality, including during armed conflict.[41] For over 25 years, these and other human rights bodies have consistently articulated that the lack of access to or the denial of SRH services constitutes discrimination against women, perpetuates harmful gender stereotypes, and violates a range of other human rights.[42] With regard to abortion, human rights treaty bodies have articulated that the denial of access to abortion and restrictive abortion laws can violate the right to nondiscrimination.[43] For example, the CEDAW Committee, in a special inquiry, found that abortion restrictions in Northern Ireland constituted discrimination because they affected only women, were a form of gender-based violence in violation of the convention, and "affront[ed] women's freedom of choice and autonomy, and their right to self-determination."[44]

IHRL also requires states to eliminate multiple and intersectional discrimination, including in the area of sexual and reproductive health and rights.[45]

Discrimination in access to SRH services in armed conflict. IHRL has specifically recognized that the right to nondiscrimination in relation to SRH services applies in armed conflict. The CEDAW Committee notes that during armed conflict or states of emergency, states should not suspend rights protections but rather "adopt strategies and take measures addressed to the particular needs of women."[46] It specifically recommends access to, among other things, sexual and reproductive health and rights information; psychosocial support; family planning services, including emergency contraception; maternal health services, including antenatal care, skilled delivery services, and prevention of vertical transmission and emergency obstetric care; safe abortion services; post-abortion care; prevention and treatment of HIV/AIDS and other sexually transmitted infections, including post-exposure prophylaxis; and care to treat injuries such as fistula arising from sexual violence, complications of delivery, and other reproductive health complications.[47] It is important to note that the CEDAW Committee's guidance does not condition the provision of safe abortion services to circumstances in which abortion services are legal.

Addressing gender stereotypes in IHL and improving access to SRH services

IHL falls short in protecting access to the full range of SRH information and services for all persons, including survivors of sexual and gender-based violence, despite the fact that IHL expressly recognizes that women face specific needs in armed conflict.[48]

Treatment of women under the Geneva Conventions. The obligation that "women shall be treated with all consideration due to their sex" can be found throughout the Geneva Conventions.[49] The 1960 Commentary on Geneva Convention III sets forth three considerations to be taken into account when applying this provision: women's "weakness," their "honour and modesty," and their role in "pregnancy and child-birth."[50] Although this concept is referring to women prisoners of war, it captures the stereotypes and normative bias against women and persons of diverse sexual orientation, gender identity and expression, and sex characteristics that are reflected throughout the Geneva Conventions. For example, article 16 of Geneva Convention IV covers treatment of the "wounded and sick" and "other persons who may be in need of immediate medical assistance or care, such as . . . *expectant mothers*," and article 27 sets forth specific protections for women, stressing that "women shall especially be protected against any attack on their honour."[51]

Although there has been progress in expanding the definition of rape in international law, IHL's formulation of rape as an attack against women's honor and its focus on women who are pregnant fails to view women as independent rights holders with the rights to autonomy and bodily integrity.[52] As one scholar notes:

> *Patriarchal societies generally attach a preeminent value to women's chastity and reproductive capacity, seeing women's reproduction as a way of guaranteeing the survival of both community and culture. A woman who is sexually violated, impregnated by enemies, or kidnapped into sexual and domestic enslavement is therefore often regarded as "disgracing family honor, being unclean or contaminated, [or] being a seductress."*[53]

It is widely accepted that international law has established and reinforced harmful stereotyped roles of women as mothers or as pregnant.[54] In fact, 9 out of the 19 provisions in the four Geneva Conventions referring to women refer to them as pregnant or mothers of small children.[55] While resulting protections, including related health care guarantees, are crucial, the root of many barriers to comprehensive sexual and reproductive health care lies in harmful gender stereotypes that see women's primary roles as mother, child bearer, and caregiver and that perpetuate binary norms in the provision of SRH services.[56]

Gender stereotypes

All UN treaty bodies have attempted to address these harmful stereotypes by recognizing them as discriminatory and in need of reform.[57] Article 5 of CEDAW creates express obligations to address harmful stereotypes and their underlying causes.[58] The CEDAW Committee, and other treaty bodies, has recognized the negative impact that harmful stereotypes have on access to SRH services specifically, noting that patriarchal attitudes and stereotypes about women as mothers and caregivers, prejudices about SRH services, and taboos about sexuality outside of marriage all contribute to the lack of access to reproductive health information, goods, and services.[59] In *L.C. v. Peru*, the committee affirmed that restrictions on access to abortion embed a harmful stereotype that "understands the exercise of a woman's reproductive capacity as a duty rather than a right."[60] The Committee against Torture acknowledges that non-conformity with gender stereotypes plays a central role in "the ways that women and girls are subject to or at risk of torture or ill-treatment and the consequences thereof" and "may be subject to violations of the Convention on the basis of their actual or perceived non-conformity with socially determined gender roles."[61] The International Covenant on Civil and Political Rights, under its nondiscrimination and equality provisions, also requires states to address gender stereotyping.[62]

More recent ICRC commentaries shift away from the harmful stereotypes found in the Geneva Conventions and earlier commentaries.[63] For example, the 2020 Commentary on Geneva Convention III, in explaining the meaning and obligations related to article 14(2)'s statement that "women shall be treated with all regard due to their sex," notes that it

> *is not to be understood as implying that women have less resilience, agency or capacity within the armed forces, but rather as an acknowledgement that women have a distinct set of needs and may face particular physical and psychological risks.*[64]

The ICRC commentaries from 2016 and 2020 note social and international legal developments under IHRL on nondiscrimination and equality, citing to the International Covenant on Civil and Political Rights and the Convention on the Elimination of All Forms of Discrimination against Women.[65]

Medical care

The updated Commentaries on Geneva Conventions I and III have also begun articulating better, albeit still limited, recognition of the comprehensive reproductive health care needed in armed conflict under articles related to medical care.

ICRC Commentaries on Geneva Convention I (article 12, protection and care of the wounded and sick) and Geneva Convention III (article 16, equality of treatment of prisoners) provide for an intersectional and substantive equality approach to the provision of health care.[66] For example, the 2020 Commentary on Geneva Convention III notes, "To ensure equal treatment of women, they must be treated with all due regard to their sex. This means that in terms of medical care, for example, female prisoners may require access to ante- and postnatal care and gynaecological and reproductive health care."[67]

Importantly, the updated commentaries expand protection beyond maternal health care to include "gynecological and reproductive health."[68] They also require that military medical services include a "range of expertise and skills" to care for "both male and female patients."[69] Moreover, they require that parties to a conflict plan and analyze the various types of health care that are needed by considering power structures and their impact, specifically

> *how the roles and patterns formed by the social, economic, cultural or political context and resulting in different statuses, needs and capacities among women and men of different ages and backgrounds could hamper the safe access to care of any one group. This may include a reluctance to seek or receive medical care, possibly owing to discrimination or a stigma of being wounded or sick. Knowledge of how social structures influence the situation should be taken into account in order to ensure that health care is fully accessible to both women and men and minimizes the risks of any group being subject to discrimination, lack of respect, harm or danger before, during or after the care.*[70]

The 2020 Commentary on Geneva Convention III's article 14 specifically recognizes the gender-specific physical, mental, and psychosocial effects of sexual violence against women, including medical complications during pregnancy and stigma.[71] It requires that "the Detaining Power take proactive measures to prevent such incidents from occurring and to ensure that women who are victims of sexual violence have access to appropriate, gender-specific health care."[72]

The widespread use of rape as a weapon of war has also raised issues concerning what types of medical treatment and care must be provided to survivors of rape, in particular whether there is an obligation to provide abortion services under IHL.[73] The Oxford University Press commentary on the Geneva Conventions notes that these instruments "do not prevent the interpretation of the notion of 'medical care' as including abortion."[74] The ICRC commentaries indicate that medical services should be equipped to handle "women's gynaecological and reproductive health issues," without noting limitations.[75]

In addition, the 2020 Commentary on Geneva Convention III's article 30, which concerns medical attention, notes that "an infirmary's lack of medical capacity may not be used as a blanket justification for being unable to address the specific needs of women prisoners."[76] This implies that it is discriminatory to deny women health care that is needed only by them, in line with the Convention on the Elimination of All Forms of Discrimination against Women and other IHRL treaty obligations.[77]

The commentary continues:

> *In all cases, the provision of medical care must comply with the applicable standards of medical ethics … respect for the autonomy and agency of prisoners of war with regard to their voluntary and informed consent—or refusal—to undergo any medical procedure; respect for medical confidentiality … and the prohibition on engaging—actively or passively—in acts that may amount to torture or other cruel, inhuman or degrading treatment or punishment.*[78]

UN agency guidance

The World Health Organization, UNFPA, and the Office of the United Nations High Commissioner for Human Rights have consistently called for stakeholders to address the dire situation regarding the lack of access to SRH services in humanitarian settings, including in armed conflict.[79] For example, they support the implementation of the Minimum Initial Service Package for SRH in crisis situations, which sets forth specific services that should be provided to address the overlooked SRH needs of affected populations, the absence of which have potentially life-threatening consequences.[80] This package is the most widely applied technical standard for the provision of SRH services in humanitarian settings.[81]

The overwhelming progressive state practice on abortion and World Health Organization guidance

Laws are an important indicator of state practice for consideration in the development of IHL.[82] This section provides an analysis of abortion laws from around the world and of trends in abortion law reform.[83]

There is an overwhelming global trend toward the greater liberalization of abortion laws and increased access to abortion. Fifty-nine countries have liberalized their abortion laws to expand the grounds for legal abortion since the 1994 International Conference on Population and Development, while only four countries have made their laws more restrictive by removing legal grounds for abortion during this time.[84] There is geographic diversity in abortion law reform, notably with nearly half the countries that have liberalized their laws located in Africa.[85] In addition, many countries have also implemented policy and programmatic measures to improve access to safe abortion services.[86]

Liberal reforms are propelled by various factors, including evidence showing that the rate of mortality and morbidity due to unsafe abortion is greatest in countries with restrictive laws and that restrictions do not reduce the number of abortions, only their safety.[87] Moreover, a gender-sensitive understanding of equality and nondiscrimination has been at the center of many of these national developments. Since 2000, at least 20 constitutional courts have issued decisions on the legality of abortion, with six courts upholding laws guaranteeing access to abortion, ten courts deciding that restrictive criminal laws on abortion in whole or in part are unconstitutional, and only four courts deciding that restrictive laws can be or are constitutional.[88]

A few years ago, the European Commission, France, the Netherlands, and the United Kingdom addressed the specific issue of abortion access for rape survivors in statements recognizing that IHL entails an obligation to provide abortion services to rape survivors in armed conflict situations, regardless of national laws.[89]

It is important to note that most countries (about 140 in total) allow abortion in relation to rape and incest. This includes countries whose laws permit abortion by specifically enumerating these grounds; permit abortion on request, without restriction as to reason; permit abortion on broad socioeconomic grounds; and permit abortion on express mental health grounds, in which rape is not an enumerated ground but could be included.[90]

State practice, as illustrated through national-level laws and regulations, however, has for decades been moving away from a grounds-based approach that provides exceptions to criminalization on the grounds of health, life, rape, or severe fetal impairment.[91] Such grounds-based laws have proven ineffective in ensuring access to abortion, even on the grounds permitted under the law.[92] Evidence also shows that grounds-based laws contribute to delays in and denials of abortion, which in turn contributes to unsafe abortion.[93] For these reasons, the World Health Organization recommends, in newly released guidance on abortion, the full decriminalization of abortion and the reform of restrictive laws, including grounds-based laws.[94] Currently, 75 countries allow abortion on request without restriction as to reason, and 13 countries allow it on broad socioeconomic grounds.[95]

Conclusion

The ICRC commentaries are important sources of law that can clarify obligations to protect persons from the effects of armed conflict. By addressing in greater detail the range of SRH services needed by all civilians and the barriers to access that persons face—two areas of IHL that are often overlooked—the forthcoming commentary on Geneva Convention IV can ensure that long-standing and ongoing guidance and obligations under IHRL and regional human rights law find their due place in IHL.

IHL protections on the rule of "no adverse distinction" and in the protection of "humane treatment" should be interpreted consistently with analogous IHRL protections on the right to be free from discrimination and the right to be free from torture and other cruel, inhuman, and degrading treatment or punishment in the context of sexual and reproductive health care. While IHL has long recognized this relationship between the bodies of law, it has to date failed to specifically recognize it in the context of SRH services, despite long-standing IHRL standards in this area.

In addition, while the current commentaries have taken important steps toward addressing some of the gender stereotypes embedded in the Geneva Conventions, the future commentary on Geneva Convention IV can go further by applying this development to the SRH needs of all civilians, not just survivors of violence or pregnant women, and by addressing barriers to health care, including stereotypes.

Abortion care is mentioned only once in the current commentaries—and even then, only in a footnote discussing health care related to sexual violence.[96] While this acknowledgment is an important step, it falls short of what is needed given the dire situation facing persons requiring SRH services in armed conflict and the significant developments under IHRL and new World Health Organization guidelines in this area, which require states to ensure access to emergency contraception and broad access to abortion for all persons, including survivors of rape.[97] Developments in state practice, through progressive law reform on abortion in every region of the world, support this inclusion.

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References

1. International Committee of the Red Cross (ICRC), "Updated Commentary Brings Fresh Insights on Continued Relevance of Geneva Conventions for Treatment of Prisoners of War" (2020), https://www.icrc.org/en/document/updated-commentary-third-geneva-convention.

2. ICRC, "Customary IHL Database," rule 134, https://ihl-databases.icrc.org/en/customary-ihl.

3. Vienna Convention on the Law of Treaties, 1155 UNTS 311 (1969), art. 31(3)(c); ICRC, "Customary IHL Database" (see note 2); Human Rights Committee, General Comment No. 31, UN Doc. CCPR/C/21/Rev.1/Add.13 (2004), para. 7.

4. A. Crowe, "All the Regard Due to Their Sex: Women in the Geneva Conventions of 1949," Harvard Research Working Paper Series (2016), https://hrp.law.harvard.edu/wp-content/uploads/2016/12/Anna-Crowe_HRP-16_001.pdf; H. Charlesworth and C. Chinkin, *The Boundaries of International Law: A Feminist Analysis* (Manchester: Manchester University Press, 2000); see also N. Quenivet, "A (Wo)Man's Honour: Have the Geneva Conventions Lost Their Gender?" (presented at Seminar to Mark 70 Years of the Geneva Conventions, Maynooth University, Ireland, April 8, 2019), https://uwe-repository.worktribe.com/output/848973.

5. United Nations Office for the Coordination of Humanitarian Affairs, *Global Humanitarian Overview 2024* (New York: Office for the Coordination of Humanitarian Affairs, 2023), p. 5.

6. Ibid. pp. 5, 6.

7. UNFPA, *Humanitarian Action 2023 Overview* (New York: UNFPA, 2022), p. 3; UNFPA, "Humanitarian Emergencies," https://www.unfpa.org/emergencies#readmore-expand.

8. UNFPA, "Humanitarian Emergencies" (see note 7); S. Elnakib, M. Fair, E. Mayrhofer, et al., "Pregnant Women in Gaza Require Urgent Protection," *Lancet* 403/10423 (2024); *Alyne da Silva Pimentel Teixeira v. Brazil*, Committee on the Elimination of Discrimination against Women (CEDAW Committee), August 10, 2011, case no. 17/2008, paras. 7.6–7.7.

9. UNFPA, "Humanitarian Emergencies" (see note 7).

10. United Nations Security Council, Women and Girls Who Become Pregnant as a Result of Sexual Violence in Conflict and Children Born of Sexual Violence in Conflict: Report of the Secretary-General, UN Doc. S/2022/77 (2022), paras. 9, 11, 13; UNFPA, *Humanitarian Action* (see note 7), p. 3; ICRC, *ICRC Special Appeal 2021: Addressing Sexual Violence* (Geneva: ICRC, 2021), pp. 9–10; World Health Organization, "Gender-Based Violence in Health Emergencies," https://healthcluster.who.int/our-work/thematic-collaborations/

gender-based-violence-in-health-emergencies.

11. N. Akseer, J. Wright, H. Tasic, et. al., "Women, Children and Adolescents in Conflict Countries: An Assessment of Inequalities in Intervention Coverage and Survival," *BMJ Global Health* 5 (2020), p. 1; Elnakib et al. (see note 8); S. Olelakan Olaleye, T. Folashade Aroyewun, and R. Abdelrahman Osman, "Sudan's Maternal Health Needs Urgent Attention amid Armed Conflict," *Lancet* 402/10405 (2023).

12. See generally Human Rights Committee, General Comment No. 31 (see note 3); CEDAW Committee, General Recommendation No. 30, UN Doc. CEDAW/C/GC/30 (2013), paras. 19–24; ICRC, "IHL and Human Rights Law" (2010), https://www.icrc.org/en/document/ihl-human-rights-law.

13. ICRC, "Customary IHL Database" (see note 2); see also generally Vienna Convention on the Law of Treaties, 1155 UNTS 311 (1969), art. 26.

14. ICRC, "Customary IHL Database" (see note 2), rule 87.

15. Geneva Conventions I–IV (1949), common art. 3.

16. ICRC, "Customary IHL Database" (see note 2), rule 87.

17. ICRC, *Commentary on the First Geneva Convention: Convention (I) for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field*, 2nd edition (2016), https://ihl-databases.icrc.org/ihl/full/GCI-commentary, art. 3, para. 553; ICRC, *Commentary on the Third Geneva Convention: Convention (III) relative to the Treatment of Prisoners of War* (2020), https://ihl-databases.icrc.org/ihl/full/GCIII-commentary, art. 3, para. 587; see also ICRC, "Customary IHL Database" (see note 2), rule 87.

18. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 3, paras. 618–621, 698; ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 3, paras. 657, 734; Committee against Torture, Concluding Observations: United States, UN Doc. CAT/C/USA/CO/2 (2006), para. 33; Committee against Torture, Concluding Observations: Kenya, UN Doc. CAT/C/KEN/CO/2 (2013), para. 27; Committee against Torture, Concluding Observations: Slovakia, UN Doc. CAT/C/SVK/CO/3 (2015), para. 12; Committee against Torture, Concluding Observations: El Salvador, UN Doc. CAT/C/SLV/CO/3, paras. 24, 28.

19. See, for example, C. Droege, "'In Truth the Leitmotiv': The Prohibition of Torture and Other Forms of Ill-Treatment in International Humanitarian Law," *International Review of the Red Cross* 89/515 (2007); see also M. Nowak and R. Janik, "Torture, Cruel, Inhuman, or Degrading Treatment or Punishment," in A. Clapham, P. Gaeta, and M. Sassòli (eds), *The 1949 Geneva Conventions: A Commentary* (Oxford: Oxford University Press, 2015), p. 320.

20. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 3, para. 588.

21. Ibid.; CEDAW, General Recommendation No. 30 (see note 12), para. 52(c) and (d).

22. Committee against Torture, General Comment No. 2, UN Doc. CAT/C/GC/2 (2008), para. 22.

23. See, for example, Committee against Torture, Concluding Observations: Poland, UN Doc. CAT/C/POL/CO/7 (2019), para. 33(d); Committee against Torture, Concluding Observations: United Kingdom of Great Britain and Northern Ireland, UN Doc. CAT/C/GBR/CO/6 (2019), para. 46; Committee against Torture, Concluding Observations: Philippines, UN Doc. CAT/C/PHL/CO/3 (2016), para. 39; Committee against Torture, Concluding Observations: Kenya, UN Doc. CAT/C/KEN/CO/2 (2013), para. 27.

24. Committee against Torture, Concluding Observations: El Salvador, UN Doc. CAT/C/SLV/CO/2 (2009), para. 23; Committee against Torture, Concluding Observations: Nicaragua, UN Doc. CAT/C/NIC/CO/1 (2009), para. 16; Committee against Torture, Concluding Observations: Philippines, UN Doc. CAT/C/PHL/CO/3 (2016), para. 39.

25. See, for example, Committee against Torture, Concluding Observations: Poland, UN Doc. CAT/C/POL/CO/7 (2019), para. 34(e); Committee against Torture, Concluding Observations: Philippines, UN Doc. CAT/C/PHL/CO/3 (2016), para. 40.

26. Committee against Torture, Concluding Observations: Nicaragua, UN Doc. CAT/C/NIC/CO/1 (2009), para. 16.

27. *K.L. v. Peru*, Human Rights Committee, views of October 24, 2005, Case No. 1153/2003, para. 6.3; *LMR v. Argentina*, Human Rights Committee, views of April 28, 2011, Case No. 1608/2007, paras. 9.2, 10; *Mellet v. Ireland*, Human Rights Committee, views of November 17, 2016, Case No. 2324/2013, paras. 7.4, 7.6; *Whelan v. Ireland*, Human Rights Committee, views of July 11, 2017, Case No. 2425/2014, paras. 7.4–7.7.

28. Human Rights Committee, General Comment No. 36, UN Doc. CCPR/C/GC/36 (2018), para. 8.

29. *Camila v Peru*, Committee on the Rights of the Child, views of June 13, 2023, Case No. 136/2021, para 8.12.

30. See, for example, African Commission on Human and Peoples' Rights, General Comment No. 4 (2017), para. 58; Committee for the Prevention of Torture in Africa, Inter-Session Activity Report (May 2017 to November 2017) and Thematic Report on Denial of Abortion and Post-Abortion Care as Torture and Other Cruel, Inhuman or Degrading Punishment or Treatment (2017), art. 5; *I.V. v. Bolivia*, Inter-American Court of Human Rights, November 30, 2016, para. 270; *R.R. v. Poland*, European Court of Human Rights, no. 27617/04, November 28, 2011, paras. 161–162; *P. and S. v. Poland*, European Court of Human Rights, no. 57375/08, January 30, 2013, paras. 168–169; *Manuela et al. v. El Salvador*, Inter-American Court of Human Rights, November 2, 2021, para. 241; *V.C. v. Slovakia*, European Court of Human Rights, no. 18968/07, August 2, 2012, paras. 119–120.

31. Human Rights Council, Report of the Special Rapporteur on Torture and Other Cruel, Inhuman and Degrading Treatment Report on the Gendered Aspects of Torture, Juan

E. Méndez, UN Doc. A/HRC/31/57 (2016), paras. 42, 44.

32. Brief of United Nations Mandate Holders as Amici Curiae in Support of Respondents, *Dobbs v. Jackson Women's Health Organization*, No. 19-1392 (September 20, 2021).

33. See ICRC, "Customary IHL Database" (see note 2), rule 88.

34. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 3, para. 578.

35. ICRC, "Customary IHL Database" (see note 2), rule 88.

36. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 3, para. 577.

37. Ibid., art. 3, para. 578; see also P. Viseur Sellers, "(Re) Considering Gender Jurisprudence," in F. Ní Aoláin, N. Cahn, D. Haynes, and N. Valji (eds), *The Oxford Handbook of Gender and Conflict* (Oxford: Oxford University Press, 2018).

38. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 3, para. 578, footnote 339.

39. CEDAW Committee, General Recommendation No. 25, UN Doc. A/59/38 (2004), paras. 8–12; Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 20, UN Doc. E/C.12/GC/20 (2009), paras. 9–10; Human Rights Committee, General Comment No. 28, UN Doc. CCPR/C/21/Rev.1/Add.10 (2000), para. 3.

40. CEDAW Committee, General Recommendation No. 24, UN Doc. A/54/38/Rev. 1 (1999), para. 11.

41. Human Rights Committee, General Comment No. 28 (see note 39), paras. 2, 3, 5, 8, 10.

42. See, for example, UNFPA and Center for Reproductive Rights, *ICPD and Human Rights: 20 Years of Advancing Reproductive Rights through UN Treaty Bodies and Legal Reform* (New York: UNFPA and Center for Reproductive Rights, 2013).

43. See, for example, Human Rights Committee, General Comment No. 36 (see note 28), para. 8; CEDAW Committee, General Recommendation No. 35, UN Doc. CEDAW/C/GC/35 (2017), para. 18; CESCR, General Comment No. 22, UN Doc. E/C.12/GC/22 (2016), paras. 10, 28.

44. CEDAW Committee, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, UN Doc. CEDAW/C/OP.8/GBR/1 (2018), para. 65.

45. CESCR, General Comment No. 22 (see note 43), paras. 2, 30–32.

46. CEDAW, General Recommendation No. 28, UN Doc. CEDAW/C/GC/28 (2010), para. 11.

47. CEDAW, General Recommendation No. 30 (see note 12), para. 52(c); see also African Commission on Human and Peoples' Rights, General Comment No. 2 (2014), paras. 21, 22, 25, 46; Committee for the Prevention of Torture in Africa (see note 30), para. 49.

48. ICRC, "Customary IHL Database" (see note 2), rule 134; Convention Relative to the Treatment of Prisoners of War, 75 UNTS 135 (1949), art. 14.

49. CRC, "Customary IHL Database" (see note 2), rule 134; Convention Relative to the Treatment of Prisoners of War, 75 UNTS 135 (1949), art. 14.

50. ICRC, *Commentary on the Third Geneva Convention: Convention (III) relative to the Treatment of Prisoners of War* (1960), art. 14.

51. Ibid.; ICRC, "Customary IHL Database" (see note 2), rule 134.

52. ICRC, "Customary IHL Database" (see note 2), rules 109, 134; *Prosecutor v. Akayesu*, International Criminal Tribunal for Rwanda, Case No. IT-96-4-T, September 2, 1988, para. 688; *Prosecutor v. Furundzija*, International Criminal Tribunal for the Former Yugoslavia, Case No. IT-95-17/1-T, December 10, 1988, para. 185.

53. R. Rubio-Marin, "Reparations for Conflict-Related Sexual and Reproductive Violence: A Decalogue," *William and Mary Journal of Race, Gender, and Social Justice* 19/69 (2013), p. 75; see also Human Rights Council, Report of the UN Working Group on the Issue of Discrimination against Women in Law and in Practice, UN Doc. A/HRC/32/44 (2016), para. 63.

54. Charlesworth and Chinkin (see note 4); Office of the UN High Commissioner for Human Rights, *Background Paper on the Role of the Judiciary in Addressing the Harmful Gender Stereotypes related to Sexual and Reproductive Health and Rights: A Review of the Case Law* (Geneva: Office of the UN High Commissioner for Human Rights, 2018); C. Pickles and J. Herring, *Women's Birthing Bodies and the Law: Unauthorised Intimate Examinations, Power and Vulnerability* (London: Bloomsbury Publishing, 2020).

55. Crowe (see note 4), p. 16.

56. Office of the UN High Commissioner for Human Rights (see note 54); R. J. Cook and S. Cusack, *Gender Stereotyping: Transnational Legal Perspectives* (Philadelphia: University of Pennsylvania Press, 2010); *Mellet v. Ireland*, Human Rights Committee, November 17, 2016, Case No. 2324/2013, paras. 14–15 (Cleveland, concurring).

57. Cook and Cusack (see note 56); Quenivet (see note 4); C. O'Rourke, "*The Rights of Women in Armed Conflict under International Law," in C. O'Rourke (ed), Women's Rights in Armed Conflict under International Law* (Cambridge: Cambridge University Press, 2020); R. Holtmaat, "Article 5," in Marsha Freeman, C. Chinkin, and B. Rudolf (eds), *The UN Convention on the Elimination of All Forms of Discrimination against Women: A Commentary* (Oxford: Oxford University Press, 2012).

58. Convention on the Elimination of All Forms of Discrimination against Women, G.A. Res. 34/180 (1979), art. 5.

59. See, for example, CEDAW Committee, General Recommendation No. 35 (see note 43), paras. 26(c), 37(a), 38(a).

60. *L.C. v. Peru*, CEDAW Committee, October 17, 2011, Case No. 22/2009, para. 7.7; see also CEDAW Committee,

Summary of the Inquiry concerning the Philippines under Article 8 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women, UN Doc. CEDAW/C/OP.8/PHL/1 (2015), para. 42; ICRC, "Women and War" (October 11, 2018), https://www.icrc.org/en/document/women-war.

61. Committee against Torture, General Comment No. 2, UN Doc. CAT/C/GC/2 (2008), para. 22; S. Cusack, "Gender Stereotyping as a Human Rights Violation: Research Report," prepared for the Office of the UN High Commissioner for Human Rights (2013).

62. See, for example, Human Rights Committee, General Comment No. 28 (see note 46), para. 5.

63. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 12, para. 1427, footnotes 159–161; ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1682, footnote 47.

64. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1682.

65. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 12, para. 1427, footnotes 159–161; ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1682, footnote 47.

66. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 12, paras. 1428–1429; ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 16, paras. 1747–1748.

67. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 16, para. 1761; see also ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 3, para. 578; Sellers (see note 37).

68. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 16, para. 1761.

69. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 14, para. 1434; ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1685; see also ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 30, para. 2230.

70. ICRC, *Commentary on the First Geneva Convention* (see note 17), art. 12, para. 1435.

71. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1684.

72. Ibid.

73. See A. Radhakrishnan, E. Sarver, and G. Shubin, "Protecting Safe Abortion in Humanitarian Settings: Overcoming Legal and Policy Barriers," *Reproductive Health Matters* 25/51 (2017); A. Bellal, "Who Is Wounded and Sick?," in A. Clapham, P. Gaeta, and M. Sassòli (eds), *The 1949 Geneva Conventions: A Commentary* (Oxford: Oxford University Press, 2015). Changes appear in the online version available at https://opil.ouplaw.com/display/10.1093/law/9780199675449.001.0001/law-9780199675449-chapter-37.

74. Bellal (see note 73), p. 765, para. 33; see also Radhakrishnan et al. (see note 73).

75. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1685; see also ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 30, para. 2230.

76. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 30, para. 2230.

77. CEDAW Committee, General Recommendation No. 24 (see note 40); CESCR, General Comment No. 22 (see note 43), para. 13.

78. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 30, para. 2232.

79. World Health Organization, "Sexual Reproductive Health and Rights in Emergencies," https://healthcluster.who.int/our-work/thematic-collaborations/sexual-reproductive-health-and-rights-in-emergencies; Human Rights Council, Follow-Up on the Application of the Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Mortality and Morbidity, UN Doc. A/HRC/39/26 (2018), paras. 41, 55.

80. Inter-Agency Working Group on Reproductive Health in Crises, "Minimum Initial Service Package (MISP)," in Inter-Agency Working Group on Reproductive Health in Crises (ed), *Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings* (2020).

81. Ibid.

82. See, for example, ICRC, "Customary IHL Database" (see note 2), rule 134, footnotes 5, 22.

83. Center for Reproductive Rights, "The World's Abortion Laws" (2021), http://worldabortionlaws.com/index.html.

84. Center for Reproductive Rights, "Global Trends: Abortion Rights" (2022), https://reproductiverights.org/global-trends-abortion-rights-infographic-9-14-22.

85. Ibid.

86. See UN Department of Economic and Social Affairs, *Abortion Policies and Reproductive Health around the World* (New York: UN Department of Economic and Social Affairs, 2014).

87. R. Cook and B. Dickens, "Learning from Comparative Abortion Law," in J. Smits, J. Husa, C. Valcke, and M. Narciso (eds), *Elgar Encyclopedia of Comparative Law*, 3rd edition (Cheltenham: Edward Elgar Publishing, 2023); B. Ganatra, C. Gerdts, C. Rossier, et al., "Global, Regional, and Subregional Classification of Abortions by Safety, 2010–14: Estimates from a Bayesian Hierarchical Model," *Lancet* 390/2372 (2017); World Health Organization, *Abortion Care Guideline* (Geneva: World Health Organization, 2022), p. 2.

88. Cook and Dickens (see note 87). Courts upholding laws: Constitutional Court, U-I-60/1991, February 21, 2017 (Croatia); Constitutional Court, August 28, 2017, corresponding to Bulletin No. 9895-11, STC Rol No. 3729(3751)-17 CPT (Chile); Constitutional Council, Décision No. 2001-446 DC, June 27, 2001 (France); Supreme Court, Acción de in-

constitucionalidad (AI) 146/2007 y su acumulada 147/2007, August 2008 (Mexico); Constitutional Tribunal, Acórdão No. 75/2010 of 26th March, Diário da República No. 60/2010, Série II de 2010-03-26 (Portugal); Constitutional Court, PL. ÚS 12/01, Dec. 4, 2007 (Slovakia). Courts finding restrictive criminal laws on abortion unconstitutional: Supreme Court, 13/3/2012, *F., A.L. s/medida autosatisfactiva (259.XLVI)* (Argentina); Plurinational Constitutional Tribunal, Sentencia 0206/2014, February 5, 2014 (Bolivia); Supreme Court, ADPF 54/DF, March 12, 2012 (Brazil); Constitutional Court, February 21, 2022, Sentencia C-055/22 (Colombia); Constitutional Court, Sentencia No. 34-19-IN/21 Y Acumulados, April 28, 2021 (Ecuador); Constitutional Court, *Case on the Crime of Abortion*, Case No. 2017Hun-Ba127, April 11 2019 (Republic of Korea); Supreme Court, A Acción de inconstitucionalidad (AI) 148/2017, 2021 (Mexico); Supreme Court, *Lakshmi Dhikta v. Government of Nepal*, Writ No. WO-0757, 2067, 2009 (Nepal); Constitutional Court, Ruling No. 4/2563, February 19, 2020 (Thailand); *Whole Woman's Health v. Hellerstedt*, 579 U.S. 582 (2016) (United States); *June Medical Services v. Russo*, 140 S.Ct. 2103 (2020) (United States). Courts holding restrictive laws constitutional: Supreme Court of Justice, Constitutional Chamber, March 17, 2004, Resolución No. 02792-04 (Costa Rica); Supreme Court, Decisión 18/98, November 20, 2007 (El Salvador); Constitutional Tribunal, Case No. K 1/20, OTK ZU A/2021, item 4, October 22, 2020 (Poland); Supreme Court, *Dobbs v. Jackson Women's Health Organization*, No. 19-1392 (2022) (United States).

89. Radhakrishnan et al. (see note 73); Bellal (see note 73), pp. 762–765; Center for Reproductive Rights, "Legal Expert Convenings on International Law in Humanitarian Settings" (June–September 2020), discussions on file at the Center for Reproductive Rights; see also Global Justice Center, "Reference Language on Abortion and IHL" (2017), https://www.globaljusticecenter.net/files/ReferenceLanguage.1.20.2017.pdf.

90. Center for Reproductive Rights, "Law and Policy Guide: Rape and Incest Exceptions," https://maps.reproductiverights.org/law-and-policy-guide-rape-and-incest; Center for Reproductive Rights (2021, see note 83).

91. Ibid.; see also World Health Organization (2022, see note 87), pp. 26–27.

92. World Health Organization (2022, see note 87), pp. 26–27; see also *K.L. v. Peru*, Human Rights Committee, views of October 24, 2005, Case No. 1153/2003; *L.C. v. Peru*, CEDAW Committee, views of October 17, 2011, Case No. 22/2009; *LMR v. Argentina*, Human Rights Committee, April 28, 2011, Case No. 1608/2007; *Tysiąc v. Poland*, European Court of Human Rights, No. 5410/03, March 20, 2007; *R.R. v. Poland,* European Court of Human Rights, No. 27617/04, November 28, 2011 *P. and S. v. Poland,* European Court of Human Rights, No. 57375/08, January 30, 2013; *A, B and C v. Ireland*, European Court of Human Rights, No. 25579/05, December 16, 2010.

93. World Health Organization (2022, see note 87), pp. 26–27.

94. Ibid., pp. 24–25.

95. Center for Reproductive Rights (2021, see note 83); see also World Health Organization, "Global Abortion Policies Database," https://abortion-policies.srhr.org/.

96. ICRC, *Commentary on the Third Geneva Convention* (2020, see note 17), art. 14, para. 1684, footnote 54.

97. CEDAW Committee, General Recommendation No. 30 (see note 12); Human Rights Committee, General Comment No. 36 (see note 28).

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The Council of Europe's Underrated Role in Fostering Equitable Access to Quality Health Care in Times of Pandemic

ÉLOÏSE GENNET

Abstract

Different Council of Europe organs have been attentive and reactive to specific human rights issues in the COVID-19 context, quickly alerting on the risks of inequitable access to quality health care, vaccines, or medicines for vulnerable groups. Yet these reactions have mainly taken the form of nonbinding instruments such as declarations, statements, and recommendations. Although these reactions derive from the interpretation of binding Council of Europe conventions, the observance or implementation of these conventions is not always monitored. Strasbourg judges have on several occasions confirmed that European Convention on Human Rights case law must consider other international instruments, especially those of other Council of Europe organs, in order to interpret the guarantees of the convention. As a consequence, soft law rules can sometimes indirectly acquire binding force when used as an interpretation and implementation tool for binding treaties. In this paper, I examine how Council of Europe organs interpret the principle of equitable access to health care of appropriate quality in the context of a pandemic and whether and how this interpretation is being implemented within the Council of Europe's interpretation of binding treaties such as the Medicrime Convention, the European Social Charter, and the European Convention on Human Rights.

Éloïse Gennet, PhD, is a junior professor in European health law at Aix-Marseille University, National Center for Scientific Research (CNRS), International, Comparative and European Law (DICE), Centre for International and European Studies and Research (CERIC), Aix-en-Provence, France.

Please address correspondence to the author. Email: eloise.gennet@univ-amu.fr.

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Introduction

The COVID-19 pandemic has uncovered many health inequalities and exacerbated their consequences. As the world continues to recover from this experience, action is gradually being taken at national and supranational levels to prevent this from happening again. Despite recognizing the importance of finding solutions at the global level, in this paper I choose to emphasize existing instruments of the Council of Europe, which, although often overlooked, could serve as a solid basis for a human rights approach to fostering health equity in the context of a future pandemic. As was noted by the Council of Europe's Committee of Ministers in early 2023, crisis situations only perpetuate or exacerbate preexisting inequities.[1] Preventing inequitable situations in the next pandemic thus inevitably implies working on day-to-day equitable health care access, and in that regard the Council of Europe's legal framework already provides for a wide range of instruments and actors.

To begin with, the Council of Europe has—almost since its creation—cooperated in the field of public health.[2] This (rather scientific) cooperation evolved into the creation of the European Directorate for the Quality of Medicines and Health Care in 1964, together with the adoption of the Convention on the Elaboration of a European Pharmacopoeia.[3] No directorate instrument per se enshrines a right to health protection or to health care access. However, some of the directorate's instruments could become powerful tools to fight against inequities. For instance, its 2011 Medicrime Convention on the counterfeiting of medical products might prove a crucial instrument, and its Medicrime Committee a crucial actor, in protecting equitable quality of medicines in contexts such as pandemics or shortages.[4] In fact, the unmet medical need created by a pandemic or shortage—because it creates attractive opportunities for counterfeiters to meet that need—increases the risk of being exposed to falsified medicines.

Second, the Council of Europe has adopted the only internationally binding instrument in bioethics: the Convention on Human Rights and Biomedicine (commonly known as the Oviedo Convention), adopted in 1997 and now ratified by 30 member states.[5] Interestingly, article 3 of this convention enshrines the principle of equitable access to health care of appropriate quality. This provision does not create an individual right on which each person may rely; it has to be assessed within the framework of national laws, which remain competent for health matters.[6] However, it can be used to interpret other Council of Europe instruments in favor of equity in health protection—"equitable" meaning "first and foremost the absence of unjustified discrimination."[7] The Committee on Bioethics (previously known as DH-BIO, since January 2022 called CDBIO) is a subsidiary body established by the Committee of Ministers to further promote human rights standards in view of scientific developments.[8] Interestingly, observing the increasing disparities in health since the adoption of the Oviedo Convention, the committee has made the question of equity in health care one of its three strategic priorities for 2020–2025.[9]

Beyond these specialized treaties, the Council of Europe also provides for more general instruments that, directly or indirectly, protect human health as well. In fact, the Revised European Social Charter enshrines the right to protection of health in its article 11, considering this right as a prerequisite for the preservation of human dignity.[10] The European Committee of Social Rights (ECSR) insists on state parties taking "practical action making available the resources and the operational procedures necessary to give full effect" to social rights, including the right to health.[11] Interestingly, when assessing whether this right is exercised effectively and without discrimination, the ECSR "pays particular attention to the situation of disadvantaged and vulnerable groups."[12]

Finally, the European Convention on Human Rights (ECHR) does not explicitly protect the right to health, but it protects this right implicitly via the protection of life (article 2), the prohibition of degrading treatment (article 3), and the protection of private life (article 8). European judges are very mindful of the wide margin of appreciation of member states in the field of health, yet they have historically shown more audacity when it comes to effectively protecting the rights and health of vulnerable groups.[13]

These instruments are at the center of the Council of Europe's legal framework on the question of (equitable) health protection. But how have they been mobilized and interpreted in the context of the COVID-19 pandemic? Are these instruments enough to ensure an equitable response and prevention if a major health event such as the COVID-19 pandemic were to happen again? To answer these questions, in the first part that follows, I will examine the concrete interpretations that different Council of Europe organs have made of the principle of equitable access to health care of appropriate quality as a direct reaction to and in the specific context of the COVID-19 pandemic. These interpretations take the form of soft law—that is, normative yet nonbinding instruments such as statements and declarations.[14] These nonbinding interpretations are then adopted by Council of Europe organs that are mandated to develop and interpret, if not monitor, the implementation of conventions that, on the contrary, are binding. It is thus tempting to hypothesize that these soft law instruments are likely to influence future interpretations of Council of Europe hard law treaties in the context of COVID-19. In fact, I subscribe to the idea that soft law constitutes at least a material source of international law and that it even impacts how hard law is interpreted and implemented in context.[15] I will thus analyze, in the second part of this paper, whether and how those soft law instruments have been effectively incorporated into the Council of Europe's binding treaties and case law.

Interpreting equitable access to quality health care in times of pandemic

Different Council of Europe organs have been attentive and reactive to specific human rights issues in the COVID-19 context and have adopted soft law instruments targeting issues of equitable access to health care. The DH-BIO (now CDBIO) published a general statement in 2020 on human rights considerations relevant to the COVID-19 pandemic, and in 2021 another statement specific to equitable access to vaccination during a pandemic.[16] The ECSR was also quick to react in 2020 when issuing a statement on the right to protection of health in times of pandemic.[17] The question of equity has played an important role in these reaction statements and is more formally supported in a 2023 recommendation of the Council of Europe Committee of Ministers regarding equitable access to medicinal products in situations of shortage.[18] Yet in conformity with article 3 of the Oviedo Convention, the question of equitable health care access is inseparable from that of appropriate quality of health care. Especially in times of pandemic, quality is an equity-relevant question for two reasons. First, and as recalled by the DH-BIO, the general quality and safety requirements of a medical product have to be adapted to (and thus tested on) vulnerable population groups despite the situation of emergency.[19] Second, in times of pandemic or shortage, the scarcity of vaccines compared to the global demand creates a market for low-quality falsified vaccines. In fact, such a heightened unmet medical need is a golden opportunity for criminals to take advantage of any despair-driven credulity or crisis-related weakened vigilance in regulatory systems. The Medicrime Committee thus issued an advice in April 2021 alerting member states about increased reports of falsified COVID-19 vaccines and the importance of implementing the Medicrime Convention in the context of the pandemic.[20]

Equitable access to health care

Pandemics are "inherently disequalizing, disproportionately affecting individuals and groups in vulnerable conditions."[21] One major element in common among the soft law instruments drafted in response to COVID-19 is the acknowledgment of the importance of identifying vulnerable groups. This identification allows for setting up priorities in health care access and thus reestablishing a balance in favor of those who usually are at a disadvantage in accessing care.[22]

Who to prioritize? Identifying the vulnerable. Recalling the principle of dignity and article 3 of the Oviedo Convention, the DH-BIO statement underlines the "critical importance of equitable access to vaccination" and of ensuring "that everyone, without discrimination, is offered a fair opportunity to receive a safe and effective vaccine."[23] In a context of scarce resources, this requires prioritizing people in a vulnerable situation: people with disabilities, older people, refugees and migrants, people with mental health problems, people with learning disabilities, minorities, homeless people, poor people, people with substance use disorders, and people deprived of liberty.[24]

The 2023 recommendation of the Committee of Ministers also targets individuals or groups that are systematically disadvantaged in relation to health, "including as a result of economic and social conditions, legal status, disability, chronic disease or age," and gives a list of examples of such individuals and groups.[25] It notes, however, that prioritization should be based on medical criteria: severity of the health condition, expected effectiveness of the medicine, possible therapeutic alternatives, and the mortality risk consequent to the lack of access.[26]

Interestingly, the ECSR also recalls the existing protection, in the European Social Charter, of health-related rights targeting specific groups, such as workers, socially disadvantaged people, older adults, and children.[27] It highlights, in the case of a pandemic, the need to provide effective and affordable access to health care for groups with "heightened vulnerabilities" who might be at particular risk of discrimination or "on whom falls the heaviest burden in the event of institutional shortcoming."[28] In an open list of examples, the ECSR refers to poor, homeless, and older people; people with disabilities; prisoners; and irregular migrants.[29] This is in line with its long-standing interpretation of article 11 of the European Social Charter, according to which effectivity of the right to protection of health depends on the particular attention given to disadvantaged and vulnerable groups.[30]

How to prioritize? Removing concrete barriers to health care access. For this prioritization to be effective during a pandemic, the ECSR invites governments to take all required measures to compensate or erase the unfair or avoidable differences among certain groups. To begin with, it underlines that long-standing shortcomings to secure social rights such as housing or freedom from poverty and social exclusion "feed directly into the vulnerability of particular social groups in a pandemic," who may lack equitable access to health care.[31] Then, to organize prioritization during a pandemic, states have to take targeted measures for those who are particularly exposed, such as measures to educate people about the risks posed by the disease in question, how to mitigate them, and how to access health care services when needed or to provide for widely accessible immunization programs.[32]

Similarly, both the DH-BIO statement on equitable access to COVID-19 and the Committee of Ministers recommendation suggest developing strategies "to ensure appropriate support and the removal of barriers" to access vaccines or medicines in a way for them to "be adapted to meet the needs of these persons," meaning the prioritized groups.[33] Adapting to those needs means having actively engaged with representatives of these groups to better understand and overcome the barriers to access, having a range of pragmatic accessibility requirements, and adapting information to people's needs (such as low literacy or speaking a foreign language).[34] In that regard, the CDBIO released a guide on health literacy in early 2023 as part of its mandate to further promote equitable access to health care.[35] This recurring narrative around equitable health care access is thus not just a reaction to the pandemic but a reflection of a preexisting political will to fight increasing health disparities, as shown in the 2019 *DH-BIO Strategic Action Plan on Human Rights and Technologies in Biomedicine*.[36]

Interestingly, what is systematically missing in the identification of vulnerable groups is the global perspective on health care access, including cooperation and solidarity between states. The focus is on what countries should do on their own territories about vulnerable groups. Prioritization strategies do not reflect health inequities between countries or regions of the world. One exception, however, lies in the Council of Europe's fight for the equitable quality of medicinal products.

Equitable quality of health care

As the Medicrime Committee stressed during the COVID-19 pandemic, "until a production capacity is reached that satisfies global demand, there is a risk that the vaccines will be illegally moved from people in need to those who do not wish to wait their turn for vaccination."[37] One of the 13 key messages of this advice is for states to recall that "every COVID-19 vaccine that is falsified is a risk both to vulnerable persons and to healthy persons," as it gives them the mistaken belief that they are protected from infection.[38]

Medicine counterfeiting represents a threat to public and individual health and to the principle of equitable access to quality health care, as it creates new factors of vulnerability. Counterfeited medicines are of low quality because they do not respect regulatory standards. They may result in patients being untreated (or incorrectly treated) and can cause their condition to (sometimes irreversibly) aggravate, which is particularly dangerous when the condition is life-threatening. They can also lead to adverse effects due to dangerous ingredients, allergic reactions, drug interactions, or high dosage, among other things.[39]

Moreover, medicine counterfeiters directly target vulnerable groups by tailoring their spamming to current shortages, such as those concerning a specific or rare medical condition.[40] However, in situations such as a pandemic, an unmet medical need can be globalized, and the vulnerable factors shift from an individual perspective to a collective one. In fact, the collective vulnerability can be related to the financial inability of certain states to acquire enough medical products to meet the needs of their population. It can also be related to the lack of harmonized and effective regulations at the international level with regard to the pharmaceutical market but also more generally to online trade and cybercrime.[41] The falsification of medical products represents a threat to any country, irrespective of the stringency of its border controls, because these illicit activities occur in such a fragmented manner that different elements of a counterfeit medicine (e.g., empty boxes, chemical components) infiltrate the legal supply chain separately, without violating any laws, and therefore remain undetected.[42]

But most of all, unequal access to medicines and vaccines inevitably leads to unequal exposure to the risk of obtaining a counterfeit drug or vaccine. The Committee of Ministers, in article 19 of its 2023 recommendation on equitable access to medicinal products in a situation of shortage, underlines the "risk of purchasing products and equipment from unofficial supply channels and of unauthorized use."[43] Similarly, in its statement on COVID-19 vaccine equity and more specifically in its section about ensuring appropriate quality of vaccination, the DH-BIO underlines the need to comply with the Medicrime Convention of the Council of Europe.[44]

The Medicrime Convention establishes as criminal offenses the manufacturing, supplying, and trafficking of counterfeit medical products, as well as similar crimes (articles 5, 6, 8). This convention has a wide scope because it covers medicinal products in general, irrespective of whether they are still protected by a patent or trademark legislation, thus including generics (article 3). This is an important added value and originality brought by the Council of Europe to the global legal landscape in this context. In fact, international efforts aimed at curbing the counterfeiting of medical products or promoting equitable access to medicines have traditionally centered around intellectual property issues.[45] By contrast, the Medicrime Convention's primary goal is to combat the falsification of medical products for the significant threat it represents for individual and public health—that is, even when no actual damage has occurred (yet) for (potential) victims.[46] Not only does it provide for another tool for equitable pandemic response, but through the dissuasive effect of the sanctions it foresees, it offers another tool to prevent negative and inequitable consequences of criminal behaviors on patients' rights during a major health event such as COVID-19. Moreover, it could also indirectly defeat some of the intellectual property regime's negative impacts on medicine prices. The high prices of medicinal products are detrimental to patients' access, especially in poorer countries, as they create an unmet demand and thus a market for counterfeited medicines. In that regard and contrary to previously mentioned Council of Europe instruments, the Medicrime Convention takes into account a perspective on vulnerability and potential health inequities not only at a national but also at a global scale.

To conclude, when reacting to the COVID-19 pandemic, Council of Europe organs were quick to alert about the risks of inequitable access to quality health care, vaccines, and medicines for vulnerable groups. But not all Council of Europe instruments are binding, nor is their observance always monitored. When observance is monitored, the actual impact of the activities of such committees as the ECSR, CDBIO, and the Medicrime Committee is difficult to assess: the causality between the monitoring or expertise and the evolution of national laws may be difficult to clearly demonstrate because it is rarely direct.[47]

Implementing equitable access to quality health care in times of pandemic

Strasbourg judges have on several occasions confirmed that ECHR case law "must take into account relevant international instruments and reports, and in particular those of other Council of Europe organs, in order to interpret the guarantees of the Convention and to establish whether there is a common European standard in the field."[48] This, for instance, includes the European Social Charter, the Oviedo Convention, and the Medicrime Convention, even when they have not been ratified by the member state in question. In fact, Strasbourg judges have established that it can be sufficient if international instruments reflect evolving norms in international law or the domestic laws of most Council of Europe member states, indicating common ground in contemporary societies within a specific domain.[49] Moreover, the court uses references to norms emanating from monitoring or expert bodies, such as the ECSR, CDBIO, Medicrime Committee, and others, even when those organs do not represent state parties.[50] As a consequence, soft law rules can acquire an "indirectly binding force" when used by the European Court of Human Rights to precise ECHR binding provisions.[51] In this section, I examine how equitable access to quality health care has been implemented within Council of Europe human rights treaties such as the ECHR and the European Social Charter, as well as within more targeted health-related treaties such as the Oviedo and Medicrime Conventions.

Implementation in the Council of Europe's general human rights treaties

Case law of the European Committee on Social Rights. Notwithstanding the difficult justiciability of social rights, the European Social Charter is binding for state parties that have ratified it; this binding nature includes cooperation with the independent monitoring committee, the ECSR, regarding the reporting procedure and, for the states that have accepted it, regarding the collective complaints mechanism.[52] The ECSR's aforementioned 2020 statement on the right to protection of health in times of pandemic is not itself binding, but it has already been repeatedly integrated into the latest national reporting procedures on article 11 of the European Social Charter.[53] In fact, the ECSR explicitly quotes its own statement in favor of equitable health care access by highlighting that nondiscrimination requires making health care effective and affordable to everyone during a pandemic, especially groups that have a higher risk.[54] But even more noteworthy is the fact that the statement made its way into several decisions on the merits.

During the COVID-19 pandemic, questions were raised as to whether certain groups of people should be considered particularly vulnerable. For instance, in *International Commission of Jurists (ICJ) and European Council for Refugees and Exiles (ECRE) v. Greece*, the ECSR considered that because of their prior insufficient access to health care, unaccompanied migrant children in Greece were likely to experience heightened vulnerability as a result of the pandemic.[55] In *Open Society European Policy Institute (OSEPI) v. Bulgaria*, noting that the vulnerability of older adults was not acknowledged by Bulgarian authorities at the beginning of the COVID-19 pandemic, OSEPI alleged "that the

Government disregarded scientific and credible statistical information indicating the higher morbidity of older persons and persons with specific vulnerabilities."[56] In contrast, being qualified as a "vulnerable group" has sometimes been contested by applicants. In *Validity Foundation v. Finland*, a mental disability advocacy center complained that some COVID-19 restrictions were inadequate considering that not all disabled people were vulnerable.[57] The ECSR "took note" of this argument without further comment, instead directly examining the contested measures deriving from this automatic categorization as a vulnerable group.

In fact, categorizing certain groups as vulnerable is important because it impacts governments' obligations in guaranteeing equitable health care access. In *Validity Foundation v. Finland*, the complainant contended that the automatic categorization as "vulnerable" had prevented some disabled—yet not vulnerable—persons the chance to move away from residential institutions that had become coronavirus hotbeds (sections 32–34). Whereas these measures could be understood as being protective of vulnerable groups, they could also be viewed as discriminatory because they were disproportionately restrictive for the disabled persons who were not particularly vulnerable to COVID-19 infection. On that question, the ECSR did not find any violation and considered that the restrictions of access to health care were aimed at protecting people's health and "to a large extent … resembled the ones applicable to the other housing service units and to those in place for the entire population" (section 54). In *ICJ and ECRE v. Greece* about unaccompanied migrant children, the decision did not examine COVID-19 measures since final submissions were received prior to the COVID-19 pandemic. The ECSR only observed that, as it has concluded on the violation of article 11 of the European Social Charter, these shortcomings "risk being exacerbated/compounded by the COVID-19 situation" (section 229).

Finally, in the case of *OSEPI v. Bulgaria*, the complainant alleged that "the situation as regards distribution of COVID-19 vaccines amounts to discrimination, in particular on the grounds of age and health, in violation of article E in conjunction with article 11 of the Charter" (section 1). It considered that the failure to acknowledge older adults' vulnerability prevented the government from adopting a proper vaccination strategy targeting older adults. In fact, "Bulgaria has the highest accumulated death rate for COVID-19 in Europe" (section 14), and as of December 22, 2021, only 35.2% of persons over 60 had completed the vaccination process (section 4). Given that the Bulgarian government had meanwhile taken effective measures to palliate this problem, the ECSR rejected the idea of taking immediate measures (sections 14–19), but noted that it would examine the alleged discrimination regarding access to vaccines for older adults in an upcoming decision on the merits.

Case law of the European Court of Human Rights. Although many COVID-19 cases have already been examined by the European Court of Human Rights, only a few of them relate to questions of access to health care or medicines, let alone inequitable access thereto. Strasbourg judges usually show self-restraint in the field of health given that member states retain a wide margin of appreciation. Yet interestingly, in several cases, the court had to assess applicants' vulnerability in the context of COVID-19 in order to determine whether their life and health were particularly at risk. In the case of *Fenech v. Malta* of March 1, 2022, the applicant, a prisoner with only one kidney, was invoking articles 2 and 3 of the ECHR, complaining that authorities had failed to protect his health and life in prison despite his particular vulnerability to a COVID-19 infection.[58] Strasbourg judges examined whether the applicant's life was genuinely at risk, considering the global mortality rate of COVID-19 (section 105), as well as the applicant's individual vulnerability to the infection, which he failed to prove. Although a consultant surgeon had indicated that his lack of a kidney could increase the risk of severe complications from COVID-19, no further studies were provided to support this claim. The court did not exclude the potential applicability of article 2 to COVID-19 cases (section 107)—for instance, to the most vulnerable, such as those with cardiovascular disease, diabetes, chronic respiratory disease, or cancer (section 137)—but the risks for the applicant himself were not high enough (or not properly demonstrated) to trigger applicability of article 2 of the ECHR on the right to life.

On the contrary, in the case of *Riela v. Italy* of November 9, 2023, the applicant, a 67-year-old prisoner suffering from several diseases, "including a severe obstructive sleep apnoea syndrome, obesity, type 2 diabetes and hypertensive cardiopathy" (section 3), was considered by the court to be vulnerable because he was "exposed to significant risk of complications in the event of contracting COVID-19" (section 20).[59] As a consequence, domestic authorities had to take into account his particular vulnerability when providing health care or protecting the applicant from getting infected. Indeed, the applicant was placed in a single cell and received a vaccine, which successfully prevented him from getting infected (section 20). Judges thus rejected the complaint based on article 2 ECHR on the right to life, because "the applicant [had] not provided sufficient evidence that the domestic authorities [had] failed to protect him from the risk of contracting COVID-19 and that, as a consequence, he [had been] exposed to a serious risk of death."[60] Nevertheless, it still found a violation of article 3 of the ECHR—not for COVID-19-related care but for prior and continued delays in providing the applicant with a ventilator for his sleep apnea since 2018 (sections 8, 36).

In the aforementioned case of *Fenech v. Malta*, the applicant had failed to prove that he was among "the most vulnerable" and his life was at risk. Yet judges still observed that it may still not be feasible, due to the practical demands of imprisonment and the unprecedented circumstances, to accommodate and provide for safer quarters to all vulnerable prisoners. They concluded that national authorities did not fail to secure the applicant's health and that there had been no violation of article 3 of the ECHR either (sections 142–143).

Surprisingly, none of the DH-BIO's COVID-19-related statements have been used to identify vulnerabilities, whereas judges have used similar Council of Europe instruments when ruling on prison-related issues.[61] Referring to the ECSR or DH-BIO statements could have led to considering prisoners as a vulnerable group, instead of having to prove a heightened vulnerability among an already vulnerable group. In the case of *Fenech v. Malta*, this could, for instance, have facilitated the demonstration of sufficiently high risks to health to trigger applicability of article 2 of the ECHR, or it could have weighed more heavily when assessing the alleged violation of article 3 of the ECHR, in the proportionality analysis of prison measures to prevent and limit the spread of the virus. Yet, as Strasbourg judges have noted in the past, "it is for the Court to decide which international instruments and reports it considers relevant and how much weight to attribute to them," be they binding or nonbinding.[62] But interestingly, the recent 2023 Committee of Ministers recommendation has been prepared by the DH-BIO and thus might constitute a more impactful medium to spread its work.[63] Although this is soft law, such recommendations to member states falling under article 15.b of the Statute of the Council of Europe benefit from a potentially high level of implementation because their adoption requires a unanimous vote and thus implies a "European consensus" between member states.[64]

The actual impact of these nonbinding instruments reacting to the COVID-19 pandemic will require further attention from legal scholars in the future, as COVID-19 jurisprudence is likely to grow tremendously in the coming years in view of the progressive exhaustion of domestic remedies and as the implementation of health-related Council of Europe treaties expands.[65]

Implementation in the Council of Europe's health-related treaties

As explained above, the Oviedo Convention is central to the question of equitable access to health care of appropriate quality because it enshrines this principle in its article 3. Both of DH-BIO's previously mentioned COVID-19 statements are nonbinding developments of this article. However, it is not possible to precisely identify how this provision is being implemented in national laws.

The CDBIO (formerly DH-BIO) is not a monitoring committee that examines and reports on countries' implementation of the Oviedo Convention, similar to the way that other committees, such as the ECSR and Medicrime Committee, monitor their respective instruments. Rather, the CDBIO's mandate is to evaluate relevant activities and advise the Committee of Ministers on future priorities in the field of biomedicine and health. Moreover, even if the Oviedo Convention has been used in the past against a member state who has not ratified it, in practice it is only rarely explicitly used as an interpretation tool by the European Court of Human Rights, especially in proportion to the high density of bioethics case law.[66] Up to now, article 3 has not been explicitly used in COVID-19 jurisprudence.

The Medicrime Convention has also never been cited in the case law of the ECSR or of the European Court of Human Rights, let alone in a COVID-19 case revolving around equitable access to quality medicines. However, this is less of a problem, for two reasons.

First, this can be explained by the fact that the Medicrime Convention is still relatively new. It was adopted in 2011 and entered into force only in 2016. To date, 23 states have ratified the convention, with a recent and continuous progression (five new signatures since 2023) showing the interest of countries including outside the Council of Europe (eight of the ratifying countries are non-member states).[67] Effective implementation and actual efficacy of this treaty will undeniably depend on further ratifications and implementation experiences.

Second, it is interesting to note that the Medicrime Convention promises to be all the more impactful given that the very content of its provisions paves the way for its future effective implementation by ensuring technical cooperation and effective monitoring.[68] In fact, the instrument provides for operational oriented provisions: it very concretely organizes the cooperation between state parties as well as between relevant administrations across sectors such as health authorities, customs, police, and others (article 17). The Medicrime Secretariat is already conducting a research project aimed at assessing countries' needs in effectively implementing this cooperation and providing technical support to improve and strengthen international cooperation.[69]

Finally, beyond this technical cooperation, the Medicrime Convention provides for the creation of a monitoring body to oversee implementation: the Medicrime Committee (article 23). As underlined by Marten Breuer, "in terms of implementation effectiveness, the existence or non-existence of monitoring mechanisms is of paramount importance," as without such a mechanism, "states are called upon to judge for themselves the conformity of their behavior with the treaty rules" and hence may claim conformity where other states or a monitoring body may claim otherwise.[70] This monitoring of the Medicrime Convention started only recently, in 2020, first with a questionnaire to state parties, and then with another questionnaire the following year focusing on the context of pandemics.[71] Hence, its effective implementation in favor of equitable access to quality health care for patients may just be a matter of time.

Conclusion

The Council of Europe is without a doubt bringing an added value to discussions on equitable access to health care of appropriate quality. Its relevant provisions are enshrined in specialized binding treaties that are unique in the international legal sphere. Its organs have quickly used their soft law powers to concretely interpret and operationalize the principle of equitable access to health care of appropriate quality in contexts such as a pandemic or major shortage. Its judges, experts, and monitoring committees are acknowledging the particular needs of vulnerable groups in accessing health care of appropriate quality. These actors are encouraged to take into account other Council of Europe soft law tools in their activities, thus guaranteeing a circulation and visibility of COVID-19 nonbinding norms in their case law. However, they remain in control of which instruments they refer to and how much weight is placed on these instruments in their review of an individual case—and, most of all, they remain bound by the obligation to respect national sovereignty and states' wide margin of appreciation in the field of public health. Yet as COVID-19 jurisprudence continues to emerge, the principle of equitable access to health care of appropriate quality may be attributed more demanding obligations for states to prepare for the unavoidable next pandemic.

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References

1. Committee of Ministers, Recommendation CM/Rec(2023)1: Equitable Access to Medicinal Products and Medical Equipment in a Situation of Shortage (2023), preamble.

2. J. Ferrero, «Conseil de l'Europe: cadre institutionnel,» *Répertoire de droit européen* (July 2022), sec. 13.

3. Convention on the Elaboration of a European Pharmacopoeia, European Treaty Series No. 050 (1964).

4. Convention on the Counterfeiting of Medical Products and Similar Crimes involving Threats to Public Health (Medicrime Convention), European Treaty Series No. 211 (2011).

5. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), European Treaty Series No. 164 (1997); Council of Europe, "Chart of Signatures and Ratifications of Treaty 164," https://www.coe.int/fr/web/conventions/full-list?module=signatures-by-treaty&treatynum=164.

6. Oviedo Convention (see note 5), explanatory memorandum, secs. 26–27.

7. Ibid., explanatory memorandum, sec. 25.

8. Ibid., arts. 29, 32.

9. DH-BIO, Strategic Action Plan on Human Rights and Technologies in Biomedicine (2020–2025) (2019), secs. 8, 9, 17.

10. European Social Charter (Revised), European Treaty Series No. 163 (1996); *FIDH v. France*, European Committee of Social Rights, No. 14/2003, decision on the merits of November 3, 2004, sec. 31.

11. *International Commission of Jurists (ICJ) v. Portugal*, European Committee of Social Rights, complaint no. 1/1998, decision on the merits of September 9, 1999, sec. 32.

12. European Committee of Social Rights, Conclusions 2005: Statement of Interpretation – Article 11 (2005).

13. For a complete overview, see *Lopes de Sousa Fernandes v. Portugal*, European Court of Human Rights, application no. 56080/13, judgment of December 19, 2017, secs. 29–43. For further analysis, see L. Peroni and A. Timmer, "Vulnerable Groups: The Promise of an Emerging Concept in European Human Rights Convention Law," *International Journal of Constitutional Law* 11/4 (2013); É. Paillissé, *Le droit à la santé dans la jurisprudence de la Cour européenne des droits de l'homme* (Perpignan: University of Perpignan Via Domitia, 2018).

14. For more on the definition of soft law, see A. Boyle, "The Choice of a Treaty: Hard Law versus Soft Law," in S. Chesterman, D. M. Malone, and S. Villalpando (eds), *The Oxford Handbook of United Nations Treaties* (Oxford: Oxford Handbooks, 2019).

15. J. Cazala, "Le *Soft Law* international entre inspiration et aspiration," *Revue interdisciplinaire d'études juridiques* 1/66 (2011), p. 49.

16. Committee on Bioethics (DH-BIO), DH-BIO Statement on Human Rights Considerations Relevant to the COVID-19 Pandemic, DH-BIO/INF(2020)2 (2020); DH-BIO, COVID-19 and Vaccines: Ensuring Equitable Access to Vaccination during the Current and Future Pandemics (2021).

17. European Committee of Social Rights, Statement of Interpretation on the Right to Protection of Health in Times of Pandemic (2020).

18. Committee of Ministers (see note 1), art. 3 and its explanatory memorandum, secs. 6–7.

19. DH-BIO (2021, see note 16), secs. 23–30.

20. Medicrime Committee, Advice on the Application of the Medicrime Convention in the Context of Counterfeit COVID-19 Vaccines (2021).

21. A. Ruckert, K. Zinszer, C. Zarowsky, et al., "What Role for One Health in the COVID-19 Pandemic?," *Canadian Journal of Public Health* 111 (2020), p. 643.

22. Committee of Ministers (see note 1), explanatory memorandum, sec. 21.

23. DH-BIO (2021, see note 16), secs. 2–3.

24. DH-BIO (2020, see note 16), p. 2; DH-BIO (2021, see note 16), sec. 9.

25. Committee of Ministers (see note 1), art. 5. For the specific examples of vulnerable groups, see Committee of Ministers (see note 1), explanatory memorandum, sec. 29.

26. Committee of Ministers (see note 1), art. 6.

27. European Committee of Social Rights (2020, see note 17), p. 4.

28. Referring to *International Association Autism-Europe v. France*, European Committee of Social Rights, complaint no. 13/2002, decision on the merits of November 4, 2003, sec. 53.

29. European Committee of Social Rights (2020, see note 17), p. 4.

30. European Committee of Social Rights (2005, see note 12).

31. European Committee of Social Rights (2020, see note 17), p. 6.

32. Ibid., pp. 3–5.

33. Committee of Ministers (see note 1), art. 7; DH-BIO (2021, see note 16), sec. 5.

34. DH-BIO (2021, see note 16), secs. 9–22; Committee of Ministers (see note 1), explanatory memorandum, secs. 30, 62.

35. CDBIO, *Guide to Health Literacy: Contributing to Trust Building and Equitable Access to Healthcare* (2023), p. 4.

36. DH-BIO (2019, see note 9), pp. 11–12.

37. Medicrime Committee (2021, see note 20), appendix, sec. 7.

38. Ibid., sec. 4.

39. Medicrime Convention (see note 4), explanatory report, sec. 3.

40. S. Negri, "The MEDICRIME Convention: Combating Pharmaceutical Crimes through European Criminal Law and Beyond," *Journal of European Criminal Law* 7/3 (2016), p. 358.

41. Ibid., p. 352; A. Lavorgna, "The Online Trade in Counterfeit Pharmaceuticals: New Criminal Opportunities, Trends and Challenges," *European Journal of Criminology* 12/2 (2015).

42. As noted by the then director of EDQM: S. Keitel, "The MEDICRIME Convention: Criminalizing the Falsification of Medicines and Similar Crimes," *Generics and Biosimilars Initiative Journal* (2012), p. 138.

43. Committee of Ministers (see note 1), art. 19(1).

44. DH-BIO (2021, see note 16), sec. 27.

45. For example, K. *Perehudoff, H. Qazilbash, and K. Figueras de Vries, "A Needle in a Haystack? Human Rights Framing at the World Trade Organization for Access to COVID-19 Vaccines," Health and Human Rights Journal 24/2 (2022); J. Kohler, A. Wong, and L. Tailor, "Improving Access to COVID-19 Vaccines: An Analysis of TRIPS Waiver Discourse among WTO Members, Civil Society Organizations, and Pharmaceutical Industry Stakeholders," Health and Human Rights Journal 24/2 (2022).*

46. Medicrime Convention (see note 4), explanatory memorandum, sec. 42.

47. On the subject, see M. Breuer, "Impact of the Council of Europe on National Legal Systems," in S. Schmahl and M. Breuer (eds), *The Council of Europe: Its Law and Policies* (Oxford: Oxford University Press, 2017), secs. 36.03 et seq.; Council of Europe Directorate General Human Rights and Rule of Law, *Practical Impact of the Council of Europe Monitoring Mechanisms in Improving Respect for Human Rights and the Rule of Law in Member States* (Strasbourg: Council of Europe, 2014).

48. *Tanase v. Moldova*, European Court of Human Rights, application no. 7/08, judgment of April 27, 2010, sec. 176.

49. *Demir and Baykara v. Turkey*, European Court of Human Rights, application no. 34503/97, judgment of November 12, 2008, sec. 86.

50. *Demir and Baykara v. Turkey*, European Court of Human Rights, application no. 34503/97, judgment of November 12, 2008, secs. 74–75.

51. Breuer (see note 47), sec. 36.91; see also J.-F. Flauss, "L'effectivité et l'efficacité de la soft law européenne dans la jurisprudence de la Cour européenne des droits de l'homme," in J. Iliopoulos-Strangas and J.-F. Flauss (eds), *The Soft Law of European Organisations* (Baden-Baden: Nomos, 2012), pp. 333–367.

52. C. Nivard, *La justiciabilité des droits sociaux : Étude de droit conventionnel européen* (Brussels: Bruylant, 2012); European Social Charter (Revised) (see note 10), arts. C, D.

53. European Committee of Social Rights (2020, see note 17).

54. Latest example: European Committee of Social Rights, Conclusions XXII-2: Czech Republic – Article 11-3 (2022).

55. *International Commission of Jurists (ICJ) and European Council for Refugees and Exiles (ECRE) v. Greece*, European Committee of Social Rights, complaint no. 173/2018, decision on the merits of January 26, 2021, sec. 229.

56. *Open Society European Policy Institute (OSEPI) v. Bulgaria*, European Committee of Social Rights, complaint no. 204/2022, decision on admissibility and immediate measures of October 18, 2022, sec. 1.

57. *Validity Foundation v. Finland*, European Committee of Social Rights, complaint no. 197/2020, decision on admissibility of September 8, 2021.

58. *Fenech v. Malta*, European Court of Human Rights, application no. 19090/20, judgment of March 1, 2022.

59. *Riela v. Italy*, European Court of Human Rights, application no. 17378/20, judgment of November 9, 2023.

60. Ibid., secs. 21–22.

61. *Fenech v. Malta* (see note 58), secs. 19–33. See, for instance, European Committee for the Prevention of Torture, Statement of Principles relating to the Treatment of Persons Deprived of Their Liberty in the Context of the Coronavirus Disease (COVID-19) Pandemic, CPT/Inf(2020)13 (2020), sec. 6. For further analysis, see A. Glazewski, "Le contentieux COVID-19 devant la Cour européenne des droits de l'homme," *RDLF* 39 (2023), p. 6.

62. *Tanase v. Moldova* (see note 49), sec. 176.

63. DH-BIO (2019, see note 9).

64. Article 20.a.i of the Council of Europe Statute, ETS 1, London, 5 May 1949; see also Breuer (see note 47), sec. 36.91; K. Dzehtsiarou, *European Consensus and the Legitimacy of the European Court of Human Rights* (Cambridge: Cambridge University Press, 2015).

65. Glazewski (see note 61).

66. *Bataliny v. Russia*, European Court of Human Rights, application no. 10060/07, judgment of July 23, 2015, sec. 55; European Court of Human Rights, *Research Report: Bio-*

ethics and the Case-Law of the Court (Strasbourg: Council of Europe, 2012), p. 52. See also CDBIO semester reports on ECHR bioethics case law: https://www.coe.int/en/web/bioethics/european-court-of-human-rights.

67. Council of Europe, "Chart of Signatures and Ratifications of Treaty 211," https://www.coe.int/fr/web/conventions/full-list?module=signatures-by-treaty&treatynum=211.

68. Keitel (see note 42), p. 139.

69. Medicrime Secretariat, *Gap Analysis Report: Needs Assessment – Falsified Medical Products (NA-FAMED) of the Medicrime Convention* (Strasbourg: Council of Europe, 2021); Council of Europe, "CRIMFAMED Project: Countering Falsified Medical Products – Global Programme," https://www.coe.int/en/web/medicrime/crimfamed.

70. Breuer (see note 47), sec. 36.17.

71. Medicrime Committee, "General Overview Questionnaire on the Implementation of the Medicrime Convention" (July 7, 2020), https://rm.coe.int/medicrime-country-profile-questionnaire-en/1680a18a01; Medicrime Committee, "Questionnaire for the 1st Thematic Monitoring Round: The Protection of Public Health through the Medicrime Convention in Times of Pandemics" (May 27, 2021), https://rm.coe.int/t-medicrime-2021-01-questionnaire-1st-thematic-monitoring-round-pandem/1680a3156c.

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Truth and Reconciliation Commissions and Health Care System Responses for Indigenous Peoples: A Scoping Review

SARAH LARSON, CORTEZ STANDING BEAR, DEVON OLSON, AND NICOLE REDVERS

Abstract

Grounded in human rights approaches, truth and reconciliation commissions (TRCs) explore an event or process that did widespread and systematic intentional harm to a group of people. Health as a fundamental right is an important component addressed by TRCs. Yet despite TRCs often having recommendations for health care systems, it is unknown how well these recommendations are being translated within health care settings. Therefore, the overarching purpose of our scoping review was to identify academic articles that discussed health care system discourse or responses to TRCs in the context of Indigenous Peoples. Our thematic analysis of the included articles identified three main themes for health care system responses to TRCs: (1) the acknowledgment of multiple ways of knowing, being, and doing in health systems; (2) current interventions as responses within health systems; and (3) suggestions for change within health systems. Although a TRC may create a specific road map and mandate for health care systems, we found considerable variability in the uptake of these actions across institutions. Concerted efforts within and around health care systems and across sectors are therefore necessary to achieve large-scale, meaningful change for Indigenous Peoples post-TRCs and to maintain accountability as a foundational human rights principle.

Sarah Larson is an MPH graduate with a focus on Indigenous health in the School of Medicine and Health Science at the University of North Dakota, Grand Forks, United States.

Cortez Standing Bear is an MPH student specializing in population health research and analytics in the School of Medicine and Health Science at the University of North Dakota, Grand Forks, United States.

Devon Olson, MLIS, AHIP, is a research and education librarian in the School of Medicine and Health Science at the University of North Dakota, Grand Forks, United States.

Nicole Redvers, ND, MPH, is an associate professor in the Schulich School of Medicine and Dentistry at the University of Western Ontario, London, Canada, and an adjunct professor in the Department of Indigenous Health at the University of North Dakota, Grand Forks, United States.

Please address correspondence to Sarah Larson. Email: sarahjlars@outlook.com.

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Introduction

Grounded in human rights approaches, truth and reconciliation commissions (TRCs) create platforms and space to explore an event or process that did widespread and systematic intentional harm to a group of people from human rights violations. Typically established at the national level by a governing body, TRCs are an opportunity to uncover, explore, and acknowledge wrongdoings in a specific context. TRCs have been established for various reasons and have become increasingly common in certain regions around the globe that have faced political strife.[1]

TRCs are very relevant to Indigenous Peoples due to many nationwide policies and practices having systematically worked against Indigenous Peoples' health and well-being in countries such as the United States and Canada. The "truth" portion of TRCs explores history and seeks to uncover previous wrongdoings, and the "reconciliation" part of TRCs focuses on healing and moving forward. For example, in 2015, born out of the Indian Residential Schools Settlement Agreement, the Truth and Reconciliation Commission of Canada reported its findings on the injustices done to Indigenous Peoples within Canada, particularly within the residential school system.[2] The commission detailed a way forward, with seven "calls to action" specific to health.[3] Other TRCs specific to Indigenous Peoples include the recent commissions established within the Nordic countries of Sweden, Finland, and Norway seeking a path forward for reconciliation with Sámi Peoples.[4] The state of Victoria in Australia has also been active in TRC efforts since 2020, and the state of Maine in the United States established a TRC in 2012.[5] While some TRCs, such as in Canada, are born out of legal settlements at the national or international level, others, such as those in the Nordic region, have been more inspired by social and political movements.[6] Although these commissions may not be focused solely on health, the need for healing has been deeply embedded in many of their processes.

Nations must recognize the human rights violations that have occurred due to colonization and the harm it has caused to Indigenous Peoples and their health.[7] The TRC process may be one pathway to accountability and may act as an impetus for health care systems to uphold human rights. The World Health Organization recognizes the right to health for all peoples, without discrimination, via services that are culturally acceptable, yet it is currently unclear how TRCs may help fulfill this right. That said, TRCs may be an effective mechanism for beginning the process of healing within communities and reversing the complex health disparities that are present within Indigenous communities globally by creating guidance around how to fulfill the human right to health within health care systems.[8]

Despite TRCs (both established and in progress) often having provisions for health care systems, it is unknown the extent to which TRCs' recommendations are applied to health care settings.[9] There has been no widespread examination of TRCs' involvement in health care, particularly in the context of Indigenous health. Therefore, the overarching purpose of our scoping review was to identify academic articles that discuss health care system discourse or responses to TRCs internationally in the context of Indigenous Peoples. The specific objectives of our review were to identify specific health system responses to TRCs in the context of Indigenous health, as well as any current recommendations, gaps, and ongoing discussions.

Positionality

"Nothing about us, without us" is an increasingly applied concept in academic writing.[10] Given this, it is best practice to ensure that authors, when writing by or about Indigenous Peoples, position themselves in relation to the work.[11] The first author of this paper (SL) is of settler descent participating as an ally in this work and is currently based in the United States. The second author (CSB) is a member of the Oglala Sioux Tribe and is currently based in the United States. The third author (DO) is of settler descent participating in this work as a medical research librarian and ally and is currently based in the United States. The senior author (NR) is an Indigenous health scholar and a member the Deninu K'ue First Nation and is currently based in Canada.

Methods

Overall design

This scoping review follows the framework developed by Hilary Arksey and Lisa O'Malley, further refined by Micah Peters et al.[12] The search process was co-created with a medical research librarian (DO) and conducted systematically. A protocol was published within the Open Science Framework on September 30, 2022.[13] The PRISMA-ScR extension was used for ensuring appropriate reporting standards for scoping reviews.[14] Our specific research question for this review was, What health care system discourse or responses exist as a result of truth and reconciliation commissions in the context of Indigenous Peoples?

Eligibility criteria, procedures, and search terms

We searched the following electronic databases using Boolean phrases and key terms to identify relevant studies: PubMed, Embase (Elsevier), CINAHL (EBSCO), Web of Science (Clarivate), and Academic Search Ultimate (EBSCO). Our specific search terms varied by database and represented combinations of the terms "truth commission," "truth and reconciliation," "health," "medicine," "wellness," "primary care," "emergency care," "tertiary care," "hospital," and "clinic" (see Table 1 for an example search strategy and Appendix A—available from the authors—for the full search strategy). We then searched Google Scholar by reviewing the first two pages, and then subsequently screened the next set of two pages until no article titles within our inclusion criteria were found. We then completed manual searches for relevant articles in the iPortal Indigenous Studies Portal, Native Health Database, *International Journal of Indigenous Health*, *International Indigenous Policy Journal*, *Turtle Island Journal of Indigenous Health*, and *Journal of Indigenous Wellbeing-Te Mauri Pimatisiwin*. We also searched the reference lists of key articles to further identify relevant articles. All articles identified as part of the search strategy were transferred into Covidence review software (v2721 a9510157) to facilitate the selection process.

Article screening

For the purposes of article selection, we defined a health care system as any system, program, or field that influences the delivery of health care. In this light, we included academic articles that discussed health system discourse or responses to TRCs that related specifically to Indigenous Peoples. Articles had to therefore mention both TRCs and an aspect of health care systems, as well as to have a focus on Indigenous Peoples. We included articles if they were published after the establishment of a TRC process or as a direct result. For the purposes of this review, we utilized the United Nations system's understanding of Indigenous Peoples, which is based on the following characteristics:

> *self-identification as [I]ndigenous [P]eoples at the individual level and accepted by the community as their member; historical continuity with pre-colonial and/or pre-settler societies; strong link to territories and surrounding natural resources; distinct social, economic or political systems; distinct language, culture and beliefs; form non-dominant groups of society; resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.*[15]

We included only those articles written in English, with no limits on the date of publication. There

Table 1. Example search strategy

Database	Search terms
Academic Search Ultimate	(DE "truth commissions" OR "truth and reconciliation" OR "truth commission") AND ((DE "health") AND (DE "medicine") OR health OR medicine OR medical OR wellness OR "primary care" OR "emergency care" OR "tertiary care" OR hospital OR clinic)

were no restrictions on article type as long as it was published in an academic journal.

For our scoping review, we engaged a two-stage article review process. The title and abstract screening stage included 100% double screening by two independent reviewers (SL and CSB). A third reviewer (NR) was brought in whenever there were cases of discrepancies, which were subsequently resolved by discussion. The full-text screening stage was completed 100% by one reviewer (SL), with a 25% double screening process (CSB) to ensure consistency, and a third reviewer (NR) brought in for any discrepancies, which were resolved by discussion.

Data characterization, summary, and synthesis

We extracted data from the relevant articles and charted them in Excel 365. These data included general article information, type of article, level or sector of health care, rural or urban setting (if known), geographic location, specific Indigenous population (if specified), and name of the TRC or truth commission involved. We uploaded included articles to NVivo software for the coding process. Articles were coded for commission responses and contexts via an inductive process to identify themes through thematic analysis as described by Virginia Braun and Victoria Clarke.[16] We tracked the stages of coding through analytic folders while refining, defining, and naming the themes. We had one author (SL) carry out the preliminary coding, and we brought in a second author (NR) for discussion and coding audit that led to ongoing refining of the codes and themes.

Results

Of the 906 articles imported for screening, 48 met the inclusion criteria (see Figure 1). Despite our search strategy being globally inclusive (i.e., no limitations on region), all 48 articles were in response to the Truth and Reconciliation Commission of Canada. The included articles represented many different health system professional fields, including occupational therapy, nursing, and physiotherapy, as well as varied sub-specialties. Some of the included articles focused on health care delivery more broadly, such as in the primary care setting. Additional articles addressed the larger health care systems in place that include hospital systems, policies, and interdisciplinary collaboration. The majority of the included articles were published relatively recently, with the oldest article dating back to 2016 (see Figure 2). (Appendix B, available from the authors, provides the full data extraction for all included articles.)

TRC responses

Our thematic analysis identified three main themes for health care system responses to TRCs in the reviewed literature: (1) the acknowledgment of multiple ways of knowing, being, and doing in health systems; (2) current interventions as responses within health systems; and (3) suggestions for change within health systems, which itself had seven sub-themes (see Table 2).

The acknowledgment of multiple ways of knowing, being, and doing in health systems

Health care services in Canada are currently created and maintained by a Euro-Western system that many articles challenged as not adequately serving Indigenous Peoples. To move forward in enacting truth and reconciliation in health care, seven articles stated that fundamental assumptions and understandings about health care must be evaluated from, and more integrated with, an Indigenous perspective (i.e., one that acknowledges explicitly multiple ways of knowing, being, and doing).[17] Some articles discussed epistemic racism within the system, which is "the privileging of one knowledge system over another."[18] Authors from one article highlighted the Euro-Western-dominated worldview in health care, where colonialism and structural racism remain ingrained: "entrenched structural racism persists and, we believe, impedes meaningful application of cultural safety and humility across the human service sector … chaotic emergency rooms are built upon colonial administrative systems."[19]

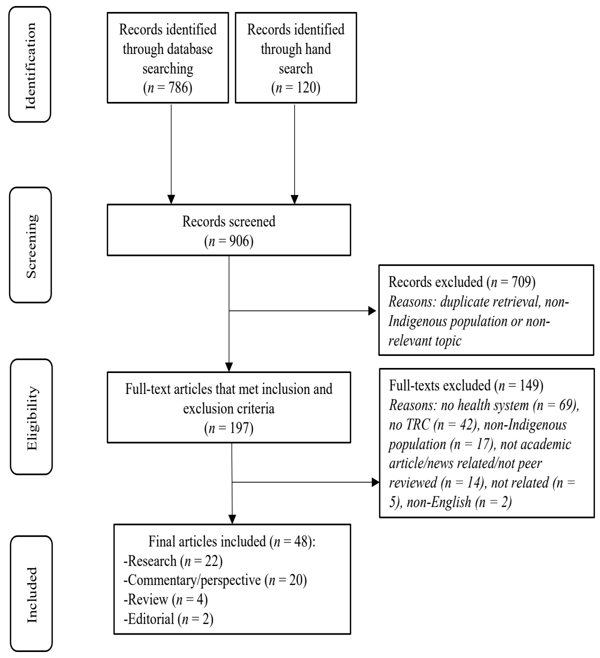
Additionally, an evaluation of the client-centered enablement model was found to not be appropriate in Indigenous contexts because "the model itself is developed within a colonial, Eurocentric context."[20] Better acknowledgment of multiple ways of being (i.e., moving away from colonial systems) lies in what they call "micro reconciliation," which builds on cultural safety to shape everyday interactions to better reflect overall reconciliation efforts.[21] Micro reconciliation is to be implemented at a systems level with "administrative and practitioner levels of engagement."[22] Another article argued that quality health care delivery for Indigenous Peoples in Canada is dependent on both individual and institutional reflection and change.[23]

Dominique Fijal and Brenda Beagan created a new theory based on the established "Two-Eyed Seeing" approach ("the gift of multiple perspectives") that incorporates balance, spirituality, community, and meaning in order to address the need for a better health system response to the TRC.[24] Another form of health system response proposed was to platform "epistemic pluralism" (i.e., acknowledging multiple ways of knowing) where dialogue and mutual understanding exist between Western evidence-based practice and Indigenous healing practices to better provide appropriate care.[25] One example of epistemic pluralism in practice was embodied in a qualitative study in which the First Nations individuals interviewed called for the increased integration of traditional healing practices in the health care system, including destigmatization, collaboration, the application of practices, and funding.[26] An article in the field of occupational therapy further identified the need for incorporating epistemic pluralism into their practice, stating that "Canadian occupational therapists working with Indigenous Peoples are armed with models of practice that do not reflect Indigenous perspectives."[27] Article authors generally found that epistemic pluralism, through micro reconciliation and the adoption of theoretical approaches in operations, such as Two-Eyed Seeing, is needed as part of the reconciliation process.

Current interventions as responses within health systems

Fourteen of the included articles discussed current interventions or strategies that exist in response to

Figure 1. Adapted PRISMA flow chart



the TRC, some seeking to respond directly to the TRC's calls to action.[28] For example, one identified program hired Elders as allied health professionals, while another incorporated Elders in primary care teams and direct patient care.[29] Another project used a "Two Row Wampum" approach to further tuberculosis programming as part of a broader human rights effort to promote health outcomes for Indigenous communities within the Canadian prairies.[30] The "Wellness Wheel" clinics additionally used a unique hub-and-spoke model to serve remote communities in a culturally safe way.[31]

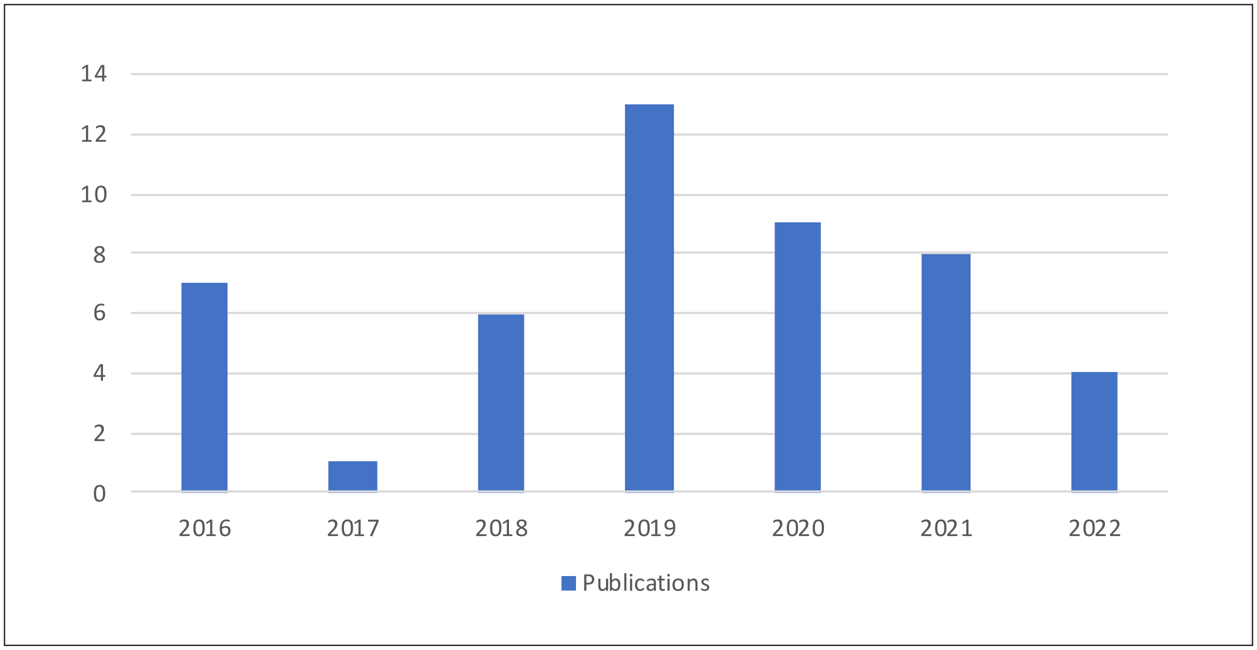
Many programs featured traditional healing options within the clinical setting, such as creating space in a hospital to hold ceremonies, for smudging, or to meet with healers, as well as ensuring that other forms of cultural supports are available.[32] The Nîsohkamâtowak program specifically integrates Indigenous practices and perspectives to serve those seeking kidney care in northern Saskatchewan via a partnership with First Nations and Metis Health Services.[33] Other approaches for diabetes trauma-informed care have emerged via guidance from Elders and Indigenous Peoples.[34] To better understand and plan how to integrate traditional practices within health care, a video and discussion guide was created by the intercultural Online Health Network at the University of British Columbia.[35]

Aside from programmatic-level activities and efforts, systems-level interventions have been identified as a response to the TRC within health systems. For example, the First Nations Health Authority was established in 2013 and was a significant transformation of the health governance structure toward self-determination that emulated the TRC recommendations that were concurrently in process at the time.[36]

Suggestions for change within health systems

Forty-seven articles presented various suggestions for change within health systems. More specifically, many of the included articles in this section outlined suggestions or recommendations for how to implement the TRC calls to action in the health care system. Notably, the need for cultural safety training was referenced in 27 out of the 48 articles. In addition, 15 of the 47 articles called for some recognition or incorporation of Indigenous knowledges or healing practices in the health care setting. There were seven associated sub-themes identified under this theme of "suggestions for change," as discussed below.

FIGURE 2. Dates of publication of the included articles



Individual-level TRC responses. Responses to the TRC in the health care setting can occur at several levels. At the individual level, many articles recognized that individual health care providers have a responsibility to engage with reconciliation.[37] There were calls for health professionals, especially those in leadership positions, to personally read, understand, and engage with the TRC report directly.[38] Caroline Tait, William Mussel, and Robert Henry wrote, "recognizing what aspects of the TRC's Calls to Action are in one's own personal power to put into practice begins a process of challenging systems that underlie settler colonialism."[39] Some articles suggested that once professionals are familiar with the TRC and its calls to action, they in turn can bring about discussion in their respective organizations and sectors.[40] These actions were stated to be imperative because "a renewed commitment and concrete steps are needed by non-Indigenous leaders and allies to support this decolonizing work so that it does not fall solely upon First Nations, Inuit, and Metis Peoples."[41] Overall, many of the articles called on Indigenous and non-Indigenous health professionals to be personally engaged in the reconciliation processes.

Cultural safety integration across health systems. One of the most frequently cited elements for change was through culturally safe practices and training within health systems.[42] The TRC calls to action specifically refer to the provision of "cultural competency" training; however, most of the articles within this section advocated for "cultural safety training" instead, with a focus on "power imbalances that characterize encounters in clinical settings."[43] In this regard, many articles called for cultural safety training that contextualizes Indigenous health within the understanding of past and ongoing colonization.[44] Colonization must be understood as one of the "upstream causes of poor health," and "the need for health care providers to understand how colonization affects the health and wellbeing of Indigenous [P]eople is compulsory."[45]

Cultural safety modules that have been established may differ across organizations. For example, one study evaluated the "Indigenous relationship and cultural safety" courses in nursing as an effective way to gain knowledge and skills.[46] Not only did the online course increase users' knowledge, but users also reported the ability to apply that knowledge in practice. Another article, however, emphasized that cultural safety as a model was an important step, yet it may not be enough without considering how to fully revise mainstream Western models while "honouring our past and reconciling with history."[47]

Table 2. Main themes and sub-themes identified in the scoping review

Themes	Sub-themes
The acknowledgment of multiple ways of knowing, being, and doing in health systems	N/A
Current interventions as responses within health systems	N/A
Suggestions for change within health systems	Individual-level TRC responses
	Cultural safety integration across health systems
	Inclusion and belonging of Indigenous healing practices
	More Indigenous health professionals and leadership
	Respectful partnerships
	Indigenous strengths-based approaches
	Collective and systemic institutional responses

Inclusion and belonging of Indigenous healing practices. Colonization has enabled the suppression and stigmatization of Indigenous knowledge systems, structures, and healing practices. The TRC calls to action specifically reference the need to return to Indigenous healing traditions as part of the reconciliation process.[48] Bringing Indigenous cultural practices and wellness concepts into care delivery has been shown to improve mental health, and there were calls in some of the articles to expand these offerings within health care settings.[49] For example, Indigenous patients have vocalized the desire for increased culturally appropriate services that may include Elders and healers.[50] With this, the integration of Elders in health care settings has been shown to be a successful approach as a response to the TRC calls to action.[51]

A survey of rheumatologists across Canada found that they generally support the integration of Indigenous healing practices.[52] However, Logan emphasized that while physicians generally seemed open to a differing worldview, "it is important for physicians not to judge, nor to simply learn about Indigenous healing practices, but rather to create space for these practices as an act of reconciliation."[53] To consider the bridging of Western health systems with Indigenous healing practices, it is important that Indigenous healing practices be truly respected.[54] Definitions of health and wellness should also be adapted to Indigenous perspectives, while addressing misconceptions about traditional healing.[55] The recognition of the importance of Indigenous healing methods must occur because "in reality, many … [First Nations P]eople are already making these choices to apply traditional healing for their wellbeing," and there are consistent calls for ensuring a collaborative approach to care.[56]

More Indigenous health professionals and leadership. The TRC calls to action advocate for an increase in Indigenous health professionals and health system leaders. Many articles noted that Indigenous health professionals and leaders can help provide culturally safe and appropriate care as well as assist organizations in creating systems to do the same.[57] The recruitment and retention of Indigenous health care workers are also stated to be important, in addition to actually listening to their guidance.[58] These elements (i.e., increasing, retaining, and listening to Indigenous health professionals) must occur in tandem. While increasing the recruitment and retention of Indigenous health professionals is important, systems must also work to ensure safe spaces, inclusion, belonging, and therefore effective care for Indigenous and all patients.[59]

In general, Indigenous leadership was noted to be an important factor in instigating changes in health care systems. This change was not only in the case of Indigenous health professionals serving clients directly, but also in cases where Indigenous leaders were active decision-makers and policy makers within the health system.[60] Indigenous health system leaders can help integrate Indigenous perspectives in decision-making, "rather than preserving norms of colonial control."[61]

Respectful partnerships. Directed by Indigenous leadership, partnerships were emphasized in many of the included articles as fundamental to health systems change.[62] Partnerships should be conducted with special attention to ground them "in Indigenous collaborative approaches such as Two-Eyed Seeing and Ethical Space … mutual trust, respect, equality, and collaboration for respectful interactions of differing ways of knowing."[63] As an example, Alberta Health Services established an Indigenous Health Core Committee, which was a 55-member network that supported the creation of guiding principles and strategic directions.[64] Other partnerships were for tuberculosis care based in the spirit of the Two Row Wampum belt, and the Wellness Wheel Mobile Outreach clinic.[65] Collaborating systems are particularly important in remote areas of service, which is reflected in the Wellness Wheel model.[66]

An article by John O'Neil et al. discussed the development of partnerships as key to systems and governance changes. The authors noted that partnerships need "to be enabled by administrative and structural changes within and between partners to align with commitments" and that "reciprocal accountability requires each partner to effectively position themselves and build their capacity to support shared commitments."[67] They found the formation of individual and personal relationships to be important in facilitating and building institutional relationships and noted that those delivering health services must be part of the partnership process and implementation.[68]

Indigenous strengths-based approaches. As health systems consider adopting changes to better meet the needs of Indigenous communities in response to the TRC, there were consistent calls within the included articles for strengths-based approaches that not only recognize the importance of traditional and Indigenous knowledges and practice but also acknowledge the strengths of the communities and individuals they serve.[69] Health system changes should acknowledge and bolster the strengths within Indigenous communities instead of perpetuating a deficit-based lens. As noted by one article, "We are recommending a shift away from deficit, disease, and disparity approaches to investigation which locate the problem in the individual and instead, move towards locating areas of improvement at a larger, systems level, with a strengths-based lens to achieve health equity."[70] Such initiatives must be guided by self-determination given that Indigenous communities already host resilience and innovative leadership within them.[71]

Collective and systemic institutional responses. Institutional and system-level responses were suggested as fundamental to the TRC process for health system change. Any institutional change process was noted, however, to require "dedicated human, material, and financial resources."[72] One suggestion was that "accountability processes such as accreditation and quality reviews for hospitals and institutions must include metrics for Indigenous health equity and reconciliation" at the systems level.[73]

One article noted specific actions that leaders in the health care system should take to shift institutional response.[74] The article suggested incorporating TRC discussions into regular meetings and strategic planning; partnering with other organizations interested in the same work; and importantly, being mindful not to overburden "First Nations, Metis, and Inuit employees with the responsibility to move Truth and Reconciliation forward" in their organizations.[75] Overall, the included articles made it clear that system-level changes would require in-depth reflection and engagement, with respect for and deep involvement of Indigenous perspectives. It was suggested that models of care be broadened to include health promotion and disease prevention, with attention on the social determinants of health and the impacts of colonization at the community level.[76] One additional suggestion for a TRC-inspired health system change was a movement toward increased infrastructure at the national level to create a "centre of excellence committed to Indigenous PHC [primary health care] to strategically frame clinical services within a population health approach" as an exemplar for other health system stakeholders.[77]

Discussion

This scoping review sought to identify health system responses to TRCs in the context of Indigenous health, as well as any current recommendations and discussions. We identified three main themes: (1) the acknowledgment of multiple ways of knowing, being, and doing in health systems; (2) current interventions as responses within health systems; and (3) suggestions for change within health systems. Notably, Canada was the only TRC represented in the health care systems literature in this review. Though several other national and subnational governments are working on their unique TRC processes, there is little formal scholarship examining these processes. This gap in the literature highlights the need for increasing discussion and transparency around TRC dialogue and implementation effects for Indigenous Peoples globally.

Overall, we identified a broad range of health care system responses to the TRC in Canada. Many of the suggested responses highlighted a need for balance between individual, relational, and institutional responsibility and action for overall change. Many of the articles noted the importance of individual health care professionals and leaders personally investing in reconciliation efforts. Challenging personal assumptions and beliefs was a central tenet to transformation through processes such as mandated cultural safety training. Leaders and those engaged in providing direct care must be active participants in this work to propel policies and changes. The incorporation of Indigenous knowledges and healing traditions must be central to the TRC process for health care institutions. The spirit of reconciliation is not just one of apology and subsequent maintenance of the status quo. Instead, it is an inspiration and mandate to instigate great change to promote human rights, equity, and justice for the health of all peoples.

The articles presented many current and ongoing challenges of responding to the TRC in the Canadian health care system. At an individual level, there may continue to be a lack of recognition of the need for changes. For example, "as physicians, we may perpetuate health inequities through ignorance about colonial determinants of health, ignoring our role in perpetuating power imbalances, complicity in institutional racism, and failing to question paternalistic models of care."[78] Physicians, while often open to change, may still be hesitant to incorporate Indigenous healing practices in their care plans in cooperation with Indigenous healers. One article noted that "they would only do so if the practices were tested and shown to fulfill their western paradigm of understanding."[79] This perspective is consistent with findings from other scholarship in this area.[80] The concepts of healing and wellness often remain different for Western practitioners and their Indigenous patients, with sometimes very different goals.[81] These differing conceptualizations of care echo a similar concern found in an article investigating nurses' cultural competency, where many respondents were overly confident in their knowledge, signifying a knowledge gap.[82] Regarding individuals being agents for change in responding to the TRC, personal perceptions are a potential barrier overall. Some health professionals and leaders may not know where to begin or how to approach implementing the TRC recommendations due to the lack of discourse and understanding within their respective fields.[83] Additionally, the length and depth of attention and investment needed from individual professionals and leaders can be a challenge to accomplish the suggested action of understanding colonial histories and their implications for health inequities.[84]

The health care system serving Indigenous communities is being called to decolonize, yet there are little to no real indicators (policy or otherwise) that this is in process or is being taken seriously by high-level operational mechanisms. In this regard, there were noted gaps in accountability mechanisms for the uptake of the calls to action across the included articles. Accountability is a foundational principle of human rights and must be included in TRC efforts. For example, very few articles noted health system indicators to assess for measured changes in meeting the TRC calls to action. There is thus a need for better discussion, research, and action to further develop, in collaboration with Indigenous communities, quality indicators that can track how health systems are meeting their TRC objectives. Without specific and detailed accountability measures in place, it is difficult to ensure that health systems are meeting their TRC commitments. Health systems attempting to meet TRC commitments are further strained by concerns about whose interests—those of the health system or those of Indigenous Peoples—reconciliation is really serving. Overall accountability is important to measure actionable change, as apologies are often currently framed as being the beginning of reconciliation, yet they are "often where actions stop."[85] Given this, partnerships for change are often "more challenging in light of the negative legacy of relationships between First Nations and federal and provincial governments, as well as the broader scope required to acknowledge the needs of many partners, which further impacts the capacity to deliver in a timely manner and endangers legitimacy."[86]

Although the need for systemic change was highlighted in some of the articles, the articles pointed to a general gap in specific policy actions at a systems level. One article noted how current changes lack "a sustained approach that allows resourcing to implement, evaluate, and eventually innovate models."[87] While solutions such as cultural safety trainings are important, "more is needed to achieve a system-level course correction."[88] The health care system generally does not seem to have a strong, cohesive, and active approach for systemic change; however, this could be due to a complete lack of investigation into related TRC system-level approaches. Some articles did recognize that it is difficult to "examine, identify, and modify policy and standards of practice that either obviously or inadvertently foster inequitable health care and health outcomes for Indigenous People."[89]

Lastly, articles emphasized the importance of addressing histories and contexts that shape health statuses. Current movements toward health equity for Indigenous Peoples may remain entrenched in Western and colonial paradigms that will not change the actual status of health. For example, one article stated that "reconciliation as a state approach that claims to take up structural violence in fact entrenches settler-colonial biogovernance through its technologies of chronic disease management."[90] The current focus on individuals "rather than societal, economic, and political contexts, further exacerbates health impacts."[91] Acknowledgment of and action on the wider Indigenous determinants of health—with a clear understanding of historical and contemporary colonial contexts—are necessary to implement effective practice and accountability, while creating health system change in the context of the TRC calls to action.[92] It must be additionally noted, however, that while TRCs provide an authoritative process and vehicle by which health care systems can engage with reconciliation, they may not be a necessary precondition.

Given the dominance of articles from Canada, the country may provide a unique TRC model for other nations to reflect on in terms of how to move forward in creating a health care system that considers culturally appropriate care as a human right. Caution is still advised, however, given the lack of accountability metrics associated within the included articles, which makes it difficult to assume overall effectiveness within the Canadian context. Indigenous Peoples in Canada still face substantial health inequities and human rights violations.[93] Even if improvements have been made since the TRC was created in Canada, these have not been adequately qualified within health systems at the national level to make any firm statements of efficacy. Regardless, the literature out of Canada may imply the importance of a formal TRC in bringing about discourse and change toward health equity and reconciliation.

Limitations

Since this review sought to understand the academic discourse on the topic, we did not include government or health system documents that may further explore the implementation of TRC recommendations in public and private arenas. Future work on this topic should therefore seek to review the gray literature to assess any additional elements focusing specifically on TRC accountability measures that may be in place outside of the academic literature. Additionally, while this review intended to gather international data, all the articles that we found were within the Canadian context. This could have been due to our being able to review only English-language articles. Therefore, generalizing to other countries and contexts may be difficult. Additional work should be done to further this review to other languages to increase the potential breadth of information on how varied health systems may be responding to TRCs or truth commissions in their respective contexts. Future research is also needed to better understand the connection between the role of TRCs, health care system changes, and social movements.

Conclusion

While the calls to action of the TRC in Canada created a specific road map and mandate for the health care system in Canada, "there is considerable variability in the uptake of these actions across institutions."[94] Concerted efforts within and around the health care system and across sectors must take place to have large-scale, meaningful change for Indigenous Peoples. Such system-level efforts, however, may be undermined by the frameworks in which they are conceived. Therefore, there is a strong need for fundamental decolonization and the centering of Indigenous Peoples and their perspectives, with both elements being imperative to all continued health care responses to the TRC.

References

1. M. B. Hirsch, M. Mackenzie, and M. Sesay, "Measuring the Impacts of Truth and Reconciliation Commissions: Placing the Global 'Success' of TRCs in Local Perspective," *Cooperation and Conflict* 47/3 (2012).

2. Truth and Reconciliation Commission of Canada, *Honouring the Truth, Reconciling for the Future: Summary of the Final Report of the Truth and Reconciliation Commission of Canada* (Winnipeg: Truth and Reconciliation Commission of Canada, 2015).

3. Truth and Reconciliation Commission of Canada, *Truth and Reconciliation Commission of Canada: Calls to Action* (Winnipeg: Truth and Reconciliation Commission of Canada, 2015).

4. A. Szpak and D. Bunikowski, "Saami Truth and Reconciliation Commissions," *International Journal of Human Rights* 26/2 (2022).

5. A. Mashford-Pringle, "How'd We Get Here from There? American Indians and Aboriginal Peoples of Canada Health Policy," *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 9/1 (2011); B. Collins and A. Watson, "Refusing Reconciliation with Settler Colonialism: Wider Lessons from the Maine Wabanaki-State Child Welfare Truth and Reconciliation Commission," *International Journal of Human Rights* 27/2 (2023).

6. Szpak and Bunkiowski (see note 4).

7. Mashford-Pringle (see note 5).

8. L. J. Kirmayer and G. Brass, "Addressing Global Health Disparities among Indigenous Peoples," *Lancet* 388/10040 (2016).

9. Truth and Reconciliation Commission of Canada, *Calls to Action* (see note 3).

10. P. Roach and F. McMillan, "Reconciliation and Indigenous Self-Determination in Health Research: A Call to Action," *PLOS Global Public Health* 2/9 (2022); M. Lock, F. McMillan, B. Bennet, et al., "Position Statement: Research and Reconciliation with Indigenous Peoples in Rural Health Journals," *Australian Journal of Rural Health* 30/1 (2022).

11. Roach and McMillan (see note 10); Lock et al. (see note 10).

12. H. Arksey and L. O'Malley, "Scoping Studies: Towards a Methodological Framework," *International Journal of Social Research Methodology* 8/1 (2005); M. D. J. Peters, C. Marnie, H. Colquhoun, et al., "Scoping Reviews: Reinforcing and Advancing the Methodology and Application," *Systematic Reviews* 10/1 (2021).

13. S. Larson, "Truth and Reconciliation Commissions and Healthcare System Responses for Indigenous Peoples: A Scoping Review Methodology," OSF, https://osf.io/5zxck/.

14. M. J. Page, J. E. McKenzie, P. M. Bossuyt, et al., "The PRISMA 2020 Statement: An Updated Guideline for Reporting Systematic Reviews," *BMJ* 372 (2021).

15. United Nations Permanent Forum on Indigenous Issues, *Fact Sheet: Who Are Indigenous Peoples?* (2006).

16. V. Braun and V. Clarke, "Using Thematic Analysis in Psychology," *Qualitative Research in Psychology* 3/2 (2006); V. Braun and V. Clarke, "Reflecting on Reflexive Thematic Analysis," *Qualitative Research in Sport, Exercise and Health* 11/4 (2019).

17. M. Anderson, "An Indigenous Physician's Response to the Settler Physician Perspective on Indigenous Health, Truth, and Reconciliation," *Canadian Medical Education Journal* 9/4 (2018); S. M. Cohen-Fournier, G. Brass, and L. J. Kirmayer, "Decolonizing Health Care: Challenges of Cultural and Epistemic Pluralism in Medical Decision-Making with Indigenous Communities," *Bioethics* 35/8 (2021); D. Fijal and B. L. Beagan, "Indigenous Perspectives on Health: Integration with a Canadian Model of Practice," *Canadian Journal of Occupational Therapy* 86/3 (2019); G. Kyoon Achan, R. Eni, K. A. Kinew, et al., "The Two Great Healing Traditions: Issues, Opportunities, and Recommendations for an Integrated First Nations Health care System in Canada," *Health Systems and Reform Journal* 7/1 (2021); N. Lachance and T. Rose, "From Colonization to Reconciliation: Increasing the Collaborative Capacity of Public Servants," *Canadian Public Administration* 63/4 (2020); C. Hunter and T. Pride, "Critiquing the Canadian Model of Client-Centered Enablement (CMCE) for Indigenous Contexts," *Canadian Journal of Occupational Therapy* 88/4 (2021); C. L. Tait, W. Mussell, and R. Henry, "Micro-Reconciliation as a Pathway for Transformative Change," *International Journal of Indigenous Health* 14/2 (2019).

18. Anderson (see note 17); M. Djkowich, C. Ceci, and O. Petrovskaya, "Bearing Witness in Nursing Practice: More Than a Moral Obligation?," *Nursing Philosophy* 20/1 (2019); Cohen-Fournier et al. (see note 17); R. Long, C. Heffernan, M. Cardinal-Grant, et al., "Two Row Wampum, Human Rights, and the Elimination of Tuberculosis from High-Incidence Indigenous Communities," *Health and Human Rights Journal* 21/1 (2019).

19. Tait et al. (see note 17).

20. Hunter and Pride (see note 17).

21. Tait et al. (see note 17).

22. Ibid.

23. Ibid.

24. Fijal and Beagan (see note 17); C. Bartlett, M. Marshall, and A. Marshall, "Two-Eyed Seeing and Other Lessons Learned within a Co-learning Journey of Bringing Together Indigenous and Mainstream Knowledges and Ways of Knowing," *Journal of Environmental Studies and Sciences* 2/4 (2012).

25. Cohen-Fournier et al. (see note 17).

26. Kyoon Achan et al. (see note 17).

27. Fijal and Beagan (see note 17).

28. R. Henderson, S. Montesanti, L. Crowshoe, and C. Leduc, "Advancing Indigenous Primary Health Care Policy in Alberta, Canada," *Health Policy* 122/6 (2018); G. Hadjipavlou, C. Varcoe, D. Tu et al., "'All My Relations': Experiences and Perceptions of Indigenous Patients Connecting with Indigenous Elders in an Inner City Primary Care Partnership for Mental Health and Well-Being," *CMAJ* 190/20 (2018).

29. Ibid.

30. Long et al. (see note 18).

31. M. Pandey, S. Nicolay, M. Clark, et al., "Wellness Wheel Mobile Outreach Clinic: A Community-Led Care Model Improving Access to Care in Indigenous Communities," *Annals of Family Medicine* 18, no. 5 (2020).

32. Cohen-Fournier et al. (see note 17); J. L. Drost, "Developing the Alliances to Expand Traditional Indigenous Healing Practices within Alberta Health Services," *Journal of Alternative and Complementary Medicine* 25/S1 (2019); L. I. A. Sanzone, E. Doucette, N. Fansia, et al., "Indigenous Approaches to Healing in Critical Care Settings: Addressing the Truth and Reconciliation Report's Calls to Action," *Canadian Journal of Critical Care Nursing* 30/3 (2019).

33. T. Blair, P. Babyn, G. Kewistep, et al., "Program Report: Nîsohkamâtowak-Helping Patients and Families Living with Kidney Disease in Northern Saskatchewan," *Canadian Journal of Kidney Health and Disease* 9 (2022).

34. R. Sovdi and B. Macdonald, "Honouring the Stories and Experiences of Indigenous Peoples with Diabetes Through Trauma-Informed Care," *Canadian Journal of Diabetes* 45/7 (2021).

35. A. Hyman, E. Stacy, K. Atkinson, et al., "Digital Storytelling and Dialogue to Support Culturally Safe Health Care for Indigenous Patients in British Columbia," *British Columbia Medical Journal* 62/3 (2020).

36. J. O'Neil, J. Gallagher, L. Wylie, et al., "Transforming First Nations' Health Governance in British Columbia," *International Journal of Health Governance* 21/4 (2016).

37. D. Jaworsky, "A Settler Physician Perspective on Indigenous Health, Truth, and Reconciliation," *Canadian Medical Education Journal* 9/3 (2018); M. E. Pearce, K. Jongbloed, L. Demerais, et al., "'Another Thing to Live for': Supporting HCV Treatment and Cure among Indigenous People Impacted by Substance Use in Canadian Cities," *International Journal of Drug Policy* 74 (2019); P. Smith, "Commentary: A Settler Physician Perspective on Indigenous Health, Truth, and Reconciliation," *Canadian Medical Education Journal* 9/3 (2018); A. Phenix and K. Valavaara, "Occupational Therapy Responses to the Truth and Reconciliation Commission," *Occupational Therapy Now* 21/4 (2019); Lachance and Rose (see note 17).

38. K. Gasparelli, H. Crowley, M. Fricke, et al., "Mobilizing Reconciliation: Implications of the Truth and Reconciliation Commission Report for Physiotherapy in Canada," *Physiotherapy Canada* 68/3 (2016); K. D. Fellner, J. Ansloos, N. L. Oullette, and G. D. Villebrund, "Reconciling Relations: Shifting Counselling Psychology to Address Truth and Reconciliation," *Canadian Journal of Counselling and Psychotherapy* 54/4 (2020); Drost (see note 32).

39. Tait et al. (see note 17).

40. G. Restall, A. Gerlach, K. Valavaara, and A. Phenix, "The Truth and Reconciliation Commission's Calls to Action: How Will Occupational Therapists Respond?," *Canadian Journal of Occupational Therapy* 83/5 (2016); A. Phenix and K. Valavaara, "Reflections on the Truth and Reconciliation Commission: Calls to Action in Occupational Therapy," *Occupational Therapy Now* 18/6 (2016).

41. L. Richardson and A. Boozary, "Truth and Reconciliation in Canada's Health System," *Lancet* 398/10303 (2021).

42. M. McNally and D. Martin, "First Nations, Inuit and Métis Health: Considerations for Canadian Health Leaders in the Wake of the Truth and Reconciliation Commission of Canada Report," *Healthcare Management Forum* 30/2 (2017); C. C. Jacek, K. M. Fritz, M. E. Lizon, and T. L Packham, "Knowledge Gaps Regarding Indigenous Health in Occupational Therapy: A Delphi Process," *Canadian Journal of Occupational Therapy* (2022); Tait et al. (see note 17); E. McGibbon, "Truth and Reconciliation: Health Care Organizational Leadership," *Healthcare Management Forum* 32/1 (2019).

43. McNally and Martin (see note 42).

44. J. Morgan, K. Jameson, S. Joolaee, and A. Ho, "Calls to Action: Truth, Reconciliation, and Indigenous Rights for Supportive Decision-Making in Health Care," *International Journal of Indigenous Health* 16/1 (2021); McNally and Martin (see note 42); T. Nguyen, V. W. L Tsang, P. A. Randhawa, et al., "Highlighting Current Needs in Addressing Youth Mental Health in British Columbia," *UBC Medical Journal* 10/2 (2019); Jaworsky (see note 37); J. Reading, C. Loppie, and J. O'Neil, "Indigenous Health Systems Governance: From the Royal Commission on Aboriginal Peoples (RCAP) to Truth and Reconciliation Commission (TRC)," *International Journal of Health Governance* 21/4 (2016).

45. L. L. Crowshoe, A. Sehgal, S. Montesanti, et al., "The Indigenous Primary Health Care and Policy Research Network: Guiding Innovation within Primary Health Care with Indigenous Peoples in Alberta," *Health Policy* 125/6 (2021); Pearce et al. (see note 37).

46. M. Rand, "Evaluation of the Indigenous Relationship and Cultural Safety Courses among a Sample of Indigenous Services Canada Nurses," *International Journal of Indigenous Health* 14/1 (2019).

47. Fijal and Beagan (see note 17).

48. Truth and Reconciliation Commission of Canada, *Calls to Action* (see note 3).

49. M. E. Morton Ninomiya, B. Tanner, L. J. Peach, et al., "Anishinabek Sources of Strength: Learning from First

Nations People Who Have Experienced Mental Health and Substance Use Challenges," *Social Science and Medicine* 309 (2022).

50. Morgan et al. (see note 44).

51. Hadjipavlou et al. (see note 28).

52. L. Logan, J. McNairn, S. Wiart et al., "Creating Space for Indigenous Healing Practices in Patient Care Plans," *Canadian Medical Education Journal* 11/1 (2020).

53. Ibid.

54. Hyman et al. (see note 35).

55. Ibid.

56. Kyoon Achan et al. (see note 17).

57. R. N. Asiniwasis, E. Heck, A. Amir Ali, et al., "Atopic Dermatitis and Skin Infections Are a Poorly Documented Crisis in Canada's Indigenous Pediatric Population: It's Time to Start the Conversation," *Pediatric Dermatology* 38/Suppl 2 (2021); Morgan et al. (see note 44); Sanzone et al. (see note 32).

58. Rand (see note 46); Nguyen et al. (see note 44); Gasparelli et al. (see note 38).

59. Hunter and Pride (see note 17).

60. Henderson et al. (see note 28); Hadjipavlou et al. (see note 28).

61. Jaworsky (see note 37).

62. Drost (see note 32); McGibbon (see note 42); Richardson and Boozary (see note 41); Jacek et al. (see note 42).

63. Hunter and Pride (see note 17).

64. K. Williams, M. L. Potestio, and V. Austen-Wiebe, "Indigenous Health: Applying Truth and Reconciliation in Alberta Health Services," *CMAJ* 191/Suppl (2019).

65. Long et al. (see note 18); Pandey et al. (see note 31).

66. T. Holt, G. Hansen, V. McKinney, and I. Mendez, "Contemplating Remote Presence Technology for Culturally Safe Health Care for Rural Indigenous Children," *AlterNative: An International Journal of Indigenous Peoples* 15/1 (2019).

67. O'Neil et al. (see note 36).

68. Ibid.

69. Morton Ninomiya et al. (see note 49); Z. Yu, A. Steenbeek, M. Biderman, et al., "Characteristics of Indigenous Healing Strategies in Canada: A Scoping Review," *JBI Evidence Synthesis* 18/12 (2020); Hunter and Pride (see note 17); Williams et al. (see note 64).

70. Crowshoe et al. (see note 45).

71. Holt et al. (see note 66); McGibbon (see note 42); Williams et al. (see note 64).

72. McGibbon (see note 42)

73. Richardson and Boozary (see note 41).

74. McGibbon (see note 42).

75. Ibid.

76. Ibid.

77. Henderson et al. (see note 28).

78. Jaworsky (see note 37).

79. Logan et al. (see note 52).

80. N. Redvers and B. Blondin, "Traditional Indigenous Medicine in North America: A Scoping Review," *PLOS ONE* 15 (2020).

81. Logan et al. (see note 52).

82. Sanzone et al. (see note 32).

83. K. Gasparelli, B. McKenzie, H. Crowley, et al., "Exploring the Implications of the Truth and Reconciliation Commission: What Is Our Role? Canadian Physiotherapy Association National Congress 2016 May 26-28 Victoria BC," *Physiotherapy Canada* 68 (2016); Sovdi and Macdonald (see note 34).

84. Williams et al. (see note 64).

85. Fellner et al. (see note 38).

86. Lachance and Rose (see note 17).

87. Henderson et al. (see note 28).

88. Ibid.

89. McNally and Martin (see note 42).

90. H. A. Howard, "History, Truth, and Reconciliation in Settler Health Care," *American Anthropologist* 122/3 (2020).

91. McGibbon (see note 42).

92. N. Redvers, P. Reid, D. Carroll, et al., "Indigenous Determinants of Health: A Unified Call for Progress," *Lancet* 402/10395 (2023).

93. Public Health Agency of Canada, *Key Health Inequalities in Canada: A National Portrait* (Ottawa: Public Health Agency of Canada, 2018).

94. Richardson and Boozary (see note 41).

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Are Rights-Based Services Important? An Adolescent PrEP Demonstration Project in Brazil

LAURA FERGUSON, ALEXANDRE GRANGEIRO, ANA ALEXANDRA NATIVIDAD, PAULA MASSA, AYRA RODRIGUES, DULCE FERRAZ, AND ELIANA MIURA ZUCCHI

Abstract

In this study, we systematically examined the importance of human rights standards and principles for rights-based pre-exposure prophylaxis (PrEP) provision for marginalized adolescents. Nested within a demonstration study of PrEP provision to adolescent men who have sex with men, *travestis*, and transgender women, we carried out interviews in São Paulo, Brazil with 25 adolescents, eight health providers, and six workers involved in community-based demand creation. Analysis focused on participants' narratives about aspects of human rights within service delivery, including the availability, accessibility, acceptability, and quality of services; informed decision-making; nondiscrimination; and privacy and confidentiality. Clients and service providers highlighted the importance of availing a range of services beyond PrEP and described how community outreach and social media helped promote accessibility. Acceptability centered around clients feeling heard and respected. Health workers appreciated having time to build trusting relationships with clients to ensure quality of care and support informed decision-making. Nondiscrimination was valued by all, including using clients' chosen pronouns. Privacy and confidentiality were primary concerns for clients who were not "out" about their sexuality or PrEP use; to mitigate this, health workers sought to accommodate clients' preferred channels of communication. Rights-based PrEP services can help promote engagement and retention in PrEP services, particularly for marginalized populations.

Laura Ferguson, PhD, is an associate professor of population and public health sciences at the University of Southern California (USC) and director of research at the USC Institute on Inequalities in Global Health, Los Angeles, United States.

Alexandre Grangeiro, Spc, is a scientific researcher in the Faculdade de Medicina, Universidade de São Paulo, São Paulo, Brazil.

Ana Alexandra Natividad, BS, Keck School of Medicine, University of Southern California, Los Angeles, United States.

Paula Massa, PhD, is a researcher in the Faculdade de Medicina, Universidade de São Paulo, São Paulo, Brazil.

Ayra Rodrigues, MPH, is a researcher in the Programa de Pós-Graduação em Saúde Coletiva, Universidade Católica de Santos, Santos, Brazil.

Dulce Ferraz, PhD, is a postdoctoral fellow at the University of Lyon, France, and a public health analyst at Fundação Oswaldo Cruz, Brasília, Brazil.

Eliana Miura Zucchi, PhD, is an assistant professor in the Programa de Pós-Graduação em Saúde Coletiva, Universidade Católica de Santos, Santos, Brazil.

Please address correspondence to Laura Ferguson. Email: laura.ferguson@med.usc.edu.

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Introduction

Brazil's HIV response, initially spearheaded by grassroots organizations, and centered around the inclusion of sexual minorities, is considered one of the most successful among low- and middle-income countries. Its past success highlights the importance of guaranteeing universal access to marginalized populations and ensuring the provision of rights-based HIV services for all.

The World Health Organization recommends oral and injectable pre-exposure prophylaxis (PrEP), as well as vaginal rings for cisgender women, as part of combination prevention approaches for people at substantial risk of HIV infection.[1] In Brazil, daily oral PrEP has been available to adults through government-run health services since 2017; event-driven PrEP started to become available in 2022.[2] Since then, 88,625 adults have started PrEP, of whom 64,474 were still taking it in March 2023.[3]

Rates of HIV among adolescents continue to increase, highlighting their need for access to the widest possible complement of HIV prevention interventions.[4] However, most PrEP intervention studies have been implemented in high-income countries and among adults; very few in any part of the world have included the 15- to 19-year-old population. A recent review of adolescent PrEP in the United States highlighted continued low uptake, while a demonstration study in Kenya and South Africa found high demand for and moderate uptake of PrEP among adolescent girls and young women.[5] Key to ensuring adolescents' engagement, openness, and adherence is providing youth-friendly differentiated services and PrEP modalities based on upholding adolescents' human rights.

Attention to human rights in PrEP delivery

Consideration of human rights in health service delivery usually comprises attention to the right to health and its key standards of availability, accessibility, acceptability, and quality of services; active and fully informed participation; nondiscrimination; informed decision-making; privacy and confidentiality; and accountability.[6] Table 1 outlines the ways in which these human rights standards and principles form the basis of our analysis.

The Convention on the Rights of the Child further elaborates rights specific to children (people under the age of 18) in the context of seeking and receiving health care.[7] The Committee on the Rights of the Child has highlighted the importance of ensuring that children, parents, and health workers have adequate rights-based guidance on consent, assent, and confidentiality.[8] However, relatively little literature exists on adolescents' evolving capacity, informed decision-making, and privacy and confidentiality in the context of PrEP, in part because of difficulties researchers (including ourselves) have experienced in securing ethical approvals for PrEP studies with adolescents where parental consent is waived.[9]

The degree to which, and ways in which, these human rights standards and principles are implemented in health service delivery can shape populations' experiences of accessing (or choosing not to access) health services, including PrEP services for adolescents who do not conform to cis-heteronormativity and who may be disadvantaged and discriminated against for this reason.

Access to HIV-related services in Brazil

In Brazil, there is a constitutional right to health, and the Health Care Law (Law 8080/90) organizes the Unified Health System (*Sistema Único de Saúde,* or SUS) and guarantees universal preventive and curative health care coverage.[10] Health is seen as citizens' right and a duty of the state. Community participation in health is also guaranteed in the Constitution.

Despite Brazil's legal guarantee of "universal access" to PrEP through the SUS, there remain several socioeconomic-related barriers for adolescents. Past experiences of homophobia and transphobia at health services can discourage individuals from visiting PrEP sites. Some studies have found that individuals who are more open about their sexuality experience less access to PrEP, most likely due to increased experience of homophobia.[11] Nevertheless, individuals who are less open about their sexuality may also be more hesitant to ask their physicians for PrEP for fear of disclosing their sexual orientation.[12] Despite services being free, the associated costs of reaching services can prevent access to PrEP, as adolescents are more likely to experience financial insecurity.[13]

Barriers to acceptability include misconceptions regarding the possible side effects, efficacy, and drug interactions of PrEP with gender-affirming hormones.[14] Conversely, high patient knowledge regarding PrEP can facilitate acceptability.[15]

Brazil's Child and Adolescent Rights Act allows for people aged 12 years and over to access health services without the consent or presence of their parents, and this notion is reinforced through Ministry of Health guidelines on adolescent health services.[16] Since 2022, PrEP has been legally available to individuals above the age of 15 in Brazil.[17]

The Brazilian Code of Medical Ethics, with select exceptions, proscribes the disclosure of minor patients' medical information, including to the patients' parents or legal guardians.[18] The ability to give informed and voluntary consent without guardian permission and guaranteed confidentiality are necessary to increase participation in PrEP programs.[19]

Some lessons can be gleaned regarding rights-based PrEP service delivery from current literature, but no study to date has systematically examined the full complement of standards and principles understood to underlie rights-based service delivery.

Table 1. Standards and principles central to a rights-based approach to health service delivery

Standard or principle	Relevance to a rights-based approach to health service delivery*
Participation	Every person is entitled to active, free, and meaningful participation in, contribution to, and enjoyment of civil, economic, social, cultural, and political development. Ensuring the inclusion and full participation of key stakeholders and affected communities at every stage of health programming is an essential component of a rights-based approach to health.
Equality and nondiscrimination	Health services and programs should respect, protect, and fulfill the rights to equality and to nondiscrimination for all people. This may require specific efforts to reach populations who may be marginalized or disadvantaged.
Informed decision-making	The principle of autonomy, expressed through free, prior, full, and informed decision-making, is a central theme in medical ethics and is embodied in human rights law. In order to facilitate informed decision-making, comprehensive information, counseling, and support should be made accessible for all people without discrimination, including young people, persons living with disabilities, Indigenous peoples, ethnic minorities, people living with HIV, and transgender and intersex people.
Availability	Availability requires making available in sufficient quantity functioning health care facilities, goods, services. Although varying by context, these should address the underlying determinants of health, including safe and potable drinking water; adequate sanitation facilities, hospitals, and clinics; trained medical personnel; and essential drugs.
Accessibility	Accessibility encompasses four distinct components, all of which require special attention to the most vulnerable and affected populations: Nondiscrimination: Health facilities, goods, and services must be accessible to all. Physical accessibility: Health facilities, goods, and services must be physically accessible to all. Affordability: Health facilities, goods, and services must be affordable for all, yielding accessibility of needed services, whether privately or publicly provided. Access to information: Includes the right to seek, receive, and impart information and ideas concerning health issues but does not impair the right to have personal health data treated with confidentiality.
Acceptability	Acceptability requires that all health facilities, goods, and services be respectful of medical ethics and culturally appropriate, sensitive to sex and life-cycle requirements, and designed to respect confidentiality and improve the health status of those concerned.
Quality	Quality requires goods and services to be scientifically and medically appropriate and of good quality. This means having skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.
Accountability	Governments are accountable to their populations and to the international community for their actions that have an impact on health and development. Accountability mechanisms exist at local, national, regional, and international levels to monitor compliance and support governments in fulfilling their human rights obligations.

* S. Gruskin, L. Ferguson, S. Kumar, et al., "A Novel Methodology for Strengthening Human Rights Based Monitoring in Public Health: Family Planning Indicators as an Illustrative Example," *PLOS ONE* 12/12 (2017); S. Gruskin, D. Bogecho, and L. Ferguson, "'Rights-Based Approaches' to Health Policies and Programs: Articulations, Ambiguities, and Assessment," *Journal of Public Health Policy* 31 (2010).

The PrEP 1519 study

In 2017, Brazil adopted HIV PrEP as part of a combination prevention strategy for the most at-risk populations. However, at that time, Brazil did not have specific guidelines for PrEP use among adolescents under 18.[20] Along with a broader team of colleagues, we carried out PrEP 1519 as a demonstration study to assess the effectiveness of oral daily PrEP and demand creation strategies to engage adolescent men who have sex with men, *travestis*, and transgender women in PrEP services and link them to other HIV- and sexual health-related services in three cities in Brazil.[21] Effectiveness results have been presented elsewhere.[22]

This paper presents findings of a sub-study, nested within PrEP 1519, that examined the ways in which study participants in São Paulo spoke about different aspects of human rights within service delivery and how that mattered to them.

In the bigger PrEP 1519 study, we sought to help inform the Ministry of Health on how best adolescent PrEP might be delivered within the SUS, taking account of challenging questions such as evolving capacity, consent, and confidentiality.[23] In this sub-study, our aim was to help inform how these PrEP services can be designed and delivered in a rights-based manner. With our focus on providing HIV information, goods, and services to marginalized men who have sex with men and transgender women, it might be described as a rights-based intervention.

A combination of online and face-to-face peer-led demand creation strategies and direct referrals from health services and nongovernmental organizations was used to enroll adolescents from diverse socioeconomic backgrounds in PrEP services. In São Paulo, between January 2019 and March 2021, 458 adolescent men who have sex with men and transgender women were recruited to the study, 354 of whom chose to initiate PrEP immediately and 104 of whom chose not to initiate PrEP immediately but to have access to combination prevention services, including post-exposure prophylaxis and HIV self-testing. Peer navigators who were health professionals or young LGBTQ+ people accompanied participants throughout the study to support adherence to PrEP and retention in care. WhatsApp was used as the primary form of communication with clients, with other social media outlets, including an artificial intelligence chatbot also used. The COVID-19 pandemic required some activities to be carried out remotely.

Methodology

Study site

PrEP 1519 services in São Paulo were organized in a counseling and testing center (CTC) managed by the Municipal Health Department and located in an area of high HIV incidence. Prior to the study, the well-established CTC already provided testing for HIV and sexually transmitted infections (STIs) to a large clientele, primarily men who have sex with men. It was staffed with a multidisciplinary team, which the study augmented, including by the addition of a doctor to manage HIV and STI treatments and the initiation of PrEP. The CTC is open every weekday until 7 p.m.; walk-ins are welcome for new clients.

Participants

Between June 2019 and February 2021, we carried out 25 interviews with adolescents enrolled in PrEP1519, eight with health providers who worked at the CTC, and six with workers involved in community-based demand creation strategies.

The qualitative investigation purposively sampled adolescent participants from within PrEP 1519 according to social markers, experiences of care, and access to the PrEP services. We aimed to interview clients who (1) self-identified as cisgender men, transgender women, *travestis*, or gender fluid; (2) represented the age range of adolescent participants (15–19 years); (3) reported diverse sociodemographic characteristics; (4) had different experiences related to adherence to PrEP; (5) used additional preventive methods; and (6) enrolled in the study through different demand creation strategies. Health providers helped identify potential participants. Subsequently, peer navigators and health providers facilitated the invitation to participate in this sub-study.

All health providers from the PrEP clinic and workers involved with the community-based strategies were invited to participate. We then established contact to arrange the best private place and type of interview (in person or remote). Due to COVID-19-related restrictions, from March 2020 onward the interviews were conducted remotely.

Data collection and analysis

The interviews with adolescents covered a wide range of topics, including perceptions of the demand creation strategies, access to PrEP services, and interactions with providers. Interviews with health providers explored perceptions of the impact of PrEP use for adolescents, barriers and facilitators to accessing services, and perceptions of the strengths and weaknesses of the services.

Interviews were carried out in Portuguese by trained Brazilian researchers. They were audio recorded and transcribed verbatim. Data were imported into and analyzed in NVivo in Portuguese by bilingual researchers. They were thematically coded using a coding scheme based on key human rights standards and principles widely recognized as the foundation of human rights-based health service delivery. We created matrixes to help identify patterns in the data, particularly between health workers and service users.

Results

This section provides an overview of participant characteristics and then organizes our findings by the human rights standards and principles that form the basis of the conceptual framework outlined above.

Participant characteristics

Tables 2 and 3 offer an overview of participants' characteristics, using their own self-descriptors.

Adolescent participants, who were all recruited into the PrEP1519 study when they were between the ages of 15 and 19, were aged between 17 and 20 years old at the time of these interviews. Seventeen self-identified as men, six as transgender, one as *travesti*, and one as gender fluid. Fourteen self-identified as homosexual, four as heterosexual, three as pansexual, two as bisexual, one as bisexual and asexual, and one as a lesbian. Fifteen participants referred to their skin color or race as Black or Brown, nine as White, and one as Indigenous.

Four health providers self-identified as men, three as women, and one as nonbinary; they were aged between 25 and 52 years old. Six self-identified as homosexual or gay, and two as heterosexual. Three self-identified as White and three as Black. Three participants were doctors, three were psychologists, one was a medical technologist, and one was a nursing technician.

Workers involved with community-based strategies self-identified as cisgender gay men and were aged between 21 and 37. Two self-identified as Black, two as White, and one Yellow. (Classification of race and skin color was self-reported and based on the categories "White," "Black," "Brown," "Yellow," and "Indigenous," which are used by the Demographic Census of the Brazilian Institute of Geography and Statistics).

Availability

Very little emerged through the interviews in relation to the availability of PrEP services, as the demonstration study centered on the provision of PrEP for 15- to 19-year-olds. There were no reported challenges with the availability of medications, supplies, or health workers.

Health workers and clients alike noted the value of having multiple services available in a single location so that visits to the health facility were not solely about PrEP and could help meet a broader range of young people's needs, such as STI treatment, psychological support, referral and navigation to other services (including gender-affirming care), and diagnostic services for HIV, STIs, and hepatitis:

> *She helped me with other issues too, like my psychological issues. I have a kidney problem and she ordered tests for me, you know? [She showed] a general concern for my health, not just PrEP alone. I liked that the best. (Jonathan, Brown man who has sex with men)*

TABLE 2. Adolescent participants' characteristics

	Number of adolescents
Gender identity	
Cisgender man	17
Transgender	1
Transgender woman	5
Travesti	1
Gender fluid	1
Age	
17	4
18	6
19	7
20	8
Race	
Black	7
White	9
Brown	8
Indigenous	1
Education	
Incomplete basic education	1
In high school	5
Incomplete high school	1
Complete high school	8
In university	10
Sexual orientation	
Homosexual	14
Lesbian	1
Pansexual	3
Bisexual	2
Bisexual and asexual	1
Heterosexual	4
Entry point to the project	
Spontaneous demand for CTC	14
Peer-led demand creation strategies:	11
• Community outreach	5
• Hookup app (Grindr)	2
• Social media (Amanda Selfie)	1
• Referrals from nongovernmental organization (Casa 1)	3

Accessibility

Interview participants noted the challenges associated with the accessibility of services in a city as large as São Paulo. The CTC is near a metro station, which somewhat facilitates access; however, for clients who live far away, transportation time and money can be a barrier. To overcome this, the project covered transport costs for some adolescents, which participants noted as a facilitator of access. In some cases, peer navigators met clients and accompanied them on the trip to the health facility or inside the CTC from the front desk through to the appointment with the PrEP prescriber. Peer navigation can help, particularly if clients are coming from distant neighborhoods, if they are visiting health services and the center of the city for the first time, or if they are concerned about experiencing violence on public transportation. Highlighting the efforts made to help make care accessible, a counselor noted:

> *There's the real world and then there's PrEP 1519, which is us taking people by the hand. (Dante, Black gay counselor)*

For some participants who work or study full time or live far away, it was a challenge to access services during regular working hours. The availability of walk-in appointments was useful for some adolescents who felt that they needed to address health concerns immediately. For health workers, their experience with social media highlighted the im-

Table 3. Health professionals' characteristics

	Number of CTC health professionals	Number of outreach staff
Gender identity		
Cisgender man	4	6
Cisgender woman	3	
Nonbinary	1	
Age		
21–25	1	4
26–30	3	1
31+	4	1
Race		
Black	3	2
White	3	2
Brown	1	
Other	1	2
Sexual orientation		
Homosexual	3	
Gay	3	6
Heterosexual	2	
Occupation		
Doctor	3	
Nurse/nurse technician	1	1
Psychologist	3	1
Medical technologist	1	
Undergraduate student		3
Health promotion agent		1

portance of extending the clinic's opening hours, since clients frequently responded to messages during evenings and weekends.

The ability to communicate with study staff through social media was highly valued by most study participants. Designed to facilitate rapid communication, WhatsApp was the primary avenue for communication between health workers and clients for recruitment, linkage to care, and retention. Interview participants described the frequent use of WhatsApp for project communication—and clients also acknowledged "Amanda Selfie," the transgender chatbot with which they could interact—as useful. The use of social media made information readily accessible to clients and helped them understand when they needed to attend the facility and when their concerns could be allayed virtually.

Participants, particularly the adolescent men who have sex with men, reported that the project's demand creation—recruiting participants at venues where the target populations spend time, as well as through apps such as Grindr—made the idea of PrEP more accessible because it could be immediately explained to them in a space in which they were comfortable.

Acceptability

Clients appreciated the demand creation strategies, including social media and community outreach. One client described apps as "a young universe," noting that this is why it is a comfortable space for them. A project psychologist, who is Black and openly gay and recruited study participants from known gay hangout spaces, spoke about how this helped him build rapport with other gay men, making them feel comfortable with the idea of PrEP and going to the health facility. When asked what makes a good counselor, he responded:

> *You have to be ready to listen, right? Listen to what that person has to say without any judgment because they already experience enough judgment, right? Whether it's because of their sexual orientation or gender identity. I think it's great for a health professional to really be able to listen.* (Dante, Black gay counselor)

The importance of listening, as well as of clients seeing themselves represented in the health workers in the study clinics, was also articulated. Clients noted that the informality of not using titles such as "Doctor" helped them feel comfortable, and one health worker reported playing pop music to help clients relax. Clients also provided positive testimony of being well-received, listened to, respected, and given good care. They felt comfortable "unloading" on staff, being honest, and, at times, crying. Staff, from the receptionists to phlebotomists and nurses, were praised highly. Clients noted that health workers make a real effort to connect with clients, not just provide the medical service:

> *I felt like they're really committed to connecting with the people who go there … And talking to the doctor, she was really kind and well-disposed. She explained and went over everything about PrEP and [post-exposure prophylaxis] and about protection and STIs, etc. She was really kind … She spoke in a way that I could really understand. And I loved this. I thought she was a sweetheart.* (Camélia, Brown trans woman)

A project psychologist spoke of the importance of the staff reflecting some of the characteristics of the clients:

> *They say "I love it. You're all gay there." And there are also trans people wandering around. So, it's no longer a health service where there are only health workers who sometimes are gay, but they don't talk about sexual orientation, but somewhere where professionals who are empowered, right? Professionals who can say "Look, I'm gay and that's just a part of me." So [clients] end up feeling really comfortable, you know? To talk about their practices because in some way or other, "You're going to understand me."* (Dante, Black gay counselor)

Participants described staff listening without judging, having honest conversations with them, and working with them to find the best solutions for their situation.

Quality

Clients reported positive experiences within the health facilities, including how they were received, supported, and given information. Many participants were effusive in their praise for PrEP 1519 services and staff:

> *Top marks for all of them. They're wonderful, attentive, polite … perfect.* (Jade, White transgender woman)

> *I think it's the best service that I've ever had in my life. All the doctors in Brazil should be like [this doctor].* (Jonathan, Brown man who has sex with men)

One participant (Renato, a Black man who has sex with men) described how when he told the doctor that he had not been adhering to his medication, instead of making him feel guilty she sought to understand why adherence was hard and congratulated him for being at his appointment.

Health workers noted the importance of a "pro-client" space, recognizing their responsibility for creating an atmosphere and relationship of trust. They reported that active listening, empathy, and team motivation were key attributes of this space.

All project staff seem well-attuned to the need to ensure that information is communicated in ways that are appropriate for young people. This might include using slang specific to the different client populations, making sketches, or simply covering material multiple times:

> *The approach is always formal, polite, and inclusive, you know? And sometimes it's even informal … to see if the person relaxes and feels comfortable … And I think it helps a lot.* (Benjamin, Black man who has sex with men)

An important theme across health workers' narratives was the value of building relationships of trust over time. Many noted that it can take young people time to open up, particularly about their sexuality or about life challenges such as experiences of violence. This means that continuity of care, including offering the same providers repeatedly, is important for gaining a fuller understanding of young people's lives.

One peer navigator highlighted concerns around many health workers' ability to provide this type of care:

> *Everyone knows that not all health professionals are equally available to their clients, not all have the same listening skills, and, mainly, when people talk about PrEP they talk about sexuality, sexual orientation, and gender identity so the health professional has to be trained to know that transgender is not about sexual orientation, and being gay doesn't define someone.* (Dante, Black gay counselor)

Some health workers noted their workload as another challenge, which can limit the time they have to spend with each client, negatively affecting the quality of care.

Two examples of internal quality control were (1) weekly meetings to discuss complex cases and any seroconversions to identify shortcomings in service provision and (2) monthly meetings between the health professionals and experts specializing in youth, gender identity, and human rights.

Participation

Even as community members participated in the design of demand creation activities, clients did not participate in the design of the study or service delivery model. Questions were not asked about community participation in HIV service delivery more generally, even though this is a core tenet of the Brazilian health system.

Informed decision-making

Health workers reported that clients often arrive at the health facility with little knowledge of PrEP, misconceptions often picked up online (such as not being able to take PrEP alongside alcohol), and associations of PrEP with promiscuity rather than risky sexual behaviors. They noted that young people have questions about sexual practices and risk, but many are embarrassed to ask health workers about these issues.

Health workers and peer navigators noted the importance of both the content of information provided and its accessibility—that is, using simple, clear language. It was important to them that there be a range of prevention options available that clients can choose from based on their needs and preferences. A counselor described his role as facilitating clients' informed decision-making:

> *The best method of prevention is the one that the client chooses for themselves … "I'm here to allow you to choose, right? I'll give you information. We'll think it through together."* (Dante, Black gay counselor)

Another health worker, when asked how he deals with behaviors such as stopping condom use when on PrEP, answered:

> *Without any moralizing, without imposing anything. My job is to provide correct information.* (Enzo, White gay health worker)

Health workers acknowledged that even when they would not choose the client's approach (e.g., PrEP on demand), they recognize everyone's right to make their own choices, so they provide full information, thus building clients' capacity to make autonomous, well-informed decisions in their own best interests. They also tailor messages to each client's reality:

> *I think that what I like about supporting linkage to care is that you can't mass produce it—you know, copy-paste the message? That doesn't work with linking. You have to really hear these people starting with their lived experiences, and you sometimes give advice that might seem universal, but you have to adapt it to the life of that person.* (Dante, Black gay counselor)

Health workers noted difficulty with the dissemination of information, particularly to younger clients. Clients suggested that social media, such as Instagram and TikTok, be used more for sharing information about PrEP, explaining that some of the study staff share good sources of reliable HIV information on social media. Participants who, for a variety of reasons, stopped using PrEP, cited access to information as an important reason for staying in the study even when no longer on PrEP.

Health workers also spoke about the additional responsibility they felt when dealing with clients under the legal age of majority (18 years). They described assessing adolescents' capacity by "what they say, how they behave, the questions they ask" (Antonela, White cisgender doctor). Health workers discussed how best to assess adolescents' capacity during their regular meetings so as to ensure that they followed the law and protected the person's best interests.

There were some reports of clients using PrEP on their own schedule rather than following clinical advice. Health workers described the need to ensure that clients understand why PrEP is important to them: they have to want to take it if they are going to adhere to the medication.

Nondiscrimination

Health workers explained that many clients experience discrimination within their own families, making it even more important that they be accepted as they are within the health facility. Health worker attitudes were seen as critical to the success of these services, particularly for clients outside mainstream society such as people who use drugs or people experiencing homelessness.

Some health workers acknowledged struggling with neutral pronouns or using the right pronoun for trans adolescents, even as they all said they were trying and were aware of the importance. A client highlighted feelings of alienation when correct names and pronouns are not used:

> *I simply didn't want to go to a dermatology appointment because the laboratory had put my birth name on the document … And this is a tough situation that I know a lot of trans people go through.* (Jade, White transgender woman)

One participant (Jackson, a Black pansexual man) described a difficult situation outside the study where he was discouraged from taking PrEP because of his young age, with the health worker suggesting that he use condoms instead.

Privacy and confidentiality

Many clients reportedly disclose their PrEP use very selectively for fear of people not understanding. Health workers noted the sensitivity required in ensuring total privacy for adolescents.

Often, families do not want to accept their child's sexual orientation or even sexuality and are not supportive of the adolescent using PrEP or other HIV prevention methods. Health workers seek to support adolescents through these challenges, including guilt induced by religious or conservative parents. Despite challenges accessing the CTC, many clients appreciated that it was not in their local neighborhood because it afforded greater privacy. Some adolescent men who have sex with men also felt that WhatsApp was a good channel to use for maintaining privacy since it was harder for their parents to access than their email or mail.

When the study started distributing PrEP by mail due to COVID-19, some people dropped out, fearing that their families, who were unaware of their PrEP use, might see the medications. Some clients requested in-person appointments throughout the pandemic because their family did not know that they were gay or on PrEP, which the project sought to accommodate.

Accountability

Only one health worker spoke about accountability, reporting that most young people who access services are not aware of their rights or of available complaint mechanisms, which could leave them vulnerable to ill-treatment.

Discussion

PrEP 1519 showed that it is feasible to deliver PrEP to adolescents through Brazil's public health services. It also highlighted the importance of strategies of demand creation, linkage to care, and retention in care. With PrEP now legal for adolescents aged 15 and over, it is critical that the government scale up these services in a way that promotes the engagement and retention of adolescents, including those from marginalized populations. This sub-study has highlighted the human rights dimensions of service delivery that can help inform this scale-up.

The provision of adolescent PrEP is a new concept in Brazil and thus requires investments to prepare facilities, particularly capacity building relating to technical and cultural competency. To facilitate the integration of adolescent PrEP into routine service delivery in Brazil, it will be useful to integrate PrEP clinical directives within standard health care directives, including pre- and in-service medical education. Attention to each of the human rights standards and principles, and direction on how to operationalize them, will be key.

General recommendations across the areas of health policy, health systems, capacity building, and communication are explored below under the subheadings of the human rights principles explored in the findings.

Availability, accessibility, acceptability, and quality of PrEP services

The Brazilian health system is designed to provide a wide range of integrated services. Many study participants appreciated the range of services available to them beyond PrEP and health workers' efforts to understand them as whole, complicated people rather than just as presenting a single, acontextual medical need, speaking to the importance of this approach.

While participants in our study did not highlight the availability of PrEP as a problem, we were analyzing a situation where adolescent PrEP was available and many demand creation strategies were in place. This is not the case in most places, and scale-up is urgently needed. As with any new health technology, it is critical that new strategies focus on ensuring that the most vulnerable populations can be reached to avoid exacerbating preexisting inequalities. This will require a health systems approach to ensure, for example, a reliable supply chain, sufficient laboratory infrastructure, and a trained workforce, as well as differentiated services and PrEP modalities. Strengthening and expanding other services, including mental health services, may also be needed.

Community health services, community outreach, and demand creation can play important roles in reaching large numbers of adolescents and promoting the availability of adolescent PrEP, including by reducing transport cost and time. However, previous studies have highlighted a need to go beyond the provision of information to adolescents and to support their journey to health services and create a trusting relationship with health professionals.[24] Low enrollment in this study may have been due to the limited accessibility of services (i.e., having a single study clinic at the time of this qualitative study), as well as to the dynamics in adolescents' relations that often shape risk perception (e.g., switching between casual sex and steady partners) and concerns over privacy and confidentiality.

Successful programs must address medical distrust and improve physician care to increase PrEP accessibility and acceptability. Many studies reveal the importance of physician-centered programs aimed at improving providers' knowledge surrounding PrEP and their ability to provide affirming care and to reduce stigma-related barriers.[25] Improving providers' knowledge ensures that they are fluent in the risks and side effects of PrEP, especially the potential drug interactions with gender-affirming hormones for transgender clients.[26]

Like many others, our study participants noted the importance of providers using their chosen name and pronoun, but we also found some health workers worrying that they were not sure of the best language and approach to use. Cultural competency training is necessary to improve physicians' ability to provide non-judgmental care for adolescents and to promote the use of inclusive language.[27]

Our study findings show that recognizing health facility staff as open members of the LGBTQ+ community made participants feel more comfortable and improved their trust in providers. Interventions to ensure that health facilities are seen as safe spaces for health workers and clients in all their diversity can also help promote overall comfort with and trust in these services. Making sure that health workers feel valued is a core piece of this.

Health worker discussions of complex cases and seroconversion of any client on PrEP are a useful quality-control practice that might be adopted in policy relating to all PrEP and combination prevention services. The measures put in place to promote retention in services during the COVID-19 pandemic provide lessons on how to sustain follow-up on PrEP for different profiles of adolescents.[28]

Participation

Limited attention to the participation of affected communities in service design and implementation constitutes a weakness of our demonstration study. This is an area for development in future intervention efforts, including government scale-up processes.

Informed decision-making

Health workers should be well-versed in identifying high-risk individuals and providing them PrEP-related information.[29] Furthermore, PrEP information should be available to everyone in order to ensure that at-risk individuals are aware of PrEP regardless of whether they feel comfortable disclosing their sexual orientation or gender identity.[30] Low knowledge about PrEP among adolescents highlights the need for better communication to reach different adolescent populations, as well as for addressing the social and structural inequalities that drive vulnerability to HIV and limited access to relevant information.[31]

Globally, many programs have successfully addressed PrEP-related stigma by diversifying PrEP messaging. Since most PrEP messaging is targeted toward men who have sex with men, messages could specifically depict and target transgender women and cisgender, heterosexual populations.[32] Dissemination of PrEP-related information through leaders in the LGBTQ+ community and peer-education models can also increase access.[33]

Social media was found to be a critical channel of communication with adolescents in this study, partly because the study took place during COVID-19 lockdowns, but also because adolescents are so immersed in the world of social media. There is increasing support for the use of social media and dating apps to reach individuals who are not publicly "out."[34] As governments make adolescent PrEP increasingly available, social media provides ample opportunities for adolescent-friendly outreach and communication.

In the context of adolescent health service delivery, capacity building around evolving capacity and informed decision-making is particularly important. Health workers in Latin America have been found to feel ill-equipped to determine adolescents' decision-making capacity, which can impede service provision.[35] Helping health workers assess capacity, talk openly about sensitive topics, and trust adolescents' capacity to make informed decisions are central components of capacity building. A socio-relational perspective of autonomy may bring light to the understanding that a person's evolving capacity is unique and is embedded in a social context that is constantly changing and is shaped by emotions, needs for social validation, and the goal of protecting a common good for collective well-being.[36] Therefore, rather than health worker capacity building focusing on a single "right" answer that works for everyone, it could be more guided toward building consensus and mapping out sources of support.

Nondiscrimination

Although some interview participants expressed concern about providing adolescent PrEP services for sexual and gender minorities through public health facilities nationwide, even prior to the study this health center already had strong and diverse staffing. The medical doctor was the only new staff member added, as there was no need for a doctor when the health center provided only STI and HIV testing. The project reoriented services to be more people centered—that is, managing health care according to each adolescent's needs and social vulnerability. This included expanding opening hours, redefining some staff roles, and allowing longer and more frequent consultations. This suggests that with training and reorganization, a similar level of service provision would seem feasible in other facilities.

Privacy and confidentiality

Concerns around privacy and confidentiality are often at the forefront for adolescents, particularly in relation to sexual health, HIV, sexuality, and gender identity, which has been found to hinder PrEP adherence among adolescents.[37] It is essential that service providers understand the importance of privacy and confidentiality for adolescents, as well as the legal protections in place that permit them to provide PrEP-related information and services to this age group.

Accountability

There exists a strong legal and policy framework in Brazil within which the government can be held legally accountable for ensuring adolescents' access to PrEP (and associated) services. While conservative political forces have sought to dismantle comprehensive sexuality education and undermine sexual rights in recent years, the election of the current administration in late 2022 signals hope for a reprioritization of health for all within Brazil.[38]

Limitations

Our study took place in São Paulo, a large city with a high concentration of HIV services compared to most other parts of Brazil. Different or additional challenges with scale-up of adolescent PrEP may be faced in other places.

Even as we know that racial and ethnic identity affect PrEP accessibility and acceptability, and that racial marginalization within the LGBTQ+ community decreases people of color's access to information and resources, we were unable to analyze potential differences in attitudes toward rights-based services by race or ethnicity.[39]

Conclusion

Given the very limited evidence available on PrEP service delivery for adolescents globally, these lessons might inform countries beyond Brazil as they consider introducing or scaling up adolescent PrEP. The value accorded—by clients and service providers alike—to the human rights principles explored above is clear. Human rights provide a useful framework for assessing system preparedness and capacity for providing youth-friendly services, particularly to marginalized adolescents. Rights also highlight what matters for clients and providers, which can promote better service delivery and improve relationships between clients and providers.

Providing adolescent PrEP, including for sexual and gender minorities, requires taking into account that current generations are characterized by a social representation of HIV as a mild disease, as well as new and more fluid gender and sexual identities. Adolescents and youth pursue greater protagonism in affective and sexual interactions, which includes more frequent use of dating apps and substances in sexual relations. The growing conservatism that has constrained the involvement of different sectors of society and weakened the response to HIV has resulted in a generation with fewer resources to deal with the epidemic.[40] This study provides useful insights into how countries can design and implement rights-based adolescent-friendly PrEP services that help promote engagement and retention in PrEP services, particularly for marginalized populations. A shift in HIV policy is needed to achieve this goal by prioritizing PrEP in the provision of preventive methods while addressing the social determinants of the HIV epidemic and guaranteeing meaningful participation of adolescents in shaping the policy.[41]

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Ethics approval

This study was conducted according to the directives derived from the Brazilian Research Ethics Commission Resolution 466/2012. The protocol was approved by the Research Ethics Review Committee of the World Health Organization (protocol ID: Fiotec-PrEP Adolescent study) and by the University of São Paulo (protocol number 70798017.3.0000.0065). Written informed consent and assent were asked for those who agreed to participate, and they could withdraw their consent at any stage of the process without penalty, or skip any questions they perceived as too sensitive, personal, or distressing.

Translation

All translations from Portuguese to English were performed by the authors.

References

1. World Health Organization, *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach*, 2nd edition (Geneva: World Health Organization, 2016).

2. Ministry of Health, Secretaria de Ciência, Tecnologia, Inovação e Insumos Estratégicos em Saúde, *Portaria Sctie/Ms No 90*, (2022), https://www.gov.br/conitec/pt-br/midias/protocolos/20220902_PCDTPrEP.pdf.

3. Ministry of Health, Painel de monitoramento da Profilaxia Pré-Exposição (PrEP) (2023), https://www.gov.br/aids/pt-br/assuntos/prevencao-combinada/prep-profilaxia-pre-exposicao/painel-prep.

4. United Nations Children's Fund, "Adolescent HIV Prevention" (2023), https://data.unicef.org/topic/hivaids/adolescents-young-people/.

5. H. Yusuf, E. Fields, R. Arrington-Sanders, et al., "HIV Preexposure Prophylaxis among Adolescents in the US: A Review," *JAMA Pediatrics* 174/11 (2020); C. L. Celum, E. A. Bukusi, L. G. Bekker, et al., "PrEP Use and HIV Seroconversion Rates in Adolescent Girls and Young Women from Kenya and South Africa: The POWER Demonstration Project," *Journal of the International AIDS Society* 25/7 (2022).

6. L. Ferguson, W. Jardell, and S. Gruskin, "Leaving No One Behind: Human Rights and Gender as Critical Frameworks for U=U," *Health and Human Rights Journal* 24/2 (2022); Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4

(2000); L. Ferguson and E. Halliday, "Participation and Human Rights: Impact on Women and Children's Health; What Does the Literature Tell Us?," in F. Bustreo, P. Hunt, S. Gruskin, et al. (eds), *Women's and Children's Health: Evidence of Impact of Human Rights* (Geneva: World Health Organization, 2013); H. Potts, *Participation and the Right to the Highest Attainable Standard of Health* (Colchester: University of Essex Human Rights Centre, 2008).

7. *Convention on the Rights of the Child,* G.A. Res. 44/25 (1989).

8. Committee on the Rights of the Child, General Comment No. 15, UN Doc. CRC/C/GC/15 (2013).

9. L. J. Bauman, C. A. Mellins, and R. Klitzman, "Whether to Waive Parental Permission in HIV Prevention Research among Adolescents: Ethical and Legal Considerations," *Journal of Law, Medicine and Ethics* 48/1 (2020); B. G. Kapogiannis, R. M. Nelson, G. Siberry, et al., "Advancing HIV Biomedical Prevention Research for At-Risk Adolescents," *Journal of Acquired Immune Deficiency Syndromes* 79/5 (2018); E. M. Zucchi, L. Ferguson, L. Magno, et al., "When Ethics and the Law Collide: A Multicenter Demonstration Cohort Study of Preexposure Prophylaxis Provision to Adolescent Men Who Have Sex with Men and Transgender Women in Brazil," *Journal of Adolescent Health* 73/S6 (2023).

10. Constitution of Brazil (1988), https://pdba.georgetown.edu/Constitutions/Brazil/english96.html; Brazil, Lei 8.080 de 19 de Setembro de 1990 (1990), arts. 196–200.

11. G. Ayala, K. Makofane, G. M. Santos, et al., "Access to Basic HIV-Related Services and PrEP Acceptability among Men Who Have Sex with Men Worldwide: Barriers, Facilitators, and Implications for Combination Prevention," *Journal of Sexually Transmitted Diseases* (2013); N. Pacífico de Carvalho, C. C. P. Mendicino, R. C. F. Cândido, et al., "HIV Pre-exposure Prophylaxis (PrEP) Awareness and Acceptability among Trans Women: A Review," *AIDS Care* 31/10 (2019); S. Wood, R. Gross, J. A. Shea, "Barriers and Facilitators of PrEP Adherence for Young Men and Transgender Women of Color," *AIDS and Behavior* 23/10 (2019); S. M. Wood, S. Lee, F. K. Barg, et al., "Young Transgender Women's Attitudes toward HIV Pre-exposure Prophylaxis," *Journal of Adolescent Health* 60/5 (2017); E. M. Zucchi, M. T. Couto, M. Castellanos, et al., "Acceptability of Daily Pre-exposure Prophylaxis among Adolescent Men Who Have Sex with Men, Travestis and Transgender Women in Brazil: A Qualitative Study," *PLOS ONE* 16/5 (2021).

12. Ayala et al. (see note 11); R. L. Behler, B. T. Cornwell, and J. A. Schneider, "Patterns of Social Affiliations and Healthcare Engagement among Young, Black, Men Who Have Sex with Men," *AIDS and Behavior* 22/3 (2018); Wood et al. (2019, see note 11).

13. R. E. Pérez-Figueroa, R. Kapadia, S. C. Barton, et al., "Acceptability of PrEP Uptake Among Racially/Ethnically Diverse Young Men Who Have Sex with Men: The P18 Study," *AIDS Education and Prevention* 27/2 (2015).

14. Ayala et al. (see note 11); R. J. Matacotta, F. J. Rosales-Perez, and C. M. Carrillo, "HIV Preexposure Prophylaxis and Treatment as Prevention: Beliefs and Access Barriers in Men Who Have Sex with Men (MSM) and Transgender Women; A Systematic Review," *Journal of Patient-Centered Research and Reviews* 7/3 (2020); Pacífico de Carvalho et al. (see note 11); Pérez-Figueroa et al. (see note 13); J. M. Sevelius, J. Keatley, N. Calma, et al., "'I Am Not a Man': Trans-specific Barriers and Facilitators to PrEP Acceptability among Transgender Women," *Global Public Health* 11/7–8 (2016); Zucchi et al. (2021, see note 11).

15. Pacífico de Carvalho et al. (see note 11); Pérez-Figueroa et al. (see note 13).

16. Brazil, Lei 8.069 de 13 de Julho de 1990 (1990).

17. L. Magno, F. Soares, E. M. Zucchi, et al., "Reaching Out to Adolescents at High Risk of HIV Infection in Brazil: Demand Creation Strategies for PrEP and Other HIV Combination Prevention Methods," *Archives of Sexual Behavior* 52/2 (2023).

18. Conselho Federal de Medicina, *Código de Ética Médica: Resolução No. 2.217 de 27 de setembro de 2018, Modificada pelas Resoluções CFM No. 2.222/2018 e 2.226/2019* (2019), art. 74.

19. C. B. Fisher, A. L. Fried, M. Desmond, et al., "Facilitators and Barriers to Participation in PrEP HIV Prevention Trials Involving Transgender Male and Female Adolescents and Emerging Adults." *AIDS Education and Prevention* 29/3 (2017).

20. I. Dourado, L. Magno, D. B. Greece, et al., "Interdisciplinarity in HIV Prevention Research: The Experience of the PrEP1519 Study Protocol among Adolescent MSM and TGW in Brazil," *Cadernos de Saúde Pública* 39/Suppl 1 (2023).

21. In contrast to other contexts in which the word "transvestite" has a derogatory meaning, in Brazil, the term *travesti* represents a political identity of transgender persons, recognized as such by the LGBTQIA+ social movement.

22. I. Dourado, F. Soares, L. Magno, et al., "Adherence, Safety, and Feasibility of HIV Pre-exposure Prophylaxis among Adolescent Men Who Have Sex with Men and Transgender Women in Brazil (PrEP1519 Study)," *Journal of Adolescent Health* 73/6S (2023).

23. Zucchi et al. (2023, see note 17).

24. A. Braksmajer, C. Zhang, and J. M. McMahon, "Associations between Relationship Power and Pre-exposure Prophylaxis (PrEP) Use among Men Who Have Sex with Men," *AIDS and Behavior* 24/5 (2020).

25. S. Z. Ching, L. P. Wong, M. A. B. Said, and S. H. Lim, "Meta-synthesis of Qualitative Research of Pre-exposure Prophylaxis (PrEP) Adherence among Men Who Have Sex with Men (MSM)," *AIDS Education and Prevention* 32/5 (2020); Fisher et al. (see note 19); R. M. Grant, J. M. Sevelius, J. V. Guanira, et al., "Transgender Women in Clinical Trials of Pre-exposure Prophylaxis," *Journal of Acquired Immune Deficiency Syndromes* 72/Suppl 3 (2016); Sevelius et al. (see

note 14); Zucchi et al. (2021, see note 11).

26. Ching et al. (see note 25).

27. Fisher et al. (see note 19); Grant et al. (see note 25); Sevelius et al. (see note 14).

28. Dourado et al. (2023, see note 20).

29. S. Cahill, S. W. Taylor, S. A. Elsesser, et al., "Stigma, Medical Mistrust, and Perceived Racism May Affect Prep Awareness and Uptake in Black Compared to White Gay and Bisexual Men in Jackson, Mississippi and Boston, Massachusetts," *AIDS Care* 29/11 (2017).

30. Ibid.; M. Charest, M. Sharma, A. Chris, et al., "Decentralizing PrEP Delivery: Implementation and Dissemination Strategies to Increase Prep Uptake among MSM in Toronto, Canada," *PLOS ONE* 16/3 (2021).

31. Zucchi et al. (2021, see note 11).

32. Fisher et al. (see note 19); B. Hoagland, R. B. De Boni, R. I. Moreira, et al., "Awareness and Willingness to Use Pre-exposure Prophylaxis (PrEP) Among Men Who Have Sex with Men and Transgender Women in Brazil," *AIDS and Behavior* 21/5 (2017); Kapogiannis et al. (see note 9); Matacotta et. al (see note 14); Sevelius et al. (see note 14).

33. Kapogiannis et al. (see note 9); M. C. McNulty, M. E. Acree, J. Kerman, et al., "Shared Decision Making for HIV Pre-exposure Prophylaxis (PrEP) with Black Transgender Women," *Culture, Health and Sexuality* (2021).

34. Pérez-Figueroa et al. (see note 13); Wood et al. (2019, see note 11).

35. M. Nair, V. Baltag, K. Bose, et al., "Improving the Quality of Health Care Services for Adolescents, Globally: A Standards-Driven Approach," *Journal of Adolescent Health* 57/3 (2015).

36. K. Kasoka, "Autonomy in HIV Testing: A Call for a Rethink of Personal Autonomy in the HIV Response in Sub-Saharan Africa," *Medicine, Health Care and Philosophy* 23/3 (2020).

37. D. Ferraz, T. A. Rossi, E. M. Zucchi, et al., "'I Can't Take This Shitty Quarantine Anymore': Sexual Behavior and PrEP Use Among Young Men Who Have Sex with Men and Transgender Women in Brazil during the COVID-19 Pandemic," Archives of Sexual Behavior 52 (2023).

38. G. B. Martins, T. F. Pinheiro, D. Ferraz, et al., "Use of HIV Prevention Methods and Contexts of the Sexual Practices of Adolescent Gay and Bisexual Men, Travestis, and Transgender Women in São Paulo, Brazil," *Cadernos de Saúde Pública* 39/Suppl 1 (2023); C. Ianni Segatto, M. Aquino Alves, and A. Pineda, "Uncivil Society and Social Policies in Brazil: The Backlash in the Gender, Sexual, and Reproductive Rights and Ethnic and Racial Relations Fields," *Public Administration and Development* 43/1 (2023).

39. Behler et al. (see note 12); E. C. Wilson, E. M. Jalil, C. Castro, et al., "Barriers and Facilitators to PrEP for Transwomen in Brazil," *Global Public Health* 14/2 (2019).

40. A. Grangeiro, D. Ferraz, L. Magno, et al., "Quarenta anos da resposta brasileira ao HIV: Reflexões sobre a necessidade do salto programático e a política como bem comum," *Cadernos de Saúde Pública* 39/13 (2023).

41. A. Grangeiro, D. Ferraz, L. Magno, et al., "Epidemia de HIV, tecnologias de prevenção e as novas gerações: Tendências e oportunidades para a resposta à epidemia," *Cadernos de Saúde Pública* 39/Suppl 1 (2023).

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"It's about Rights": The Bunya Project's Indigenous Australian Voices on Health Care Curricula and Practice

DANIELLE MANTON, MEGAN WILLIAMS, AND ANDREW HAYEN

Abstract

Indigenous community-controlled health care organizations provide timely, sustained, and culturally safe care. However, their expertise is often excluded from health professional education. This limits the transfer of knowledges and protocols to future practitioners—those positioned to shape health care systems and practices that could achieve the health rights of Indigenous people and reduce health and social inequities. In Australia, despite national government commitments to transforming curricula, services, and systems related to Indigenous health, health care training organizations such as universities generally have low numbers of Indigenous staff and few strategies to engage Indigenous experts. The authors of this paper are part of the Bunya Project, an Indigenous-led participatory action research effort designed to support non-Indigenous university staff and curriculum development through partnerships with Indigenous community-controlled organizations. We conducted 24 interviews with Indigenous individuals to ascertain recommendations for health care curricula. Three themes emerged: (1) role-modeling and leadership of Indigenous-controlled health organizations; (2) specific learnings for health professionals; and (3) achieving human rights in practice. Interviews also highlighted the need for health professionals' extension beyond clinical caregiving, and staff and students' development of knowledge, skills, and actions regarding client self-determination in order to promote clients' rights across all aspects of their health care. Critical self-reflection by health professionals is a foundational individual-level skill necessary for cultural safety.

DANIELLE MANTON is a PhD candidate and senior lecturer in Indigenous teaching and learning at the University of Technology Sydney, Australia.

MEGAN WILLIAMS, PhD, is a professor of Indigenous health at the University of Technology Sydney, Australia.

ANDREW HAYEN, PhD, is a professor of biostatistics at the University of Technology Sydney, Australia.

Please address correspondence to Danielle Manton. Email: Danielle.Manton@uts.edu.au.

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Introduction

The right to health and Indigenous rights

Indigenous peoples' right to health is affirmed in international conventions and declarations pertaining to health, human rights, and the specific rights of Indigenous peoples. The United Nations Declaration on the Rights of Indigenous Peoples identifies conditions necessary to achieve the right to health and social justice, including self-determination, maintaining traditional health practices, protection from vulnerabilities, and improved social conditions and determinants of health.[1] The right to culturally appropriate health care is affirmed in General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights, and cultural dimensions of health are recognizable in the Declaration on the Rights of Indigenous Peoples' provisions on the right to maintain traditional knowledge, including medicines and knowledge of the properties of fauna and flora.[2]

Indigenous peoples' right to health is affirmed in legal and policy documents in the local jurisdictions of Indigenous peoples across the world.[3] These documents highlight the key principles of cultural safety in health care, access to land and resources, and accountability through legal recourse when violations of the right to health occur.

Statements in legal and policy documents frequently reflect the holistic worldview of Indigenous people—that health is not just physical well-being but also social, emotional, spiritual, mental, and environmental well-being.[4] These dimensions of health are affected and influenced by experiences across generations, particularly the influences of colonization, colonialism, racism, and multitudinous forms of social exclusion.

Self-determination

Self-determination in health care is articulated in human rights instruments.[5] Indigenous peoples have the right to self-determination, including in health care.[6] Nonetheless, many health care systems have been identified as structurally racist, with clear examples of interpersonal racism in health care settings.[7] In Australia, the health care system and processes are seen as an instrument of colonization that continues to suppress Aboriginal and Torres Strait Islander peoples.[8] The recent framework to address health inequity in Australia, entitled *Closing the Gap*, involves federal, state, and local governments. The framework was first developed in 2008 with minimal consultation with Indigenous peoples or organizations; a majority of the inequities to be addressed worsened over the following decade.[9] A policy refresh occurred in 2018 with input from Aboriginal and Torres Strait Islander peoples and organizations, and in 2020 the Australian government formed a partnership with the Coalition of Aboriginal and Torres Strait Islander Peak Organisations to shift the approach to include self-determination.[10]

Working in partnership with Indigenous communities is a key strategy for improving self-determination, health care quality, and the potential for cultural safety.[11] Health professionals receive little training on how to work in partnership with Indigenous communities or on key concepts of cultural safety, Indigenous rights, and specific Indigenous content underlying general evidence-based practices.[12] Overwhelmingly, health care education focuses on the ill health of Indigenous peoples, with limited exposure to Indigenous perspectives on holistic health care models.[13] Without this knowledge, health care providers risk continuing to devalue Indigenous models of health care by rendering them invisible.[14]

Cultural safety

Culturally safe practice is defined by the Australia Health Practitioner Regulation Agency and National Boards as "the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practicing behaviours and power differentials in delivering safe, accessible and responsive health care free from racism."[15]

There is growing pressure in the Australian health sector to demonstrate culturally safe practice. Indeed, cultural safety is one of the objectives of the Australian Health Practitioner Regulation National Law.[16]

However, there have been too few strategies to teach cultural safety in practice.[17] In 2014, the Australian government developed the Aboriginal and Torres Strait Islander Health Curriculum Framework consisting of nine capabilities, including respect, relationships, and partnerships.[18] These capabilities are often not well modeled at the university level.[19] Additionally, capabilities valued by Indigenous peoples—such as respect, communication, advocacy, and reflection—are rarely explicitly developed or measured.

Aboriginal community-controlled health organizations workforce and leadership

The 145-plus Aboriginal community-controlled health organizations (ACCHOs) in Australia demonstrate leadership in delivering culturally safe holistic health care.[20] ACCHOs are the largest employers of the Indigenous workforce in Australia.[21] Their staff enter a health care career wanting to achieve systemic change and positive outcomes for their families and communities.[22] ACCHOs are well placed to facilitate partnerships with universities to build the Indigenous workforce.[23]

Education

Universities play a key role in perpetuating and reinforcing structures of inequality and oppression. They have very few partnerships with ACCHOs to develop curricula or strategies to work with Indigenous peoples.[24]

Graduates are typically underprepared to work with Indigenous peoples and have little understanding of the burden of colonial contexts, histories, and ongoing trauma.[25] Coupled with assumptions, stereotyping, and lack of reflective insight, this perpetuates an inequitable power dynamic.[26]

Inclusion in health care education is limited to observation *about* Indigenous peoples rather than *with* Indigenous peoples. Indigenous Australians frequently report experiences of racism as part of their daily life and in the health system.[27]

Universities produce graduates who immediately have positions of power in relation to Indigenous peoples.[28] Recent graduates play an important role in how Indigenous patients engage with the health care system.[29] If recent graduates are equipped with the appropriate knowledge, skills, and strategies, they can become proactive agents in promoting and providing space for Indigenous leadership and in identifying and addressing racism.

Health curricula often include first-person accounts of lived experience to bridge theory and practice in health care.[30] The Indigenous-led participatory action research project, the Bunya Project, was designed to support non-Indigenous university staff and curriculum development through partnerships with Indigenous community-controlled organizations and strategic opportunities to share firsthand accounts of health needs and recommendations.[31]

Methodology

The Bunya Project is centered in an Aboriginal worldview, recognizing the value of the knowledge held with Indigenous peoples for millennia and its importance and relevance in today's context. This project is grounded in the centering and privileging of Indigenous ways of knowing (epistemologies), being (ontology), and doing (axiology).[32] The design of the Bunya Project has been described in full elsewhere; here, we provide only a short overview and a focus on the qualitative research component pertaining to this paper.[33]

Methods

The qualitative research conducted as part of the Bunya Project aimed to develop, implement, and evaluate Indigenous health curricula and resources in New South Wales, Australia, from 2019 to 2023. Data collection involved focus group discussions. The focus group discussions were followed by interviews, with the interviews exploring concepts raised in the focus groups.

Interviews, conducted in a relaxed setting known as Kapati Time, emphasized storytelling and knowledge sharing, reflecting the project's centrality of Indigenous expertise and methodologies.[34]

The structured interviews focused on Indigenous self-determination in health care education and asking participants what they thought mainstream health students should incorporate into their professional practice.[35]

While the interviews were semi-structured, based on Kapati Time and yarning principles, guiding questions were provided to all invited participants. The interview duration ranged from 15 to 60 minutes and was determined by the participants and the conversation.

Ethical approval

The Bunya Project adhered to the ethical guidelines of Australia's National Health and Medical Research Council, ensuring free and informed consent from participants and respecting their ownership of all collected data, including videos, audio recordings, and transcripts. The project was approved by the University of Technology Sydney Human Research Ethics Committee (ETH18-2618) and the Aboriginal Health and Medical Research Council of New South Wales Human Research Ethics Committee (1451/18). We used participant-selected pseudonyms to maintain confidentiality while honoring their Indigenous identities and roles within the community.

Recruitment

The convenience sample for the study consisted primarily of Indigenous staff and community members from the four partner organizations, with a total of 24 participants evenly distributed across genders and age groups. All participants identified as Aboriginal peoples and resided in New South Wales, with interviews conducted between 2019 and 2022, mostly in person but some via Zoom due to the COVID-19 pandemic.

Analysis

The first author conducted all interviews, collecting firsthand data, including context, non-verbal behaviors, and participants' voices.[36] After reading all transcripts without annotation, we created codes from emerging themes through active coding, leading to the identification of overarching themes.[37] We then refined these themes, emphasizing rights as a driver of analysis, through focused coding, resulting in three key findings with 12 subthemes.[38] Feedback from participating organizations and individuals ensured the reflective nature of the findings.

Findings

Accessing Indigenous voices is crucial for integrating Indigenous perspectives into curricula. The diverse stories gathered in the Bunya Project, while varied, share common themes, such as Indigenous people feeling unsafe in health services, being blamed, and feeling responsible for accessing services rather than services prioritizing accessibility for them.[39] The common message is the aspiration that health care practices in Australia will meet their basic human rights.

"What we show you": Self-determination of Indigenous-controlled health organizations to create culturally safe health care

The participants conveyed that Aboriginal peoples have immense expertise and experience that mainstream health services could learn from—not only with regard to cultural knowledge but also concerning flexible and multifaceted ways to make health care accessible. Access to health services and the right to the highest attainable standard of health are fundamental human rights, as is Indigenous people's right to self-determine programs and services that affect their well-being.[40] For Aunty Ivy, a respected Gamillaroi Elder, culturally safe access to health care services meant an understanding of indigeneity:

> *I use an Aboriginal Medical Service because I don't have to explain.*

When Aboriginal people use Aboriginal services or see Aboriginal health care providers, they often do not have to explain the experiences that Aboriginal people have with, for example, colonization, racism, and complex family and community relationships, which non-Indigenous people tend not to know about.[41] One participant, Kaurna Elder Aunty Lily-Jo, outlined the benefit of removing barriers such as anxiety related to attending appointments with set times.[42] In her words:

> *At the Aboriginal Medical Service, I just did a walk-in, they have that on Mondays and Tuesdays where you can just get a quick script and go. So that was accessible, and I found that really helpful.*

Unlike mainstream health organizations and hospitals, ACCHOs offer preventive health care.[43] They also address the needs of the whole community across the lifespan and proactively develop relationships within the community.[44] Aunty Lily-Jo continued:

> *So, I think they work. I've seen it in early years, high school and then the Aboriginal health days for community are really good.*

The approaches implemented by ACCHOs demonstrate leadership in understanding the needs within the local context.

Advocacy and empowerment. Alinta, a Biripi woman in her mid-20s, spoke of the importance of advocacy within the health care environment, empowering her to the benefit of herself and her community. Indigenous people globally have connected individually and collectively to become active in advocating for human rights.[45] As Alinta explained:

> *Being able to stand up and actually have a voice for them within their health is something that has made me stronger and being able to help myself but also be able to stand up and be a voice for the ladies that we help as well.*

Kahi, a Saltwater man in his early 30s, spoke of the confidence he has when accessing eye health care, self-advocating:

> *I don't know if it's me as a person who establishes those boundaries and I have that willpower and I guess that confidence to say, "This is where I'm at. You need to tell me the point of difference. You need to tell me what I need to do." But they were willing to listen and learn from what I needed for my eyecare.*

"What you need to know": Health care free from discrimination, and learnings for health professionals

Mainstream health care professionals and education providers have much to learn about how to work with Indigenous peoples.[46] In Australia, policies and regulations are beginning to hold health care practitioners and education providers accountable to this learning, but there is still much ambiguity about how to approach learning and what curriculum content should be.[47] The participants in this study identified points that they felt were important for health care practitioners to understand when working with Aboriginal peoples. These reflect the United Nations' work on health professional education from a human rights-based approach, which includes providing information and skills to address and prevent bias and discrimination.[48]

Legacy of colonization. The interviews suggest the importance of understanding the ongoing legacy of colonization and how past policies and power relations continue to impact Aboriginal peoples. Exclusionary practices—especially assumptions, stereotyping, and oppression—are in the fabric and culture of Australian health care systems and structures.[49]

Uncle Rex, a Gandangara man, reflected on this through his own experiences and journey:

> *Something that I'm working now to find out, about the history and everything of my culture, and especially my history of my family. Aboriginal people don't have a great history in the past, especially medical influences, because they haven't been able to get the access that everyone else has had.*

Alinta recognized the ongoing impact of colonization and the continued negative impact of introduced food sources:

> *I know the high risk that is involved with my people and culturally, health wise, what we've been through with colonization and things like sugar, how much it's affected our diet and diabetes.*

Health practitioners play a vital role in recognizing the ongoing impact of colonization on health and health care. Aunty Joy, a Kuku Yalanji and Kuku Thaypan Elder, shared her story interacting with health professionals:

> *If you don't really know who your parents are. See, that's what happened in my case because I thought somebody else was my father and I didn't know the history of the other side.*

Riley spoke of a similar experience featuring a constant expectation and pressure to know ancestorial medical details:

> *Yeah. Just not assuming that everyone has just that nuclear family structure. I know, even just going back to mum, because she was adopted, she used to get a lot of questions when she was pregnant with my brothers and I, from the doctors of what's her medical history and everything. She couldn't provide that, at that time.*

The ongoing legacy of colonization is extremely personal, and sometimes traumatic, for many people. This legacy affects how Aboriginal peoples engage in the health system and often how the health system engages with Aboriginal peoples.

Racism and distrust. Many Indigenous peoples face racism as a daily reality, despite racism being illegal in many nations, including Australia, and a breach of human rights.[50] Aboriginal peoples experience frequent racism in health settings, leading to a profound distrust of the system.[51] Nulla, a Gamilaraay woman in her early 30s, spoke of her experience with interpersonal racism, being told that

> *"You don't look Aboriginal. You're white." And I was like, I am, but I am also Aboriginal.*

Uncle Jim, a respected Wiradjuri Elder, spoke of his experience with his daughter, first to justify her Aboriginality based on her "white" appearance and then to challenge stereotyping and assumptions—devoid of clinical reasoning—based on her cultural identity. Uncle Jim described the experience:

> *And all along that way I had to justify her Aboriginality and them saying, well she's not really Aboriginal, she doesn't look Aboriginal. But because her Aboriginality, she had these medical histories, and they weren't listened to. And that's happened to me as well in emergency situations where they stereotype Aboriginal people and they don't relate that to our medical histories.*

Aunty Ivy, a respected Gamillaroi Elder, shared a similar experience where conclusions were drawn without any clinical diagnostics:

> *So that convinced them that I was a drug addict. They did no obs [clinical observation] on me in triage in the casualty.*

As a result of these experiences, participants noted that they felt distrust and apprehension toward accessing health services and working with non-Indigenous health professionals.

Tidam, an Aboriginal man from the east coast of Australia in his mid-30s, spoke of wanting to know specific information about the health care professional who was treating him:

> *I'd want to know about their history and how long they've been in the profession, success rate and things like that.*

Jarrah, an Aboriginal and Māori man in his mid-20s, spoke of the legacy of the past and how it continues to influence Indigenous peoples' attitudes and approaches to health care:

> *I think a lot of us are scared to go to the doctor's, I think that's been passed down. You only sort of go to the doctor's if you're going to die if something bad used to happen.*

A health system that is responsive to the health care of all Australians should not rely on the ability of the parent to navigate the system to ensure a positive outcome for their child. Aunty Ivy recalled:

> *That could have been a very different pathway for*

> *her if her parents didn't have the skills to be able to navigate through that system.*

Cultural load. Cultural load refers to the extra responsibility placed on Indigenous individuals in personal and professional settings whereby these individuals are expected to educate, provide insight, and offer support on topics perceived as "Indigenous."[52] In Australia, it is against the law to discriminate against someone based on race or culture, and operating in ways that lead one's culture to result in differential practices is discriminatory.[53]

Nulla, a Gamilaraay woman in her early 30s, described an example where she was required to explain a federal pharmaceutical benefits scheme (related to *Closing the Gap*) to a pharmacist. This knowledge should be foundational among pharmacists in Australia. Nulla described the encounter:

> *"Oh, what's CTG [Closing the Gap]?" Then you are the one who has got to educate them.*

Nulla continued:

> *I've never hated being Aboriginal, but I hate having to educate and inform people.*

Stereotypes and assumptions. Stereotyping and assumptions relate to power, race, and positionality.

Monti, a Noongar man in his mid-40s, warned:

> *Just because someone's from that community, you don't want to label them as everyone's got the same problem, as well.*

Nulla reflected on her experiences where health professionals made assumptions based on stereotyping rather than clinical reasoning and diagnostic testing:

> *"Are you Indigenous? Do you have diabetes?"*

Aunty Tahnee, a respected Wonnarua Elder, spoke of a similar experience in which health professionals made assumptions without clinical reasoning or diagnostic testing:

> *But because I've got that tick of being Aboriginal, they assumed I'd come in there to get drugs off them.*

Interview participants noted that some health care professionals believe that all Aboriginal patients should primarily be attended to by Indigenous staff members, such as the Aboriginal liaison officer. However, often these staff members cannot see patients without the clinical input of a health care professional.

Nulla described the reality of this:

> *And it's like, oh, okay. There, if they're Aboriginal or Torres Strait Islander, they will just like, oh, Aboriginal liaison officer. But that Aboriginal liaison officer doesn't necessarily have any health care experience, so it's not like they're putting a nurse in there or a psychologist or a speech [pathologist]. That's just what I see.*

Uncle Jim identified the potent influence of bias and assumptions about indigeneity, as well as the importance of critical self-reflection to challenge them:

> *And of course, they come with preconceived notions of what an Aboriginal person is, have sort of stereotypical ideas and they never question those ideas, so they don't question themselves, they're always right. So they need to understand that they cannot always be right, they can be wrong sometimes.*

Ed, a Noongar man in his 40s, emphasized the significance of critical self-reflection, urging health practitioners to engage in community-centered work and understand the issues affecting all community members, recognizing their strengths, to challenge preconceived assumptions. He provided clear advice:

> *I think knowing that community and knowing the problems in the community. I think also people in general, especially non-Aboriginal people, they paint a picture of Aboriginal people are very sick people. And I know a lot of Aboriginal people are very, very much switched on into their health and looking after themselves quite well. I think just*

> *knowing the problems in the community maybe and trying to change that, it can help, but if you going for work research, I think it's a good idea, to know what those problems are, as well.*

Assumptions can lead to fatal outcomes in the immediate and long term; this fear was reflected in many participants' comments above, and further below.

"What you need to show us": Quality health services and human rights in practice

Interview participants described many foundational skills and concepts that health care practitioners should demonstrate when working with Indigenous peoples. Cultural safety is now legislated for in Australia, as discussed below.

Cultural safety. Participants were able to remember health practitioners who had demonstrated culturally safe practice.

Sarah, a Worimi and Kuku Yalanji woman in her late 30s, appreciated the opportunity to self-determine and direct her own health care:

> *She respected what I wanted to do, I asked for it. She followed through with what I wanted to do.*

Kahi shared an experience of working with a family where a child required health care treatment, highlighting the practitioner's skill in fostering a culturally safe environment by involving the child's family:

> *I was just so, I guess, relieved and elated at the same time that she was able to consider the implications of this young kid's issues within the family setting and the role that each and everyone in that family had to play to support this young person's motor skills and their movement so they could eat, so they could communicate. It was a really great experience.*

Jiemba, an Aboriginal, Irish, and Scottish man in his mid-40s, identified how the people and the culture at the facility he attended created a safe space where he felt comfortable staying longer. As a result, they were able to perform thorough diagnostics:

> *They found a lot of things that were underlying with me. And they were very good with our people and culture and that there. They've got a good understanding. They were actually pretty good there.*

Participants' comments generally demonstrated that cultural safety principles do occur in practice and can be replicated.

Security of person and relationships. When Indigenous peoples require health care, they often find themselves in vulnerable positions—for several reasons outlined above and because they must navigate uneven power dynamics—which can compromise their rights to physical and mental integrity, as well as security of person.[54] Establishing relationships is crucial in addressing these power dynamics and fostering feelings of safety, which are core components of cultural safety. This involves practitioners prioritizing communication, respect, and the creation of safe relationships that value each client as a person.[55]

In Kahi's words:

> *Relationships are key. It's not always about the service that you can provide to make someone feel better through their medical concerns. It's really about grounding yourself in understanding their walk of life, understanding where they've come from to get to where they are when you first meet them. And sustaining those relationships with either them, themselves, their family, or even their community that matters.*

Aunty Lily-Jo added to this concept by describing aspirations for her own health care:

> *I would like to ensure that I have an accessible, trusting, respectful relationship, especially with our non-Aboriginal staff health staff.*

Uncle Jim provided insight and direction about how to begin forming relationships:

> *Forming that relationship, the same as what we do, who we are, where we're from, which breaks down a lot of barriers. I think, those first initial barriers.*

Aunty Ivy provided an example from her own experience when a health practitioner understood the importance of relationships:

> *And he was excellent and very much wanting to know more about Aboriginal culture and he actually had a lot of Aboriginal clients and they were being referred to him from the Aboriginal Medical Service. So it was very good relationship.*

While developing relationships takes time, it is an investment in the ongoing care of the patient.

Communication. Communication in health care is a fundamental quality standard in patient and workforce safety and a fundamental human right (the right to be able to seek, receive, and impart information).[56] Uncle Rex identified the importance of communication in establishing relationships and trust:

> *I believe that if you communicate well and show that we've got an open mind when it comes down to meeting different people even the first time. I think it's important.*

Yindi, a Wiradjuri woman in her early 30s, discussed how the language used by health practitioners can create distance between them and the patient. While acknowledging the importance of understanding clinical language, Yindi emphasized the need for practitioners to scaffold this process and recognize that each person's story is unique:

> *I think language is a really big thing. The first thing that I can think of is, I don't know, the more clinical you are, the more detached I feel from a health worker. If you can speak to me like a human and try to have that connection, I think is really important. So language and the way that you're speaking to Aboriginal peoples.*

Monti provided an example of when he felt that the practitioner implemented communication skills to work with him, and together they were able to challenge him to achieve a better outcome:

> *They were great in the way that they worked with me, understood my limitations physically and then even pushed the boundary to where mentally I was like, "Oh, I can't do this, I can't do this." But they knew better than I did in terms of my physical. So they really supported me physically and mentally through that.*

Ed pointed out that communication is more than what is said; it includes the importance of listening:

> *But I think it's important, to know that you're there even just to listen to what they are saying.*

Sarah developed this point further, recognizing that communication includes a non-verbal dimension:

> *I think it's their body language, their tone in their voice. You could be like talking nicely, at the same you can feel they're not really interested. Acknowledging in just a handshake or whatever, all those things. Don't rush it.*

Steven, a Noongar, Worimi, and Kuku Yalanji man in his early 20s, identified the broader implications of communication:

> *Because I believe everyone should have the chance to be part of community, and communication is an important part of developing relationships and belonging in community.*

Steven's broader reflections also explain his perspective that communication is foundational to relationships in communities and that health care providers' willingness and ability to develop relationships in the community helps Indigenous people feel more comfortable accessing and complying with health care.

Interpersonal skills. Interpersonal skills such as communication style are often subjective, hard to articulate, and difficult to teach and assess.[57] These skills, however, can have a beneficial impact on patients, often leading to a positive experience and improved adherence and outcomes.[58] The interpersonal skills of a health professional support all peoples' right to access health services, as well as the right to maintain the highest attainable standard of health.

Monti, who lives in regional New South Wales, spoke fondly of the interpersonal skills of a local pharmacist:

> *He always remembers my name. We have a yarn. He doesn't—probably seen me kids once or twice, but, how's the wife and kids? What grade are they in school now? Talks about [town]— what's the weather like in [town]? Because he knows I live here now, and yeah.*

The ongoing impact of colonization, oppression, and racism compels Indigenous peoples to adopt defensive mechanisms, which increases the need for strong interpersonal skills among health professionals. Uncle Warrin, a Worimi man, issued a warning for current and future health care practitioners working with Aboriginal people:

> *I think Kooris are very good at reading people. And if there's bullshit in the health professional, the Kooris would react with a wall. Or just be nice, but wary.*

Annabelle, a Worimi and Kuku Yalanji woman in her mid-30s, built on this:

> *Learn a person's story, not just treat a symptom. Find out more about the person as much as you can in the small timeframe you have. Listen, don't just go and judge. Understand cultural and historical traumas as well as the strength that that culture has, because the white way isn't always the right way. There is always a different side and a different lens and a different view that you could explore. But that takes time, practice, and patience on your behalf to do that. And you're going to want to have to learn it.*

Riley spoke about the difference between community experiences and expectations, on the one hand, and practitioners' experiences and expectations, on the other. He reflected that it is important for health practitioners to know that difference is not wrong.[59] Riley emphasized the importance of respect as a demonstration of authenticity and the need for practitioners to understand the complexities of the local context and be respectful. He said:

> *Not to judge people, they look to understand the area you live in and to also show that you are respectful to them.*

When considering what is important for health practitioners to know when working with Aboriginal peoples, Jarli, Aboriginal ancestry unknown, in his late 30s, named salient points:

> *It's just having respect. Respect and education.*

Discussion

This research among 24 Aboriginal people explored their health care experiences, uncovering positive and negative examples within mainstream and Indigenous-led services. Participants provided recommendations for university health care curriculum development, in keeping with the Bunya Project's purpose to positively influence university staff, support them in transforming and evaluating their curricula, and in training health students to be more culturally appropriate and respect the rights of Indigenous peoples. The health care curriculum is only a starting point, and as participants explained, practitioners also benefit from learning within and from Aboriginal communities during and after graduation. Participants highlighted the importance of educators equipping future health professionals with the skills and knowledge needed to promote human rights, emphasizing active listening, respect, trust-based relationships, and empowering Indigenous people to self-determine solutions to complex health issues.[60] They called on health professionals to understand the social context, particularly of the local Aboriginal communities, because it influences health, well-being, and rights; Aboriginal community life is a cultural determinant of health.[61]

Participants in the Bunya Project consistently emphasized the importance of human rights and Indigenous rights in health care practices and curriculum development. However, there is a notable lack of professional development opportunities for academic staff, many of whom lack experience engaging with Indigenous communities.

Subjugation embedded in the health care system perpetuates systemic racism, necessitating critical reflection to shift the narrative from blaming Indigenous peoples to recognizing systemic problems. By equipping health students with skills to become culturally capable clinicians, the burden on Indigenous peoples as educators can be reduced. Partnering with ACCHOs offers universities opportunities to improve health curricula and practices collaboratively and respectfully.[62]

Conclusion

Australia's health sector has the largest Indigenous workforce of all sectors, largely because this is a priority area where Indigenous people feel they can make the most impact to the benefit of their communities.[63] By partnering with Indigenous community-controlled organizations, universities can develop health curricula that involve Indigenous health care providers and users. Through these partnerships, universities can also feasibly and valuably contribute to Indigenous communities and engage more deeply with local cultures. Finally, including Indigenous knowledges and community members in the teaching of health care practice creates potential for intergenerational change—not only among Indigenous people but among health care providers and educators—and for fulfilling human rights.

References

1. United Nations Declaration on the Rights of Indigenous Peoples, G.A., Res 61/295 (2007); J. Gilbert and C. Lennox, "Towards New Development Paradigms: The United Nations Declaration on the Rights of Indigenous Peoples as a Tool to Support Self-Determined Development," *International Journal of Human Rights* 23/1–2 (2019).

2. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000); United Nations Declaration on the Rights of Indigenous Peoples (see note 1), art. 31.

3. A. Moscoso, C. Piñones-Rivera, R. Arancibia, and B. Quenaya, "The Right to Health Care Viewed from the Indigenous Research Paradigm: Violations of the Rights of an Aymara Warmi in Chile's Tarapacá Region," *Health and Human Rights Journal* 25/1 (2023).

4. L. Jackson Pulver, M. Williams, and S. Fitzpatrick, "Social Determinants of Australia's First Peoples' Health: A Multi-level Empowerment Perspective," in P. Liamputtong (ed), *Social Determinants of Health* (Oxford: Oxford University Press, 2019).

5. Gilbert and Lennox (see note 1).

6. Committee on Economic, Social and Cultural Rights (see note 2); United Nations Declaration on the Rights of Indigenous Peoples (see note 1), arts. 3, 24.

7. C. Watego, D. Singh, and A. Macoun, "Partnership for Justice in Health: Scoping Paper on Race, Racism and the Australian Health System," Lowitja Institute Discussion Paper (2021); C. Parter, D. Murray, J. Mohamed, et al., "Talking about the 'R' Word: A Right to a Health System That Is Free of Racism," *Public Health Research and Practice* 31/1 (2021); Y. Paradies and J. Cunningham, "Experiences of Racism among Urban Indigenous Australians: Findings from the DRUID Study," *Ethnic and Racial Studies* 32/3 (2009).

8. W. M. Foucault, *Archaeology of Knowledge and the Discourse on Language* (1972, trans. A. M. Sheridan Smith), p. 49; P. Wolfe, "Settler Colonialism and the Elimination of the Native," *Journal of Genocide Research* 8/4 (2006); Parter et al. (see note 7).

9. C. Holland, *A Ten-Year Review: The Closing the Gap Strategy and Recommendations for Reset* (Close the Gap Campaign Steering Committee, 2018).

10. Council of Australian Governments, *COAG Statement on the Closing the Gap Refresh* (December 12, 2018); Coalition of Peaks and Australian Governments, "National Agreement on Closing the Gap" (2020), https://www.coalitionofpeaks.org.au/national-agreement-on-closing-the-gap.

11. C. Sheila, B. J. Smith, A. Possamai-Inesedy, and A. M. N. Renzaho, "Exploring the Role of Community Engagement in Improving the Health of Disadvantaged Populations: A Systematic Review," *Global Health Action* 8/1 (2015); M. Wright, D. Getta, O. Green, et al., "Co-designing Health Service Evaluation Tools That Foreground First Nation Worldviews for Better Mental Health and Wellbeing Outcomes," *International Journal of Environmental Research and Public Health* 18/16 (2021).

12. D. Manton and M. Williams, "Strengthening Indigenous Australian Perspectives in Allied Health Education: A Critical Reflection," *International Journal of Indigenous Health* 16/1 (2021).

13. Jackson Pulver et al. (see note 4); National Aboriginal Health Strategy Working Party, *A National Aboriginal Health Strategy* (Canberra: National Aboriginal Health Strategy Working Party, 1989); D. Manton, M. Williams, and A. Hayen, "The Bunya Project: Protocol for a Mixed-Methods Approach to Developing a Culturally Informed Curriculum," *JMIR Research Protocols* 12/1 (2023).

14. Manton et al. (see note 13).

15. Australian Health Practitioner Regulation Agency and National Boards, *The National Scheme's Aboriginal and*

Torres Strait Islander Health and Cultural Safety Strategy 2020–2025 (Australian Health Practitioner Regulation Agency and National Boards, 2020), p. 9.

16. Ibid.; Australian Health Practitioner Regulation Agency and National Boards, *Regulatory Guide* (Australian Health Practitioner Regulation Agency and National Boards, 2022).

17. Manton and Williams (see note 12).

18. Department of Health, *Aboriginal and Torres Strait Islander Health Curriculum Framework* (Canberra: Department of Health, 2014).

19. R. Delbridge, L. Garvey and J. Mackelprang, et al., "Working at a Cultural Interface: Co-creating Aboriginal Health Curriculum for Health Professions," *Higher Education Research and Development* 41/5 (2022).

20. Manton et al. (see note 13).

21. National Aboriginal Community Controlled Health Organisation, "NACCHO Members" (August 11, 2023), https://www.naccho.org.au/naccho-members.

22. J. Bailey, I. Blignault, C. Carriage, et al., *We Are Working for Our People: Growing and Strengthening the Aboriginal and Torres Strait Islander Health Workforce; Career Pathways Project Report* (Melbourne: Lowitja Institute, 2020).

23. M. Davis, "Community Control and the Work of the National Aboriginal Community Controlled Health Organisation: Putting Meat on the Bones of the UNDRIP," *Indigenous Law Bulletin* 8/11 (2013).

24. D. Saxe and J. Gale, "Unsettling the 'White University': Undermining Color-Blindness through Critical Race Theory and Testimonio," *Journal for Critical Education Policy Studies* 19/3 (2022); B. M. Brayboy, H. R. Gough, B. Leonard, et al., "Reclaiming Scholarship: Critical Indigenous Research Methodologies," in S. D. Lapan, M. T. Quartaroli, and F. Riemer (eds), *Qualitative Research: An Introduction to Methods and Designs* (San Francisco: Jossey-Bass, 2012).

25. Manton and Williams (see note 12).

26. J. Marcelin, S. Dawd, R. Siraj, et al., "The Impact of Unconscious Bias in Healthcare: How to Recognize and Mitigate It," *Journal of Infectious Diseases* 220/2 (2019).

27. Parter et al. (see note 7); Reconciliation Australia, *2020 Australian Reconciliation Barometer* (Parkes: Reconciliation Australia, 2020).

28. Manton and Williams (see note 12); Manton et al. (see note 13).

29. Y. S. Poon, Y. P. Lin, P. Griffiths, et al., "A Global Overview of Healthcare Workers' Turnover Intention amid COVID-19 Pandemic: A Systematic Review with Future Directions," *Human Resources for Health* 20/1 (2022).

30. T. Parnell, K. Fiske, K. Stastny, et al., "Lived Experience Narratives in Health Professional Education: Educators' Perspectives of a Co-designed, Online Mental Health Education Resource," *BMC Medical Education* 23/1 (2023).

31. Manton et al. (see note 13).

32. S. Wilson, "What Is Indigenous Research Methodology?," *Canadian Journal of Native Education* 25/2 (2001).

33. Manton et al. (see note 13).

34. R. Ober, "Kapati Time: Storytelling as a Data Collection Method in Indigenous Research," *International Journal of Learning in Social Contexts* 22/1 (2017).

35. Ibid.

36. K. Charmaz, *Constructing Grounded Theory* (London: Sage Publishing, 2014), p. 111.

37. Ibid., p. 115.

38. Ibid.

39. G. Bodkin-Andrews, S. Page, and M. Trudgett, "Shaming the Silences: Indigenous Graduate Attributes and the Privileging of Aboriginal and Torres Strait Islander Voices," *Critical Studies in Education* 63/1 (2022); S. Topp, A. Edelman, and S. Taylor, "'We Are Everything to Everyone': A Systematic Review of Factors Influencing the Accountability Relationships of Aboriginal and Torres Strait Islander Health Workers (AHWs) in the Australian Health System," *International Journal for Equity in Health* 17/1 (2018).

40. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966); United Nations Declaration on the Rights of Indigenous Peoples (see note 1).

41. S. Fitzpatrick, *Inner Qualities versus Inequalities': A Case Study of Student Change Learning about Aboriginal Health Using Sequential, Explanatory Mixed Methods*, PhD thesis (UNSW, 2023).

42. S. Avery, *Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability* (Sydney: First Peoples Disability Network Australia, 2018).

43. D. Coombs, "Future-Proofing Indigenous Self-Determination in Health: Goals, Tactics, and Achievements of Aboriginal Community Controlled Health Organisations in New South Wales, Australia," in N. Moodie and S. Maddison (eds), *Public Policy and Indigenous Futures* (Singapore: Springer Nature, 2023).

44. S. C. Thompson, E. Haynes, S. Shahid, et al., "Shedding Light or Fanning Flames?: A Consideration of the Challenges in Exploring the Relative Effectiveness of Aboriginal Community Controlled Health Services," *Quality in Primary Care* 23/3 (2015).

45. T. Calma and D. Dick, "Social Determinants and the Health of Indigenous Peoples in Australia: A Human Rights-Based Approach," (International Symposium on the Social Determinants of Indigenous Health, April 29–30, 2007), https://humanrights.gov.au/about/news/speeches/social-determinants-and-health-indigenous-peoples-australia-human-rights-based.

46. Manton and Williams (see note 12).

47. Ibid.

48. United Nations General Assembly, Interim Report of the Special Rapporteur on the Right of Everyone to the

Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/74/174 (2019).

49. Parter et al. (see note 7).

50. Ibid.; Australia, Racial Discrimination Act (1975); Human Rights Watch, "An Approach to Reparations" (July 19, 2001), https://www.hrw.org/legacy/campaigns/race/reparations.pdf.

51. Parter et al. (see note 7).

52. M. Gooda, "Aboriginal and Torres Strait Islander Social Justice Commissioner," *Social Justice and Aboriginal and Torres Strait Islander Peoples Access to Services* (2011).

53. Australia, Racial Discrimination Act (1975).

54. United Nations Declaration on the Rights of Indigenous Peoples (see note 1), art. 7.

55. L. Tynan, What Is Relationality? Indigenous Knowledges, Practices and Responsibilities with Kin," *Cultural Geographies* 28/4 (2021).

56. Australian Commission on Safety and Quality in Healthcare, "Communicating for safety standard" (August 11, 2023), https://www.safetyandquality.gov.au/standards/nsqhs-standards/communicating-safety-standard; S. McLeod, "Communication Rights: Fundamental Human Rights for All," *International Journal of Speech-Language Pathology* 20/1 (2018).

57. McLeod (see note 56).

58. V. Rosequist, *Mind Your Manners: An Investigation on Patient Perception of Bedside Manner and Its Effect on Their Visit*, master's capstone project (University of Tampa, 2023).

59. M. Wright, A. Lin, M. O'Connell, et al., "Understanding and Working with Different Worldviews to Co-design Cultural Security in Clinical Mental Health Settings to Engage with Aboriginal and Torres Strait Islander Clients," *Primary Health Care Research and Development* 22 (2021).

60. Australian Commission on Safety and Quality in Healthcare (see note 56).

61. Lowitja Institute, *Culture Is Key: Towards Cultural Determinants-Driven Health Policy* (Melbourne: Lowitja Institute, 2020).

62. S. Page, M. Trudgett, and G. Bodkin-Andrews., "Creating a Degree-Focused Pedagogical Framework to Guide Indigenous Graduate Attribute Curriculum Development," *Higher Education* 78 (2019); J. Cranney, C. Turnbull, S. C. Provost, et al., "Graduate Attributes of the 4-Year Australian Undergraduate Psychology Program," *Australian Psychologist* 44/4 (2009); O. Humberto, L. Konjarski, and S. Howe, "Does University Prepare Students for Employment?: Alignment between Graduate Attributes, Accreditation Requirements and Industry Employability Criteria," *Journal of Teaching and Learning for Graduate Employability* 10/1 (2019); L. Matson, C. Ng, M. Dockry, et al., "Transforming Research and Relationships through Collaborative Tribal-University Partnerships on Manoomin (Wild Rice)," *Environmental Science and Policy* 115 (2021); H. J. Mackey, D. Luecke, J. Robinson, et al., "Partnership through Story: Promising Practices for Meaningful Research," *Tribal College Journal of American Indian Higher Education* 33/2 (2021); V. Hiratsuka, S. Brown Trinidad, et al., "'You Actually View Us as the Experts in Our Own System': Indigenous–Academic Community Partnership," *Progress in Community Health Partnerships: Research, Education, and Action* 14/2 (2020).

63. Bailey et al. (see note 22).

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“They Had to Catch Me Like an Animal”: Exploring Experiences of Involuntary Care for People with Psychosocial Conditions in South Africa

ALEX FREEMAN AND LESLIE SWARTZ

Abstract

Protecting the rights of people with psychosocial conditions is an important and controversial global aim, particularly in light of multiple calls for reduced coercion catalyzed by General Comment 1 of the United Nations Committee on the Rights of Persons with Disabilities, which stipulates the replacement of substituted care with supported care. Responding to this and other global calls for reduced coercion is complex globally but can entail particular challenges in developing countries, where resource shortages and environmental barriers are sometimes a significant factor in how people with mental conditions experience involuntary care and encounter limitations to their autonomy. To better understand these complexities, our study explored experiences of involuntary care among people with psychosocial conditions in South Africa. Participants described varying degrees of coercion within involuntary care and found that different approaches from professionals when they were in crisis significantly impacted their illness experience, including their ability to make decisions and feel dignified. Participants' reports include variable feelings and embodied experiences of coercion in different forms and degrees, ambivalence about compliance and resistance while being treated against their will, and gray areas between conventional separations of autonomy and paternalism. On the whole, our analysis troubles binaries about the use or disuse of involuntary care and illustrates the complexity of participants' experiences and views of coercive intervention, which could hold multiple possibilities for both care and autonomy.

Alex Freeman is a counseling psychologist and a PhD candidate in the Psychology Department at Stellenbosch University, South Africa.

Leslie Swartz is a clinical psychologist and professor in the Department of Psychology at Stellenbosch University, South Africa.

Please address correspondence to Alex Freeman. Email: alexfreeman@sun.ac.za.

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Introduction

People with psychosocial conditions continue to face many barriers that can constrain their well-being and make access to health care and service provision difficult, particularly in developing countries.[1] The 2017 report on mental health and human rights issued by the Special Rapporteur on the right to health calls for a paradigm shift from biomedical approaches that are deficit-based and locate illness within the individual, toward a human rights-based approach that considers the social determinants of mental health.[2] The report also stresses the importance of prioritizing the voice of people with lived experience of psychosocial conditions, reducing negligence, and challenging assumptions that "mental health interventions always require pharmacological and psychological treatments."[3] The emphasis on zero coercion forms part of a wider challenge to coercive care, exemplified in the adoption of General Comment 1 by the United Nations Committee on the Rights of Persons with Disabilities in 2014, which stipulates that all forms of substituted care (including involuntary and assisted care) for people with psychosocial conditions should be replaced by supported care that is "in the objective 'best interests' of the person concerned."[4] The sentiments of General Comment 1 are further reiterated in the World Health Organization's *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches*.[5] Some mental health care theorists and practitioners have expressed concern regarding this approach, worrying that emphasis on lack of coercion and on will and preferences may lead to consequences that are not in the long-term interests of people with psychosocial conditions. Debate surrounding the use or prohibition of involuntary care creates the potential impression of a binary of opinions regarding this issue.[6] As Michael Stein et al. note, the complexities surrounding provision for people with psychosocial conditions may be conceived of as moving between two paradigms, from a more paternalistic approach to one more universally focused on individual autonomy.[7]

To consider these global calls for reduced coercion, *Health and Human Rights Journal* held a roundtable discussion in 2022 considering the impact of the Special Rapporteur's report on mental health.[8] Many participants in the discussion praised the report for being a progressive and necessary measure in safeguarding the rights of individuals with psychosocial conditions, while emphasizing the importance of ensuring that responses also foster a community-oriented approach to human rights.[9] Faraaz Mahomed, South African speaker and technical advisor at UNICEF, used the platform to emphasize the 2015 Esidimeni scandal in South Africa, where 144 people housed at psychiatric facilities lost their lives due to neglect and starvation.[10] In the context of such crises, it is particularly important to understand and explore the voices and experiences of people with psychosocial conditions as they navigate the health care system in the country.

One key aspect of community- or rights-based approaches is understanding the views and challenges faced by people with psychosocial conditions themselves, including how people with psychosocial conditions experience coercive care in context. There are few qualitative studies exploring how people with psychosocial conditions in South Africa understand and experience involuntary care, particularly in the context of the General Comment 1 paradigm shift.

To contribute to this research, we conducted a phenomenological analysis of people with psychosocial conditions' experiences of involuntary care. We interviewed participants at various psychosocial rehabilitation centers in South Africa. Considering our theoretical frameworks focusing on phenomenology of illness and relational capacity, we were particularly interested in two things: first, the extent that participants felt that involuntary care can cause harm or good, and second, how participants' experiences of coercion and different forms of support could impact the mental capacity of people with psychosocial conditions. We also considered how and in what ways participants' experiences and opinions about care were relational.

Coercive care and General Comment 1

The Convention on the Rights of Persons with Disabilities is a binding legal document with over 160 signatories and the support of numerous disability groups.[11] General Comment 1's interpretation of the convention, in favor of supported care and rejecting substituted care, is globally influential and marks a radical departure in thinking from conventional "functional models."[12] Functional models are based on the notion that people with psychosocial conditions are at risk of losing their mental capacity to cognitively comprehend information about their condition and make decisions about treatment. On such occasions, a "substitute" may be appointed, who makes decisions in the best interest of the person with a psychosocial condition and promotes the restoration of their autonomy.[13] Safeguards often exist in cases of substituted interventions to ensure the use of least force for the shortest time possible to promote the return to health and decision-making autonomy of people with psychosocial conditions.[14] Nevertheless, functional models require that the right to autonomy of a person lacking mental capacity be suspended in the interests of that person's recovery.

General Comment 1 states that suspending a person's universal legal rights in this way violates article 12 (equal recognition before the law) of the Convention on the Rights of Persons with Disabilities and therefore unfairly discriminates against people with psychosocial conditions.[15] The general comment also challenges functional care by refuting the idea that loss of mental capacity is an adequate precondition for treating a person against their will. It states that "perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity."[16] The general comment recommends supported care as a replacement, in which a person is offered environmental and systemic support but has their decisions, or "will and preferences," fully respected regardless of their psychosocial condition or measurements of their mental capacity.[17] Further, the general comment emphasizes that stereotypes about people with psychosocial conditions that they lack mental capacity and therefore cannot exercise their legal capacity are discriminatory. Extending from this, the presence of involuntary care could be said to discursively perpetuate this belief.[18] Accordingly, the only way to reduce involuntary care is to abolish it. The debate is a complex one, and people with psychosocial conditions straddle both the risks of unnecessary coercion and the impacts of illness if left untreated.

Coercion itself has various definitions—ranging from interpersonal influence to physical restraint—which serve as "treatment pressures" facilitating psychosocial or medical intervention for a reluctant patient. Involuntary care is one form of coercion, though the extent to which a person with a psychosocial condition feels coerced within involuntary care can also lie on a continuum, as becomes evident in our findings and discussion.[19]

A 2018 report of the Special Rapporteur on the right to health emphasizes that questions of human rights and the value of coercion are embedded in sociopolitical and historical contexts.[20] Read, Sakyi, and Abbey reiterate this sentiment by highlighting that there are great challenges to implementing General Comment 1's recommendations in developing countries, where stigma and insufficient resource provision remain an obstacle.[21] They also argue that tensions can arise between universalist human rights and local beliefs about mental disorder, which can make the prohibition of involuntary care precarious.

In this context, it is especially interesting to consider how an overarching set of international guidelines, such as the Convention on the Rights of Persons with Disabilities and General Comment 1, are experienced in different parts of the world by the people whose lives they are designed to improve. In this paper, we focus on people with psychosocial conditions in South Africa, a country with complex legislation but rather limited access to mental health care services and supports.[22] As is clear, questions surrounding coercive care exist in the contextually diverse interface of social relationships, manifesting both locally and in more universal and institutional rhetoric. The voices of people with psychosocial conditions require more representation and consideration, particularly where putative policy and ideological decisions surrounding the use of involuntary care can eclipse contextual complexity.

Theoretical framework

This research is located within a phenomenological paradigm and draws theoretical guidance from Havi Carel's *Phenomenology of Illness* and Camilia Kong's phenomenological work on "capacity in relationship."[23]

Carel's *Phenomenology of Illness* describes the life-altering experiences of illness holistically through the experiences of the person. Illness is associated with a breakdown in the habitual body, which can result in a variety of experiences, including losses in continuity, feelings of objectification and re-subjectification in the eyes of the self and other, loss of recognition, and loss of tangible relationships with the world.[24] When we use the term disability in this paper, we are most closely referring to the social model, where environmental circumstances can present barriers to the functioning of people with underlying "impairments." A person's recounted experience of their illness can include experiences of disability, but an analysis using phenomenology of illness aims to observe a person's overall reported experience, which can include but transcends the impacts of impairment, disability, interactions with doctors and others, and existential questions linked to illness and embodied change. Whereas disease conventionally refers to a combination of biological symptoms, illness is broader than this, referring to a subjective view of the person rather than aiming to determine an independent "concrete reality."

Some of the key experiences of illness that Carel describes, and that we consider in our analysis, include the following:

loss of wholeness, where the body feels unrecognizable and disconnected from the self;

loss of certainty, where participants could find themselves unsure if they are able to describe their experiences accurately, or struggle to find direction in their lives and experience;

loss of control and continuity, where the predictability of a person's life is upended, often leaving them feeling stranded and having an experience of their body as no longer transparent, but limiting and awkward; and

loss of the everyday world, which could include an experience of there not being a shared world with others that makes sense and is safe.[25]

Each of these experiences could also result in bodily doubt, where a person loses confidence in their embodied participation in the world, accompanied by an experience of being disconnected.[26] In the words of Giovanni Stanghellini, "if my body-based involvement in the world is switched off, my *grasp* onto the world will fade away too."[27]

Following General Comment 1's stipulations on the use of supported rather than substituted care, we also draw on Kong's work on phenomenology and capacity, particularly her relational and interpersonal conceptualizations of the latter concept.[28] Kong understands capacity as being contingent on the environmental and interpersonal relationships that are present in a person's life and in the decision-making process.[29] She argues that certain normalized environments and relationship limits can constrain or enable the flexibility with which people with psychosocial conditions can exercise embodied mental capacities.[30] The texture of relationships between people with psychosocial conditions and professionals, she argues, can also impact whether people with psychosocial conditions' normative decisions about their lives are respected as valid, which can in turn affect the possibilities of these individuals to express themselves adequately. She writes that capacity "competencies" can be increased in terms of "socially acquired perceptual, psychological, emotional, and cognitive skills necessary to engage with the world and make choices in accordance with one's values."[31]

She further recommends that more work be done to understand what the experiences of people with psychosocial conditions are in this interface, and what will be useful in supporting capacities. Conducting a phenomenological analysis can in itself represent a form of radical empathy toward suspending our views of the experiences of people with psychosocial conditions, representing them in their complexity and contradiction.[32]

Methodology

This research was performed in accordance with the Declaration of Helsinki. We attained ethical approval for the study from the Research Ethics Committee: Social, Behavioural and Education Research at Stellenbosch University. We recruited participants through nonprobability, purposive, and snowball sampling. Selection criteria were that participants had previous experience of being involuntarily admitted in South Africa and were in psychosocial rehabilitation. We located most of our sample at two of the main psychosocial rehabilitation facilities in Johannesburg, which we visited in person to conduct interviews and to snowball participants. Rehabilitation facility staff approached certain residents to request interviews on our behalf, which may have resulted in selection bias. Some participants were also snowballed from other residents whom we interviewed. We conducted all the interviews in Johannesburg.

We conducted nine individual interviews and two focus group discussions. Individual interviews ranged between 60 and 90 minutes. Our focus groups included six and five participants, respectively. The first was 120 minutes long, and the second was 90 minutes. In the interviews and focus groups alike, our questions centered around participants' experiences and views of involuntary detention, hospital admission and treatment, and possible alternatives or improvements to current systems. In the focus groups, we used semi-structured questions to introduce a topic, after which the participants discussed these issues. As far as possible, we encouraged participant interaction and limited researcher questions. There was no specific age range, race, or gender requirement, but we made efforts to ensure that participants varied in these aspects. While we note that demographic characteristics may impact the participants' frames of reference and experience, a close analysis of race, gender, class, and other demographic factors and their influence on results is beyond the scope of this study.

Analytic method

We first thematized our transcribed interviews in a table. We then grouped these phenomenologically, with an emphasis on how embodied and inter-relational interactions impacted participants' experiences of involuntary care. We used a combination of Carel's *Phenomenology of Illness* and Kong's conceptualization of capacity as guiding frameworks for our analysis.[33]

Findings

Our findings begin with participants' views about whether involuntary care should be practiced. We then focus on how participants' embodied experiences of illness impacted their experience, before addressing some of the complexities in participants' accounts of experiences of loss, fear, and embodied restraint. This then leads us to analyze the different ways that participants experienced and responded to coercion, including a consideration of participants' descriptions of cooperation and compliance. We conclude our findings with participants' views about how the health care system could be improved, as well as an exploration of some of the gray areas that certain participants introduced that fall between the binary nodes of "autonomy" and "subjugation."

Participant views about whether involuntary care should be practiced

Participants' accounts of their experience of involuntary care were extremely complex and often held contradiction. Nevertheless, participants sometimes shared their overall feelings about whether involuntary care should be practiced. This seemed important to capture since some participants held overarching beliefs about involuntary care even though the content of their accounts about involuntary care could be subtle and hold mixed feelings. The participants we interviewed had various opinions. Some felt that involuntary care was an unnecessary injustice they had to bear, and some felt that it was a beneficial practice important to their well-being and safety, even though it could be traumatic.

The extract below is from a participant who, on the whole, opposed the practice and felt they had to "survive" it:

> No, I didn't think I needed it, not at all, but it happened. You see, I can survive. I'm a survivor. So when I realized, okay, I'm locked up in this ward, then I will behave myself and I will be a model patient. I mean, that's how it is, we survive. (participant 1)

Some participants viewed involuntary care as a necessary function that prevented them from harming themselves or others or from humiliating themselves in public:

> The police had to come and fetch me and, um, out of that perspective, I think it was excellent. If it hadn't been for those two incidents, I wouldn't be here today, where would I have ended up who knows. (participant 2)

Some justified their support for involuntary care by arguing that the system had few motives to intervene if not in the interests of people with psychosocial conditions. The word *minag* in the following excerpt is an Afrikaans word that means "to condemn" or "to slight," and the participant seems to suggest that involuntary care is intended not to demean people but to help them:

> We use the word "minag" is to denounce a person's right to decide about his own health and whether it should go into an institution or not, whether he should be hospitalized or not, it's [involuntary care] not to undermine that, it is to um, uh protect the various parties, both the patient and bystanders. (focus group 1)

Some participants emphasized that despite involuntary care potentially being undermining and distressing, it protected them and was ultimately the best way to preserve their safety and well-being:

> So sort of it felt, it felt like quite invasive at the time, and quite traumatic. But in retrospect, you feel like it was the necessary action and it's and it's benefited your life. As it stands now, having had that experience, having been institutionalized you feel like it was the best thing for you. (participant 10)

The participant below advocated for involuntary care, noting that objections or "complaints" that people with psychosocial conditions have about the practice are unwarranted in that they believe that it protects people with psychosocial conditions and others:

> I think, I think, people with mental illness shouldn't complain too much, the system is trying what they can to do for us, and I am really here today to try to improve things … They have to do it [treat a person who is "wild"] against your will for their safety and your own safety, so that you don't hurt yourself and other people around you. (participant 5)

While participants expressed some of their opinions about the practice of involuntary care as either in favor or against the practice, most participants had very nuanced and sometimes ambivalent views and experiences of involuntary care that were often relational and contextual, as explored below.

Embodied and inter-relational experiences of involuntary care

In this section, we represent participants' experiences in more localized interactions with police and psychiatric professionals. We begin by outlining some participants' experiences of fear and dislocation and how this experience and its causes could impact the decision-making capacity of people with psychosocial conditions. We then consider participants' inter-relational experiences as they negotiated their care with professionals.

Disconnection and loss. Many participants described forms of loss and disconnection in their experience of being involuntarily committed:

> It felt like, I don't even know do I have the words, but let me try. It was um … very alarming, because you realize that, your worth, you lose all your total worth. It undermines your total worth, you don't even exist as a, as a lesser voter in this country,

> nothing. No rights. You have no say. Ja, that was quite, quite difficult to say, harsh realization. When they said you've been certified. And to know your rights and to be subjected to that was, it was just a nightmare. (participant 1)

The participant's description portrays how traumatic the loss of autonomy and rights was. A level of bodily doubt accompanies this trauma, expressed in her sense of a loss of self-worth and feeling outside of recognizable embodied and linguistic frames with which to understand and express her experiences ("I don't even know do I have the words").

Several other examples of participants' experience akin to what phenomenologist Stanghellini describes as a "losing a grasp on the world" are presented below.

Loss of memory was a particularly significant experience for many participants:

> Very little, I can remember that I was in a straitjacket in the back of the ambulance, But very little. (participant 2)

Another experience was a loss of a sense of time and space:

> I was trying to see out the window, what, where the van is headed and it seems to journey forever. (focus group 2)

Finally, participants expressed a loss of a sense of embodied self-determination and autonomy:

> I didn't know what I was doing. (participant 9)

These examples illustrate how participants could feel a strong sense of detachment and what might be described in *Phenomenology of Illness* as a loss of continuity, certainty, and control and a loss of wholeness in the experience, which felt undignified to some. A theme that we noticed was that involuntary care could sometimes make thinking and being present in the moment difficult for participants; where participants' autonomy was constrained, it seemed harder for some to reflect on their circumstances and make decisions. The section below builds on this theme.

Fear, criminalization, and decision-making capacity. Fear and criminalization are potentially significant factors impacting the capacity of people with psychosocial conditions to think, express, and communicate their experience and decisions.

In the following extract, the participant expresses how their illness caused debilitating fear that required an involuntary intervention. We asked the participant if they felt they would have been able to go with the police voluntarily if someone had spent more time explaining the nature of their illness:

> That's a difficult question to answer because I was also afraid and I always do feel fear when I become ill. I was afraid, so, it maybe because of the fear that the sort of quiet approach with me … "Jane, you're not well, we need you to go to hospital" … take it slow … whereas sister Flora [pseudonym] was fast and furious, she didn't waste time. So as I say … a fear that is there … I begin to feel afraid, that slow very gentle approach might have been wasted. (focus group 1)

This participant experienced the nurse's use of force as necessary on the basis that a less firm response may not have been helpful. Nevertheless, the question remains as to whether this kind of response by the nurse also caused the fear that necessitated its use. In other words, it raises the question whether the participant would respond in the same way to someone using a more or less forceful response.

Interestingly, experiences such as this coexisted alongside scenarios where the experience of being picked up by the state was frightening and dislocating in itself:

> I was shocked, it shocked my body. It was a big shock to me because your mind, suddenly your mind goes clumsily, what have you done, because when you see a police van, it was like, they only there for something terrible that you've done. (participant 4)

On the whole, experiences of fear, criminalization, and pressure were part of the illness experience for participants. These experiences could become disabling for some and make it difficult to make congruent decisions. For some, it seemed like stronger forms of coercion that were against their will were a valuable response to their fear and confusion, while at the same time the experience of involuntary coercion was felt as criminalizing and even accentuated or caused some fear. Some participants seemed to describe how coercion could become "disabling" and iatrogenic, which could increase the likelihood that involuntary measures would be required. Based on these varying and complex experiences, some participants seemed to describe involuntary care as contributing to their struggles and the unpleasantness of their illness experience, while still being valuable in certain circumstances.

Experiences of restraint and restriction. Participants had various views and experiences regarding being restrained and constrained. Some described being difficult to control:

> They had to catch me like an animal, like a wild animal at the police station and Gordon's Bay. The police had to surround me and make the circle smaller until they could grab me. Yes and that was really unpleasant. But I was running around in my speedo and um, I was completely naked. So that's what they had to do. (participant 10)

In the second example, the participant feels that the police response was a necessary response to their actions ("had to"). However, in some cases, participants felt that professionals could overextend their paternal authority:

> I have to walk at night, the Sister didn't want me to walk beyond a certain point and uh, I felt I needed that space and I took it. I went beyond that certain point and, wow! She was very bitter, whoever else was there on duty, and I was strapped to the bed. (focus group 2)

This participant felt that the professionals responded over-restrictively or vindictively, and seemed to have some resentment about this.

On the whole, restraint and restriction resulted in complex and sometimes tense negotiations between people with psychosocial conditions and professionals, in which some experienced shame, indignation, and disempowerment, despite many feeling that it was a necessary response to their behavior and mental state.

Experiences of compliance

Compliance with detention exemplified people with psychosocial conditions conforming or adapting to requirements set by police or hospital staff. Some participants found that compliance prevented violent confrontations and was helpful in grounding them. Nevertheless, participants also associated compliance with discomfort, loss of control, and loss of wholeness:

> I was also manic um, I went into a park and they followed me into park and they spoke to me. Eventually they grabbed me and they put me in the back of the bakkie. I didn't resist. So it wasn't violent. But it was all the same traumatic for me. (participant 1)

The participant's use of language such as being "grabbed" and "put" exemplifies the experience of being objectified, which could result in loss of a sense of control and wholeness, as previously described.

One interesting tension occurred where a participant was asked to take personal responsibility by a professional in the detention process:

> Professional [as recalled by participant]: I know you don't like this now and we, we pinning you down and whatever, but if you promise me that you will not be aggressive, I will ask them to let you go. What's your answer?
>
> Participant: Doctor, I will be calm now.
> [So they left me and they treated me.] (participant 5)

Participants in this type of scenario seem to agree to fulfill their role in the involuntary encounter without necessarily embracing its use. This raises interesting questions about whether being given choices to conform to the requirements of involuntary care is useful or whether it is undermining and an exploitation of power on the part of professionals. The data support both scenarios. Being given a choice did seem to afford some participants a measure of agency, although they felt uneasy:

> Professional [as recalled by participant]: Do you want the police to take you to hospital, or do you want the ambulance?
>
> Participant [to interviewer]: I didn't want to go to hospital but I didn't want to travel in a police vehicle. So I got the ambulance. (focus group 2)

Thus, participants did exercise these choices despite sometimes feeling compelled or objectified in doing so. Some level of ambivalence seems evident from the experiences of participants in these interviews.

Experiences of cooperation and collaboration

Participants often appreciated when police were especially kind and helpful, and at times there was a sense of camaraderie and collaboration between the two parties. In some cases, there was a mutual sense of responsibility for ensuring that detention did not become violent:

> I want to say that the police are well-behaved—hey, even the guy who took me to Sea Point was polite and friendly, and the guys who took me to Tara from Helen Joseph uh, it was funny actually because it was like the judge, because I was polite and I was friendly and I wasn't misbehaving at all and the policeman came and dropped me off and said, "Well, we hope this doesn't happen again." [giggling] (focus group 1)

In this example, there is a humorous tone in which participants and police officers together seem to mock the procedural nature of the participant's involuntary detention. The tone could have various functions. On the one hand, it could be a way for the two parties to diffuse tension around the fact that the police personnel are in the process of suspending the autonomy of people with psychosocial conditions. This could be a way of deflecting from the violence of the situation and therefore minimizing and perpetuating that this is a necessary though undesirable act and circumstance.

However, the humor could also represent a subversion, where both participants are aware of the process and procedures of which they are a part, and mischievously satirizing the legal process and its procedural nature. For example, an involuntary certification could determine that people with psychosocial conditions have no mental capacity, but the people with psychosocial conditions and policeman are able to recognize that they are nevertheless communicating clearly and cooperating with each other. In the above exchange, the participant does not seem to find the encounter to be shameful or traumatic as in other scenarios outlined above, and the greater level of trust seems to mitigate the violence and trauma associated with the confrontation.

Related to this, some felt that taking personal responsibility for recovery was the best way to make use of a system designed to promote their health and reintegration into society. They somewhat paradoxically saw engaging with and accepting involuntary care as a form of participation and cooperation with health care workers that was intrinsic to their recovery—and that of people with psychosocial conditions in general—even if care and detention could be difficult, involuntary, and sometimes traumatic:

> No matter what happened to you, yes, it must, might feel embarrassing to you, but by sharing with other people they, they are able to help you and understand you. If you don't, you, you, just, you just, if you don't cooperate then it means it's to your own downfall, it's not going to benefit you in the end. (participant 9)

In the extract below, the participant suggests that professionals do not intrinsically wish to treat a person against their will, and in fact might struggle while trying to do so, but follow through with their practice in order to help people with psychosocial conditions. Cooperation could therefore make life easier for both parties and facilitate opportunities for the recovery of people with psychosocial conditions. For some participants, being "difficult" and losing the commitment of professionals to their care and recovery could be a lost opportunity:

> They won't understand you so they might just feel, "Oh this guy is just stubborn, we're just going

> to treat him and you know, we're not going to bother much about him because he doesn't want the help. He's not responding to, to our action of trying to treat him, to treat him to get him better." (participant 1)

On the whole, experiences of cooperation and collaboration seemed less traumatic for participants, though many inevitably felt the discomfort of being involuntarily confined.

Suggestions for improvement: Support and understanding

Many participants felt that the system could be improved by police and health care workers offering empathy to people with psychosocial conditions that is comparable to the empathy offered to people without such conditions:

> I just feel, I just feel the, the, the police and all these people working with people with mental illness could just have a softer approach with these people. Try and really think what's going to be the best for this person, not to, to hurt him or anything physically, hurt him or whatever … if someone is a normal person, you, you going to approach him in a different way ok. (participant 6)

Similarly, another participant felt the system did work, and served a valuable function, but could be improved by a degree of greater empathy:

> Alex, you know, um, you know, all I think the system must bring in more is a little bit more understanding and empathy. But you know what, sometimes, you have to take control when a mental patient is out of control. So they can't stop this completely. (participant 10)

They also put particular emphasis on the importance of understanding a person's past experiences and vulnerabilities and choosing or finding people who the person with a psychosocial condition is more likely to respond well to:

> What I feel, if health care workers get, if they talk to a person, if they say this guy is not responding to men, because like I said he might have been molested or raped or something, try a woman, try a woman, but let someone sit in for safety or be close by. (participant 10)

Some participants felt that they could understand the struggles of professionals and why empathy was sometimes difficult:

> Ja, ja, I can do. I can carry on doing. I do get into a condition where I'm quick to anger and I get annoyed fast … So I do do that, ja, I can make it hard. (participant 3)

Overall, there is a sense that greater empathy and understanding can be enabling for many and can reduce the discomfort and suffering associated with involuntary care.

Gray area: Peer support, self-reflection, and "voluntary proxies"

Some participants raised the possibility of peer support, where a person with previous experience of the illness and treatment explains the process to the person who is in the process of being admitted:

> Like, maybe like, arrange a meeting with a person that like, had a previous experience of what a person is going through that time. And, like, let them talk like about what, what this condition is, like, what it does to one's health. Because like, just some, some facts, like they can make a person change a decision … it's a mental, it's a chemical imbalance in your brain, which causes you to hear voices. (participant 7)

Others described a gray area in which they consented to having a person assist them in making decisions, even if this was in a broader context of refusing treatment:

> Like for instance, when I was sick at some point and my dad had to come here and I had to see a psychiatrist, and my psychiatrist told my dad we might need to change medication and whatever, and my dad would look at me and say, are you comfortable with that, what difference will this medication make? That kind of thing, so in a way I felt empowered and cared for and when I was confused I'd say, dad please choose for me, you know. (participant 1)

The participant shares the decision with her father in a consensual and supported manner. This highlights a theme throughout, whereby participants often have varying degrees of autonomy in a given moment and can often actively participate in how they would like to be treated, even if they are considered unable to make overarching decisions about whether they will be treated.

Discussion

In the above, we used a phenomenological analysis to explore participants' experiences of involuntary care. There are many bifurcations in policy and rhetoric concerning whether involuntary care is discriminatory and disempowering or beneficial and protective. Our phenomenological analysis troubles the binary by illustrating intersections, complexities, ambivalences, and subtleties in participants' experiences and views about involuntary care.

Many participants held many mixed feelings toward involuntary care. Some positive and negative experiences are encapsulated in Christina Katsakou and Stefan Priebe's systematic review, with particular emphasis on how difficult participants found the loss of autonomy and dignity, and the benefits they experienced in being treated like a person.[34] Adding to this, we found that participants' experiences were often "ambivalent" in that participants encountered contradictory views surrounding involuntary care. Participants described involuntary care as traumatic and a source of confusion, disorientation, and fear, while simultaneously having beneficial impacts on their overall well-being. Participants also often spoke about involuntary care as traumatic, disorienting, constraining, and undignified and yet also as a relief, containing, and a salvation.

Another complexity is where participants described how a person with a psychosocial condition in crisis can paradoxically consent to involuntary care and see the benefit of it despite initially refusing. Researchers such as Kevin Iversen et al. have referred to something similar as "uncoerced involuntary" treatment.[35] Such a paradoxical situation would account for why some participants in our study encourage people with psychosocial conditions to recognize their impaired decision-making and embrace involuntary care despite some discomfort surrounding limitations to their autonomy. These instances also show participants' perception that involuntarily certification does not mean that people in involuntary care lack agency to deliberately rebel or comply in different degrees, despite their status as lacking sufficient mental capacity to make legal decisions.

Additionally, it was difficult to determine the cause of a positive or negative experience or impact on mental capacity—for instance, when one participant described involuntary care as both a cause for and a necessary response to loss and fear. In this circumstance, the participant stated their preference for the use of involuntary care, but it is unclear to what extent this form of care caused the fear that made decision-making difficult. It was also interesting to note that "complying" did not necessarily mean that a person did not feel coerced—and vice versa, that sometimes participants appreciated and did not feel coerced when more assertive, forceful measures were employed. This observation is reinforced by George Szmukler's observation that even the use of "lighter" forms of coercion such as persuasion (rather than threats or physical restraint, for example) does not guarantee that a participant will feel that an interaction is uncoercive or dignified.[36]

On the other hand, there was the instance where police and participants had a mutual understanding and identified their roles as part of a system, and this seemed to foster some solidarity, which one participant seemed to appreciate judging by the light-heartedness of the interaction. And there was another instance where decision-making was voluntarily shared with a relative, which seemed to allow the participant to feel autonomous while also allowing someone else to make a decision on their behalf. Our findings emphasize the phenomenological complexity surrounding coercion, the significance of individual experience, and the range of experiences that can be possible surrounding involuntary care and coercion.

Despite the complexity of these instances, for many participants greater empathy was a defining factor in their views about their care, and this often became as important to people with psychosocial conditions as the question of whether involuntary care should be practiced in the first place. Several participants in our study seconded the view that their experience could be improved by receiving increased levels of empathy, whether before, replacing, or during their involuntary certification. This places emphasis as much on the "how" of care as on the "what" form of care, and greater attention to environmental and interpersonal factors seems critical to the quality of the experience participants had, whether in involuntary or supported care scenarios. There is a particular challenge in that where resources are deficient, it is more likely that people with psychosocial conditions will refuse care, have a negative experience, or fail to receive empathetic provision. Such people also seem more likely to be treated against their will due to a lack of support and sensitive care in unpleasant and under-resourced environments. A lack of support in community and hospital environments may also contribute to the likelihood of participants supporting the use of involuntary care, as well as to the likelihood of their experiencing substituted care as a beneficial response to their condition, despite their unpleasant experiences. Participants' experiences in South Africa are often ambiguous and contingent, and bifurcated global policy recommendations can sometimes overlook the voice of people with psychosocial conditions in the midst of these challenges.

Conclusion

The reduction and alleviation of coercive care is an important global agenda that has gained attention in the last decade. Various human rights organizations and committees have debated how to move away from conventional biomedical models of care toward more social and human rights approaches that promote the voice of people with psychosocial conditions, take a community-oriented approach to rights provision, and eliminate stereotypes that people with psychosocial conditions in crisis require restrictive medical and pharmacological intervention. Strategies toward achieving this are contentious, with professionals, policy makers, academics, and people with psychosocial conditions taking stances both for and against the use of substituted practices.

To better understand and radically empathize with the complex and varied embodied experience of people with psychosocial conditions who have undergone involuntary care, we conducted an analysis of people with psychosocial conditions' experiences of involuntary care in South Africa. Participants described complex and dialectical experiences of involuntary care where trauma, discomfort, loss, and dislocation often coexisted with support for involuntary care as a practice.

The data and tensions we have described here highlight that issues of autonomy include, but extend beyond, whether involuntary care as a practice should be performed. The complexity of participants' voices emphasizes that binaries can sometimes be unhelpful and that what people with psychosocial conditions value can depend on a myriad of circumstantial factors. Nevertheless, we felt, based on participants' accounts, that greater interpersonal empathy could open opportunities for people with psychosocial conditions to feel more satisfied and participative. We also noted that focusing on specific circumstances in the midst of this complexity is important, given that the "how" of provision is often as important as "what kind" of provision.

Based on the data analyzed here, binaries surrounding involuntary care tell only part of the story of the complexity, inter-relationality, and nuance in the experiences of people with psychosocial conditions in diverse contexts.[37] It is critical to consider the voices and experiences of people with psychosocial conditions in the face of contextually complex psychosocial barriers.

Overall, our study has shown the complexity of the issue of involuntary care, as well as many of the embodied possibilities that people with psychosocial conditions exercise in their engagement with professionals and the wider psychiatric community. There is still much scope to explore new horizons of understanding that can inform the thinking, feeling, and awareness of the community involved in people with psychosocial conditions' decision-making practices.

References

1. B. Watermeyer, L. Swartz, T. Lorenzo, et al. (eds), *Disability and Social Change: A South African Agenda* (Cape Town: HSRC Press, 2006).
2. Human Rights Council, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/35/21 (2017).
3. C. Williams and A. Chapman, "Virtual Roundtable: Impact of Human Rights Council Reports on Mental Health," *Health and Human Rights Journal* 24/2 (2022), p. 85.
4. Committee on the Rights of Persons with Disabilities, General Comment No. 1, UN Doc. CRPD/C/GC/1 (2014), para. 27.
5. Williams and Chapman (see note 3).
6. M. C. Freeman, K. Kolappa, J. M. C de Almeida, et al., "Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities," *Lancet Psychiatry* 2/9 (2015).
7. M. A. Stein, F, Mahomed, V. Patel, and C. Sunkel (eds), *Mental Health, Legal Capacity, and Human Rights (Cambridge: Cambridge University Press, 2021).*
8. Williams and Chapman (see note 3).
9. Ibid.
10. K. Hodal and R. Hammond, "Emaciated, Mutilated, Dead: The Mental Health Scandal that Rocked South Africa," *Guardian* (October 14, 2023), https://www.theguardian.com/global-development/2018/oct/14/emaciated-mutilated-dead-the-mental-health-scandal-that-rocked-south-africa; E. Durojaye and D. K. Agaba, "Contribution of the Health Ombud to Accountability: The Life Esidimeni Tragedy in South Africa," *Health and Human Rights* 20/2 (2018).
11. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006).
12. M. Burch, "Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis," *Journal of Applied Philosophy* 34/3 (2017); C. de Bhailís and E. Flynn, "Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD," *International Journal of Law in Context* 13/1 (2017); Freeman et al. (see note 6).
13. Burch (see note 12).
14. L. Berghmans and G. A. Widdershoven, "Ethical Perspectives on Decision-Making Capacity and Consent for Treatment and Research," *Medicine and Law* 22 (2003).
15. Committee on the Rights of Persons with Disabilities (see note 4).
16. Committee on the Rights of Persons with Disabilities (see note 4), para. 13.
17. Ibid., para. 2.
18. E. Kaminskiy, "The Elephant in the Room: A Theoretical Examination of Power for Shared Decision Making in Psychiatric Medication Management," *Intersectionalities: A Global Journal of Social Work Analysis*, *Research, Polity, and Practice* 4/2 (2015).
19. E. Rossero, *Care in a Time of Crisis: An Ethnography of Coercive Practices in Italian Acute Mental Health Provision* (London: Palgrave Macmillan, 2023).
20. United Nations General Assembly, Interim Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/73/216 (2018).
21. U. M. Read, L. Sakyi, and W. Abbey, "Exploring the Potential of a Rights-Based Approach to Work and Social Inclusion for People with Lived Experience of Mental Illness in Ghana," *Health and Human Rights Journal* 22/1 (2020).
22. C. Lund, "Mental Health and Human Rights in South Africa: The Hidden Humanitarian Crisis," *South African Journal on Human Rights* 32/3 (2016).
23. H. Carel, *Phenomenology of Illness (Oxford: Oxford University Press, 2016); C.* Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy* (Cambridge: Cambridge University Press, 2017).
24. Ibid.
25. Ibid.
26. Ibid.
27. G. Stanghellini, "Embodiment and Schizophrenia," *World Psychiatry* 8/1 (2013).
28. Kong (see note 23).
29. Ibid.
30. Ibid.
31. Ibid., p. 5.
32. M. Ratcliffe, "Phenomenology as a Form of Empathy," *Inquiry* 55/5 (2012).
33. Carel (see note 23); Kong (see note 23).
34. C. Katsakou and S. Priebe, "Patient's Experiences of Involuntary Hospital Admission and Treatment: A Review of Qualitative Studies," *Epidemiologia e Psichiatria Sociale* 16/02 (2007).
35. K. I. Iversen, G. Høyer, H. Sexto, and O. K. Grønli, "Perceived Coercion among Patients Admitted to Acute Wards in Norway," *Nordic Journal of Psychiatry* 56/6 (2002).

36. G. Szmukler and P. S. Appelbaum, "Treatment Pressures, Leverage, Coercion, and Compulsion in Mental Health Care," *Journal of Mental Health* 17/3 (2008).

37. Human Rights Council (see note 2); World Health Organization, *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches* (Geneva: World Health Organization, 2021).

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A Human Right-Based Approach to Dealing with Adverse Events in Residential Care Facilities

NIALL MCGRANE, LAURA BEHAN, AND LAURA M. KEYES

Abstract

Managing residential care facilities (RCFs) includes the ability to manage adverse events while maintaining a human rights-based approach to care and support. Literature investigating rights-based approaches in RCFs is scarce; therefore, an investigation of the current approach in RCFs will inform improvements. This study sought to identify whether RCFs in Ireland upheld a rights-based approach during the course of adverse events by analyzing notifications of adverse events from 2021 taken from the Database of Statutory Notifications from Social Care in Ireland. Data analysis was conducted independently by two researchers. Notifications of adverse events were coded according to whether the human rights principles of fairness, respect, equality, dignity, and autonomy were upheld or violated during the adverse event and its subsequent management. There was some evidence of violations, including staff violations during adverse events and their management, as well as residents violating fellow residents' autonomy, respect, and dignity in notifications of "serious injury" and "allegations of abuse." However, overall, good practice was identified, with residents' human rights upheld by staff. Our findings indicate that a rights-based approach to care and support is being upheld during adverse events and their management, which may indicate that such an approach to care and support has been adopted

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Niall McGrane, PhD, is a regulatory researcher at the Health Information and Quality Authority, Dublin, Ireland.

Laura Behan, PhD, is a senior regulatory researcher at the Health Information and Quality Authority, Cork, Ireland.

Laura M. Keyes, PhD, is a regulatory practice and researcher manager at the Health Information and Quality Authority, Cork, Ireland.

Please address correspondence to Niall McGrane. Email: nmcgrane@hiqa.ie.

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Introduction

Human rights are the basic rights and freedoms that all people should enjoy. They are protected under the Universal Declaration of Human Rights and the European Convention on Human Rights.[1] How these rights are understood and applied so that people with disabilities can fully enjoy their human rights is further addressed in the Convention on the Rights of Persons with Disabilities.[2] A convention on the rights of older persons has not been adopted to date but has been advocated for in the academic literature.[3] Respect for human rights is also implicit within many published codes of conduct and ethics of health and social care professionals.[4] A human rights-based approach to health care and to social care can be considered as adherence to the underlying principles in human rights instruments.

A rights-based approach to delivering care and support for people with disability and older persons ensures that their human rights are protected and supported while availing of health care and social care.[5] Residential care facilities (RCFs) provide health care and social care in the form of accommodation, nursing, and supportive services to people who cannot live independently. In Ireland, RCFs can encompass nursing homes, supportive care facilities, residential homes, rehabilitation centers, and palliative care centers, among other facilities. The care provided by RCFs encompasses both health care and social care and can range from full nursing care to assisted living and from full-time care to respite. Embedding a rights-based approach in the service culture of RCFs ensures that people availing of services are treated with fairness, dignity, respect, and equality and that they can participate fully in decisions about their own care.

The human rights principles outlined in legislation are often used to make up frameworks that can serve as practical tools to guide the implementation of a rights-based approach in practice without the need for knowledge of human rights legislation.[6] Frameworks such as the PANEL principles (participation, accountability, nondiscrimination, and equality) and the FREDA principles (fairness, respect, equality, dignity, and autonomy) have been adopted by national regulators of health and social care to promote and monitor a rights-based approach.[7] Ireland's Health Information and Quality Authority has published rights-based guidance for RCFs underpinned by the FREDA principles.[8] These tools can also be used by health and social care regulators and researchers to assess for a rights-based approach in health and social care settings.

RCFs are typically regulated with the goal of maintaining and improving the quality of care and safeguarding residents.[9] Regulation can improve the quality and standard of care by implementing improvements across all regulated organizations and by focusing on poorly performing organizations.[10] A rights-based approach to caring for older persons and for people with disability has been called for in the literature.[11] It is a strategic objective of the regulators of RCFs in Ireland and elsewhere, who, in addition to promoting a rights-based approach, identify, challenge, and report on breaches of rights in health and social care services.[12]

A common aspect of regulating RCFs is the statutory mandate to notify the regulator of adverse events, as is the case in Ireland.[13] Statutory notifications from RCFs in Ireland, similar to other jurisdictions, provide detail on the incident, the actions taken by the RCF, and the outcome.[14] They include valuable information that is utilized to assess compliance with regulations, assess levels of risk to residents, and monitor the quality of care and support provided. Analyzing statutory notification data can provide insight into the approach to care and support taken during the management of adverse events in RCFs. This can inform quality improvement across the system.[15] Analyzing notifications can also identify system failures and contributing factors that can inform risk management recommendations and opportunities for quality improvement.[16] Adverse events are complex, can have multiple contributing factors, and are high-stress situations for both residents and staff.[17]

There is a scarcity of literature investigating a rights-based approach in social care and analyzing adverse events, specifically in RCFs. Reviewing statutory notifications provides a method to investigate the approach taken to care and support in health and social care settings. In this light, we designed a study reviewing and analyzing the narratives that are part of statutory notifications of adverse events from RCFs in order to identify if FREDA principles were being violated or upheld during the course of adverse events and their management. This can help inform interventions aimed at improving the quality and safety of RCFs.

Methods

Context

In Ireland, the regulation of RCFs is the responsibility of the chief inspector of social services of the Health Information and Quality Authority. The regulator receives statutory notifications of adverse events from all RCFs that detail the circumstances of the incident, the number of residents involved, and the actions taken by the RCF throughout the adverse event.[18] The free-text data contained in each notification are entered by staff members of the RCF submitting the notification and by the regulatory inspector that reviewed the notification. The nine types of notifications mandated in Ireland are "unexpected death," "outbreak of infectious disease," "COVID-19 outbreak," "serious injury to residents," "unexplained absence of residents," "allegations of abuse," "staff misconduct," "staff under professional review," and any "fire, loss of service or unplanned evacuation." The regulator must be notified of these adverse events within three days of their occurrence. Quarterly reporting is also mandated. Such notifications must describe the RCF's use of restraints, its operation of fire safety equipment, and the occurrence of theft, non-serious injuries, pressure sores, and expected deaths in the facility. These quarterly notifications differ fundamentally from the three-day notifications because they take a trend approach to monitoring care and safety rather than one based on individual incidents.

We used the Database of Statutory Notifications from Social Care in Ireland 2013–2021 as the basis for our analysis.[19] This database is a comprehensive national repository of all notifications received by the regulator. Each notification received by the regulator is risk rated by the inspector responsible for monitoring the center that submitted the notification. The risk rating is a combination of two values: the risk likelihood and the risk impact. Both of these values range from 1 (lowest risk) to 5 (highest risk). These values are multiplied to derive the risk rating for the notification. The risk rating is color-coded as follows: green=1–3, yellow=4–6, orange=8–12, and red=15–25.

Sample

In order to draw a representative sample that included all service types (n=4; RCFs for older people, RCFs for adults with disabilities, RCFs for children with disabilities, and RCFs for people of all ages with disability), notification types (n=9), and risk rating colors (n=4), we stratified the sample by service type, notification type, and risk rating color. Upon receipt, each notification is assigned a reference number. Notifications received in 2021 (total n=39,336) were extracted from the Database of Statutory Notifications from Social Care in Ireland. Quarterly notifications were excluded from the analysis (n=15,357). Using the random number generator in Microsoft Excel, we drew the top two of each type of notification, stratified as above. Not all types of notifications or risk ratings were received from each type of service. Thus, this method resulted in a total of 194 notifications in our sample for analysis.

Data analysis

Data were imported into NVivo 1.3 (QSR International) for analysis. The free-text data describing the circumstances surrounding the incident were analyzed independently by two researchers. Line-by-line coding was completed through a deductive approach for each notification in the sample, looking for violations and upholding of the FREDA principles during the adverse event and its management. Both researchers together devised a decision-making framework, assisted by the Health Information and Quality Authority's published guidance on a rights-based approach to care and support (Table 1).[20] This framework illustrates how each FREDA principle could be violated or upheld. This framework was applied independently to each notification.

Incidents could be coded to one or more of the FREDA principles if one or more were violated or upheld. Each incident was also classified as involving either staff upholding or violating principles, or resident peers upholding or violating principles. Each incident was also classified as to whether it occurred during the adverse event or during the management of the adverse event.

The researchers met to compare the results of their analyses. Disagreements were resolved through discussion or by the involvement of a third researcher. Results are presented as a narrative review of each FREDA principle, with consideration of the notification type and supported by verbatim quotes from the notification. This study is reported in line with the Standards for Reporting Qualitative Research.[21]

Results

The sample drawn consisted of 194 notifications of adverse events, constituting 0.81% of all three-day notifications received in 2021. Table 2 contains a breakdown of the sample, including totals for each stratification by risk rating and percentages of these totals. Notifications of COVID-19 outbreaks were the only notification type in our sample to contain notifications submitted by all types of RCFs and include all risk rating colors (n=32).

Fairness

There was evidence of the principle of fairness being upheld by staff in the management of adverse events in all but notifications of "staff being under professional review." Examples of upholding fairness included ensuring the correct staffing ("adequate staffing levels remaining, with use of relief & over-time" [NOT-0455444]); appropriate assessments and management of care and support needs ("Effective care planning and interventions in place to support the high risk of fracture, equipment and manual handing procedures and plans in place" [NOT-0413405]); learning from adverse events ("Additional Supervision and 'early warning/indication' measures have been put in place, to seek to ensure a non-reoccurrence" [NOT-0480060]); supporting access to appropriate care and support ("A social story was prepared and read to BM09 to inform her that she would be going to the hospital" [NOT-0386103]); supporting access to complaints procedures ("the residents [*sic*] has been met and a statement of account taken. The residents [*sic*] understands the issue is being taken seriously" [NOT-0495511]); and explaining rules and expectations and treating people equally ("notified families and residents of these restrictions" [NOT-0513341]).

Violations of fairness by staff in the sample were rare but were found in notifications of "serious injury," "unexplained absence," and "fire, service loss or unplanned evacuation." These violations of fairness included inadequate staffing ("not all staff were on duty as per the planned roster" [NOT-0421817]); not supporting access to the required care ("Resident overnight without medical treatment and/or pain relief and injury not noted until next staff member came on duty" [NOT-0435668]); and not learning from the adverse event ("No details of actions taken to reduce risk of recurrence outlined in notification form" [NOT-0456168]).

Respect

There was a lot of evidence of the principle of respect being upheld by staff in the management of adverse events in all but notifications of "staff under professional review." The most common manner of upholding respect was by providing reassurance and support to residents in the management of an adverse event, both verbally and physically ("emotional support offered by way of conversation, back and hand rubs" [NOT-0386103]). Respect in communication was also evident ("Social stories were completed with the residents to communicate the loss of water and change in plans" [NOT-0513252]). Respect for choices was also evident in the management of an adverse event ("It was explained to XXX that they were positive for COVID-19, XXX expressed that they did not want to be transferred to hospital and that they wanted to stay" [NOT-0496881] and "XXX and YYY were brought out of the center for activities of their own choosing" [NOT-0441808]). Respect for privacy and values was also evident ("attempted to prevent fellow res-

TABLE 1. Framework for assessing adherence with or violations of FREDA principles

Principle	Description	Upholding	Violation
Fairness	Fairness means ensuring that when a decision is made with a person using a service about their care and support, the person's views are sought, listened to, and weighed alongside other factors relevant to the decision. Decisions are made in a way that is clear and fair to allow others to know how they might be treated in similar circumstances. If a decision interferes with a person's human rights, this must be legally justified, proportionate, and taken only when all other alternatives have been considered.	• Ensuring correct staffing levels • Appropriate assessments of care and support needs • Appropriate management of care and support needs • Learning from adverse events • Supporting access to appropriate care and support • Supporting access to complaints procedures and the ability to make a complaint without fear of negative consequences • Explaining rules and expectations to all • Treating people equally and openly in order for others to know they can expect the same treatment • Placing the individual at the center of the decision-making process • Providing comprehensive information in an accessible and meaningful format to the person using services • Staff implement safeguards to ensure that restrictive practice is used only when it is in the person's best interests; such practice is regularly reviewed and removed as soon as possible	• Not taking a person's views about their care and support into account • Unclear decision-making processes that do not allow others to know how they will be treated in similar circumstances • Denying or not supporting a person's access to appropriate care and support • Denying or not supporting a person's access to complaints procedures • Not learning from adverse events • Not providing comprehensive information in an accessible and meaningful format to the person using services • Failing to follow care plans
Respect	Respect refers to objective, unbiased consideration and regard for the rights, values, beliefs, and property of other people. Respect applies to the person and to their value systems.	• Providing reassurance and support during adverse events • Listening to and considering the person's views, wishes, feelings, and choices and ensuring that decisions are aligned to the person's wishes as much as possible • Respecting values	• Disrespectful communication • Not considering a person's choice or views • Not respecting a person's values • Not respecting a person's property
Equality	Equality means having equal opportunities and being treated no less favorably because of one's status or characteristics. Equality can relate to equality of access to and outcomes from care and support.	• Equal access to supports, services, and advocacy regardless of status or characteristics • Equitable care and support • Ensuring that people with more complex and varying needs achieve the same outcomes as others through the provision of additional support • Supporting a person's full inclusion and participation in society • Supporting access to independent advocacy or legal representation of a person's choosing when requested or needed	• Denying access to supports, service, or advocacy due to a person's status or characteristics • Having blanket policies, conditions, or rules in place in the service • Unequal outcomes in care and support based on civil status; disability; family status; gender; membership of the Traveller community; race, color or nationality; religion; or sexual orientation • Not supporting access to independent advocacy or legal representation of a person's choosing when requested or needed • Not supporting a person's full inclusion and participation in society

ident entering as XXXX was undressed from the waist down" [NOT-0386103] and "to be examined by a female physician" [NOT-0375386]).

Violations of respect were evident in notifications of "serious injury," "allegations of abuse," and "staff misconduct." The vast majority of these violations, excluding those in notifications of "staff misconduct," involved peer-on-peer interactions and were relatively minor physical altercations ("Resident XXXXXX tried to knock the dessert out of their hand and threw a spoon at Resident YYYYYY" [NOT-0430676]) or verbal violations of respect ("the other resident said 'shut the fuck up, don't talk to me, go away'" [NOT-0413804]). Staff violations of respect involved disrespectful communication ("staff member alleged to have shouted at a resident" [NOT-0495511]); violations of privacy ("carer had made inappropriate comments and exposed resident inappropriately" [NOT-0418805]); and disrespect in their actions ("staff member has allegedly made the resident feel uncomfortable about calling out for assistance as he presents as annoyed and frustrated when he responds. He is reported to also take longer than needed to respond" [NOT-0456947]).

Equality

Upholding the principle of equality was evident in the management of "outbreaks of infectious disease," "serious injury," "unexplained absence," and "staff misconduct." Only one violation of equality by staff was identified. This was in a notification of "staff misconduct."

Evidence of equal treatment with regard to medical concerns was evident ("All residents symptomatic have been reviewed by GP and referred to Dietician" [NOT-0453528]), as was evidence of facilitating equal access to medical treatment ("resident was brought to the A and E where she was met by members of the staff team from the residential service" [NOT-0458542]) and advocacy ("Residents have been offered further supports of contact-

Table 1. *continued*

Principle	Description	Upholding	Violation
Dignity	Dignity means treating people with compassion and in a way that values them as human beings and supports their self-respect, even if their wishes are not known at the time.	• Treating people with compassion • Supporting self-respect and dignity • Valuing people • Ensuring that basic needs are met • Respecting the privacy of individuals when supporting them in undressing, bathing, and dressing and when discussing their health and care and support • Communicating sensitively with people • Minimizing restrictive practices • Learning and considering a person's lifestyle in all decisions made about their care	• Not treating people with compassion • Denying basic needs • Neglecting or treating people in any way that is likely to cause harm • Not respecting the privacy of individuals when supporting them in undressing, bathing, and dressing or when discussing their health and care and support • Communicating in a patronizing or condescending way toward a person • Inappropriate use of restrictive practices • Not considering a person's lifestyle in all decisions made
Autonomy	Autonomy is the ability of a person to direct how they live on a day-to-day basis according to personal values, beliefs and preferences. In a health and social care setting, autonomy involves the person using a service making informed decisions about their care, support or treatment.	• Obtaining consent by ensuring that the person is provided with adequate and relevant information about their care and support options • Supporting individuals' participation in decisions regarding their care and support • Understanding and supporting the will and preference of individuals • Supporting independence • Presuming that a person has capacity and working to fully support them in making decisions for themselves	• Denying opportunities for individuals' participation in decision-making processes • Not obtaining consent or doing so without providing adequate and relevant information to the individual on their care and support options • Denying a person's will and preferences • Not supporting independence • Failure to support a person's decisions regarding their care and support • Presuming that a person does not have capacity and making decisions on their behalf

Source: Adapted from Health Information and Quality Authority, *Guidance on a Human Rights-Based Approach in Health and Social Care Services* (Dublin: Health Information and Quality Authority, 2019).

Table 2. Sample breakdown, including percentages of 2021 total notifications

	Green			Yellow			Orange			Red			Totals		
Notification type	Sample	2021 total	% of total	Sample	2021 total	% of total	Sample	2021 total	% of total	Sample	2021 total	% of total	Sample total	2021 total	% of total
Unexpected death	5	224	2.23	4	615	0.65	4	80	5.00	4	1,051	0.38	17	1,970	0.86
Infectious disease outbreak	6	67	8.96	5	53	9.43	6	22	27.27	4	66	6.06	21	208	10.10
COVID-19 outbreak	8	4,380	0.18	8	531	1.51	8	171	4.68	8	2,548	0.31	32	7,630	0.42
Serious injury	8	452	1.77	8	3,100	0.26	8	405	1.98	4	5	80.00	28	3,962	0.71
Unexplained absence	5	34	14.71	8	210	3.81	5	77	6.49	3	3	100.00	21	324	6.48
Allegations of abuse	8	1,272	0.63	8	5,825	0.14	8	977	0.82	5	6	83.33	29	8,080	0.36
Staff misconduct	7	38	18.42	8	220	3.64	7	53	13.21	0	0	0.00	22	311	7.07
Professional review of staff	0	0	0.00	2	4	50.00	2	4	50.00	0	0	0.00	4	8	50.00
Fire, service loss, or unplanned evacuation	8	1,076	0.74	8	387	2.07	4	22	18.18	0	1	0.00	20	1,486	1.35
Total	55	7,543	0.73	59	12,966	0.46	52	3,832	1.36	28	5,701	0.49	194	23,979	0.81

ing an advocate or an identified representative" [NOT-0426556]). Only one instance of a violation of equality was found in a notification of "staff misconduct," where equal access to care was denied: ("Staff failed to follow protocol around head injury, in particular, failure to get appropriate medical advice following a head injury" [NOT-0417548].)

Dignity

Upholding the principle of dignity was evident in all adverse event notifications except notifications of "unexpected death" and "unexplained absence." There was evidence of residents being treated with compassion ("Compassionate visits occurring and virtual calls with family" [NOT-0453528] and "additional measures we were putting [*sic*] in place such as familiar staff only to support resident" [NOT-0497781]) and with value ("nurse who had been assisting her managed to hold her at this stage and prevented the resident from falling to the ground" [NOT-0468320]). Dignity was upheld by staff supporting residents' self-respect ("care staff remained outside the partly opened door allowing for her privacy" [NOT-0458967]); ensuring that basic needs were met ("Staff ensured person was cleansed & dignity maintained" [NOT-0458967]); and comforting residents in the event of an adverse event ("Emotional first aid and support to regulate" [NOT-0433644]).

Staff violating the principle of dignity was evident in notifications of "serious injury" ("Resident overnight without medical treatment and/or pain relief and injury not noted until next staff member came on duty" [NOT-0435668]); "allegations of abuse" ("Resident XXXXXX had not been brought to the toilet between the hours of 10:30 and 18:30" [NOT-0414757]); "staff misconduct" ("staff member was being aggressive and verbally abusive towards the resident" [NOT-0441070]); "staff under professional review" ("non-adherence to controls in place including lack of social distancing, overstaying time allocated for visit and not wearing a face shield" [NOT-0421899]); and "fire, service loss or unplanned evacuation" ("they could not bath/shower for one day" [NOT-0513252]).

Violations of dignity also occurred in peer-on-peer interactions and were reported only in notifications of "serious injury" ("Resident XXXX sustained 3 knife wounds, inflicted by peer" [NOT-0442910]) and "allegations of abuse" ("Staff then witnessed XXX intimidatingly staring at YYY and said 'Shut up', in a threatening tone. XXX picked up his walking stick and struck YYY with an upwards motion making contact with YYY left wrist" [NOT-0470480]).

Autonomy

Staff supporting and promoting the principle of autonomy was evident in the sample in all but notifications of "outbreaks of infectious disease," "staff misconduct," and "staff under professional review." Obtaining consent and supporting informed decisions about their own care was evident ("advised for hospital transfer to rule out injury- resident agreeable" [NOT-0456217]), even if it was against what had been advised ("resident is refusing to comply with full medical advice, in that he is refusing to wear the boot at night" [NOT-051879405]). Supporting participation in decisions made on care and support was evident ("handover at 8am with consultation with XXXX so he can plan his daily activity" [NOT-0457704]). Understating and supporting the will and preferences of residents was evident ("resident wishes to contact family when choosing to do so" [NOT-0491340]) and ("requested to go out on the bus which staff facilitated and he got a takeaway which he appeared to enjoy" [NOT-0431685]). Supporting independence was also evident in the sample ("Resident went on a planned outing unaccompanied as per protocol" [NOT-0462696]).

Incidents of staff violating autonomy occurred in notifications of "unexplained absence," "allegations of abuse," and "staff misconduct." Violations included restrictive practices ("restrictions now in place for minimum of one month, no friend visits, no internet access, no use of smart phone. House doors locked at all times, no independent shopping trips" [NOT-0447579]); failure to support decisions regarding care ("The advocate neglected to facilitate the resident's stated wishes when they agreed to the advocate visiting" [NOT-0491401]); and failing to facilitate care plans ("A staff member is alleged to have fed a service user in a manner that did not adhere to a resident specific FEDS plan" [NOT-0426556]).

Human rights-based approach during the adverse event and its management

The vast majority of adverse events in our sample contained examples of staff upholding a rights-based approach to care and support in the management of an adverse event. There were numerous examples of staff upholding all of the FREDA principles in each type of adverse event notification, excluding "staff under professional review." There was also evidence of staff upholding each FREDA principle during the adverse event, although not as numerous as in the management of an incident.

Violations of the FREDA principles occurred mainly in the adverse event itself (and not in the management of such events), where there was evidence of violations of all five principles. In the management of such events, there was evidence only of the violation of autonomy and fairness.

Staff and peer-on-peer evidence

In the majority of notifications in our sample, staff upheld a rights-based approach when managing adverse events and during events. There were a small number of notifications containing staff violations of the FREDA principles, with the majority being notifications of "staff misconduct."

Peer-on-peer interactions were responsible for violations of respect, dignity, and autonomy, and these were in notifications of "serious injury" and "allegations of abuse."

Discussion

Summary of findings

Notifications of adverse events from RCFs in Ireland contained evidence that a rights-based approach to care and support is being upheld by staff during adverse events and their management. RCF staff upholding FREDA principles was evident in all types of notifications except for notifications of "staff under professional review." Although there were examples of the FREDA principles being violated by staff, these were few in number, and no violations were identified in notifications of "unexpected death," "outbreaks of infectious diseases," and "outbreaks of COVID-19." Evidence of residents violating their fellow residents' autonomy, respect, and dignity were observed, but only in notifications of "serious injury" and "allegations of abuse."

Statutory notifications from RCFs in Ireland, similar to other jurisdictions, provide detail on the incident, the actions taken by the RCF, and the outcome.[22] This valuable information can be utilized in a variety of ways: assessing compliance with regulations, assessing risk, monitoring quality of care, or providing insight into the approach to care and support taken during the management of adverse events. Adverse events are complex, can have multiple contributing factors, and are high-stress situations for both residents and staff.[23] Evidence of a rights-based approach during times of high stress may indicate that a rights-based approach to care and support in general has been widely adopted in RCFs in Ireland. Staff ensuring that the FREDA principles are protected and supported during adverse events may point toward a rights-based approach being embedded in the service culture. Conversely, an adverse event—being complex, a time of high stress, and out of the ordinary—may be the only time a rights-based approach is taken.

This is the first study to rely on notifications of adverse events to investigate whether a rights-based approach is being implemented in RCFs, and there is a scarcity of literature that investigates experiences of a rights-based approach in social care. Applying the same FREDA framework used here to other data sources, such as inspection reports or investigations of complaints received by the regulator, may provide insight into the approach taken by RCFs during the routine care and support of everyday life. In support of our finding, a review of rights-based approaches in mental health and disability and dementia care settings indicated that a rights-based approach can be successfully implemented and is of benefit to those receiving treatment.[24] A study published in 2020 that used regulator inspection reports to investigate human rights in RCFs for people with an intellectual disability in Ireland indicated that a rights-based approach had not been implemented.[25] This study, which developed its own human rights framework based on the United Nations Convention on the Rights of Persons with Disabilities, indicated that restrictive practices are in use and that residents are subject to abuse, neglect and isolation and are not empowered.[26] In contrast, our study indicates that a rights-based approach to care and support is being embraced by RCFs. This contrasting finding may be because our focus was on acute incidents and not routine care, using adverse event notification data instead of inspection reports. This suggests that the presence of a rights-based approach during adverse events may not translate to the presence of a rights-based approach in routine care and support. In support of this lack of generalizability, a study using the same database as our study investigated the use of restrictive practices in nursing homes in Ireland and showed the indiscriminate use of restrictive practices in RCFs, suggesting that the FREDA principles are being violated.[27] The measurement of the implementation or impact of a rights-based approach is not simple, however, as measuring typical health outcomes does not capture the effects of a rights-based approach to health care and to social care, and statutory notifications do not portray the everyday approach to care and support.[28]

Human rights legislation, codes of professional conduct, and national standards advocate for a shift away from a paternal approach to care and support toward a rights-based approach.[29] There has also been a call in the literature to implement a rights-based approach to health care and social care since the United Nations outlined the need for a rights-based approach in all of its agencies.[30] Education on human rights for health care professionals and care workers can improve decision-making skills in practice.[31] Educating the public can also benefit those being cared for and supported in RCFs, as it can provide confidence to question the nature and quality of care for older people.[32] A review, published in 2015, on the impact of human rights legislation in health care and social care in England and Wales, however, indicated that a rights-based approach was not realized. The author of this review states that the Human Rights in Healthcare Programme, which was introduced in 2005, had not led to a shift away from a paternalistic approach to care and support toward a rights-based approach.[33] The author argues that the development of human rights-based resources has had a beneficial effect but that the overall implementation has not been as successful, for a multitude of reasons.

The people being cared for in RCFs are residents, not patients, and the goal of care differs from other health care services. While there is substantial research into adverse events in acute settings, there is a paucity of data and research relating to adverse events in other settings, including RCFs.[34] In RCFs, a rights-based approach may result in compromises being made that would not be made in acute services and this, in certain circumstances, may cause a disparity in risk management and conflict with restrictive practices aimed at reducing the risk of adverse events. Adverse events in RCFs are complex and can have multiple causes, and striking the balance between risk management, control, and monitoring and the promotion of autonomy, liberty, independence, choice, comfort, quality of life, and positive risk taking may explain some of the violations of the FREDA principles that were evident in our sample. There are competing demands of empowerment and the duty of care for staff; however, staff have a responsibility to, and not a responsibility for, residents.[35] In nursing practice studies, it has been identified that challenges can arise when practitioners need to achieve a balance between upholding the human rights of individuals while protecting these individuals' health and well-being and maintaining their duty of care as practitioners.[36] This has also been identified with supporting people who are at risk and may lack the capacity to make a decision but still require their human rights to be upheld.[37]

The comprehensive reporting of adverse events is important for understanding the event and for learning by both those reporting and those receiving notifications.[38] Identifying violations of the FREDA principles by staff in statutory notifications of adverse events can assist RCFs and the regulator in the further implementation of a rights-based approach and in making the elimination of violations of FREDA principles by staff potentially achievable. Violations of FREDA principles in notifications of "staff misconduct" suggest that the RCFs are aware of violations from staff and are actually upholding the FREDA principles and implementing a rights-based approach by reporting these violations. However, the complete elimination of violations during resident-to-resident interactions may not be achievable, as is the case in almost all situations where people live with other people. Monitoring for patterns of these interactions and taking preventative action, however, would help reduce incidents of violations of dignity and respect by fellow residents.

Strengths and limitations

To the best of our knowledge, this is the first investigation of the use of a rights-based approach to care and support in RCFs. Our work is also unique in that it utilized notifications of adverse events to the regulator to investigate the approach to care and support during adverse events. The sample was extracted from the Database of Statutory Notifications from Social Care in Ireland, a national database that contains all notifications of adverse events received by the regulator from RCFs in Ireland commencing in 2013.[39] This national database may not be complete, as it may not contain every adverse event that occurs in RCFs in Ireland. However, the risk of this is low given that reporting adverse events to the regulator is legally required and RCFs are monitored and inspected. Our sample was stratified for types of notifications, types of RCFs and risk ratings, ensuring that a large representative sample was analyzed.

The free-text data in statutory notifications are written by RCF employees and regulatory inspectors. This is both a strength and a limitation. Using data contained in notifications means that the data collection method is commensurate across events and no bias was introduced by the researchers in its collection. Notifications are, however, a single point of view that include personal opinions and biases and are influenced by the culture of the RCF.[40] Those completing forms may attempt to put their best foot forward and not apportion blame or reveal a non-rights-based approach to the management of the adverse event. Although the form is the same for everyone, the language, terminology, and writing skills are not. Establishing an evidence base on the implementation of a rights-based approach requires the use of a variety of study designs using a range of sources. These include audits, regulatory inspection reports, focus groups with residents and staff, and observational studies.

The interpretation of the FREDA principles and the framework for coding the notifications was devised by the authors without input from service providers or from residents of RCFs. Their input on the interpretation of the FREDA principles in the development of the framework may have resulted in a different framework. The findings presented are therefore limited to our interpretation of the FREDA principles. That said, the framework was devised using the Health Information and Quality Authority's guidance on a rights-based approach to care and support, which was published in 2019.[41] This meant that stakeholders had over two years to become familiar with the Health Information and Quality Authority's interpretation of the FREDA principles.

The authors who performed the analysis were experienced in the method and complemented each other in their experience of the fields of care, statutory notifications, and human rights. A third researcher strengthened the analysis by resolving any disagreements. The sampling strategy was developed by researchers with in-depth knowledge of the nuances of adverse events in RCFs and the nuances in the provision of care and support in RCFs. As a result, the sample should reflect the approach taken during adverse events in RCFs in Ireland.

Conclusion

Our analysis of a sample of notifications received by the social care regulator in Ireland detailing adverse events in RCFs indicates that a rights-based approach to care and support is being upheld during adverse events. There was evidence of violations of human rights by staff and by residents, but these were minor in nature and few in number. In RCFs, there are competing demands to promote a rights-based approach and to avoid harm or injury that are not present in other health care services, such as acute care, which may explain the violations by staff. In these situations where human rights are competing with risk management, staff need to consider the applicability and weighting of each right within that situation and their duty of care to ensure safety and fairness for all residents. While eliminating violations of human rights by staff is potentially achievable, eliminating violations during resident-to-resident interactions may not be. Monitoring for patterns of these interactions and taking preventative action, however, would help ensure that residents' human rights are upheld in RCFs.

Ethics

We did not seek ethical approval for this analysis given that it is a secondary analysis of routinely collected regulatory data pertaining to events as opposed to individuals. The data do not contain any identifiable personal data.

References

1. Universal Declaration of Human Rights, G.A. Res. 217A (III) (1948); European Convention on Human Rights, European Treaty Series No. 5 (1950).

2. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006); M. A. Stein, P. Stein, D. Weiss, and R. Lang, "Convention on the Rights of Persons with Disabilities," *European Journal of Health Law* 14/3 (2007).

3. I. Doron and I. Apter, The Debate around the Need for an International Convention on the Rights of Older Persons," *Gerontologist* 50/5 (2010); C. Peisah, C. de Mendonça Lima, H. Verbeek, and K. Rabheru, "IPA and WPA-SOAP Joint Statement on the Rights of Older Persons with Mental Health Conditions and Psychosocial Disabilities," *International Psychogeriatrics* 34/11 (2022); C. Peisah, E. L. Sampson, K. Rabheru, et al., "The Human Rights of Older People with Mental Health Conditions and Psychosocial Disability to a Good Death and Dying Well," *American Journal of Geriatric Psychiatry* 29/10 (2021).

4. Irish Association of Social Workers, *Code of Practice* (Dublin: Irish Association of Social Workers, 2020); Nursing and Midwifery Board of Ireland, *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives* (Dublin: Nursing and Midwifery Board of Ireland, 2021); Irish Medical Council, *Guide to Professional Conduct and Ethics*, 8th edition (Dublin: Irish Medical Council, 2019).

5. M. J. Curtice and T. Exworthy, "FREDA: A Human Rights-Based Approach to Healthcare," *Psychiatrist* 34/4 (2010).

6. Ibid.

7. Scottish Human Rights Commission, Health and Social Care Alliance, and NHS Health Scotland, *Human Rights in Health and Social Care: Putting it into Practice; Case Studies from Scotland* (Scotland: Scottish Human Rights Commission, 2019); Health Information and Quality Authority, *Guidance on a Human Rights-Based Approach in Health and Social Care Services* (Dublin: Health Information and Quality Authority, 2019); Quality Care Commission, *Our Human Rights Approach for How We Regulate Health and Social Care Services* (London: Quality Care Commission, 2019).

8. Health Information and Quality Authority (2019, see note 7).

9. K. Walshe and A. Boyd, "Designing Regulation: A Review," *Regulation* 3/2 (2007).

10. Ibid.

11. Peisah et al. (2022, see note 3); Peisah et al. (2021, see note 3); Walshe and Boyd (see note 9); N. Rushford and D. Harvey, "Dementia as a Disability and Human Rights Issue," *Healthcare Papers* 16/2 (2016); E. Evans, S. Howlett, T. Kremser, et al., "Service Development for Intellectual Disability Mental Health: A Human Rights Approach," *Journal of Intellectual Disability Research* 56/11 (2012); D. Banerjee, K. Rabheru, C. A. de Mendonca Lima, and G. Ivbijaro, "Role of Dignity in Mental Healthcare: Impact on Ageism and Human Rights of Older Persons," *American Journal of Geriatric Psychiatry* 29/10 (2021); S. Fitzgerald, L. Behan, S. McCarty, et al., "Translating a Human Rights-based Approach into Health and Social Care Practice," *Journal of Social Care* 3/1 (2020).

12. Health Information and Quality Authority, *Annual Report* (Dublin: Health Information and Quality Authority, 2022); Scottish Human Rights Commission et al. (see note 7); Quality Care Commission (see note 7); Health Information and Quality Authority (2019, see note 7).

13. Australian Government, *Aged Care Quality and Safety Commission Act 2018* (2018); Government of Ireland. *Care and Welfare of Residents in Designated Centres for Older People Regulations 2013* (2013); Government of Ireland, *Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013* (2013); Government of Northern Ireland, *Article 23 (7)(d) The Health and Social Services (Quality, Improvement and Regulation) Order 2003* (2003); Government of the United Kingdom, *Health and Social Care Act 2008* (2008); S. Abimbola, J. Negin, A. L. Martiniuk, and S. Jan, "Institutional

Analysis of Health System Governance," *Health Policy Plan* 32/9 (2017).

14. Government of Ireland, *Care and Welfare of Residents* (see note 13); Government of Ireland, *Care and Support of Residents* (see note 13); Government of Northern Ireland (see note 13).

15. N. McGrane, S. O'Regan, P. Dunbar, et al., "Management and Reporting of Safety Incidents by Residential Care Facilities in Ireland: A Thematic Analysis of Statutory Notifications," *Health and Social Care in the Community* 30/6 (2002); I. Leistikow, S. Mulder, J. Vesseur, and P. Robben, "Learning from Incidents in Healthcare: The Journey, Not the Arrival, Matters," *BMJ Quality and Safety* 26/3 (2017).

16. N. McGrane, P. Dunbar, and L. M. Keyes, "Contributing Factors to Adverse Events in Long-Term Care Facilities in Ireland: A Content Analysis," *Journal of the American Medical Directors Association* 25/4 (2024).

17. Ibid.; R. Amalberti, D. Benhamou, Y. Auroy, and L. Degos, "Adverse Events in Medicine: Easy to Count, Complicated to Understand, and Complex to Prevent," *Journal of Biomedical Informatics* 44/3 (2011); A. Cobos-Vargas, P. Pérez-Pérez, M. Núñez-Núñez, et al., "Second Victim Support at the Core of Severe Adverse Event Investigation," *International Journal of Environmental Research and Public Health* 19/24 (2022).

18. Government of Ireland, *Care and Welfare of Residents* (see note 13); Government of Ireland, *Care and Support of Residents* (see note 13); Government of Ireland, *Health Act 2007* (2007).

19. S. O'Regan, N. McGrane, P. Dunbar, et al., "Public Reporting of Adverse Events from Long-Term Care Facilities for Older Persons and People with Disability in Ireland 2013–2019: Development of an Openly Accessible Database and Descriptive Analyses," *Journal of the American Medical Directors Association* 23/8 (2022).

20. Health Information and Quality Authority (2019, see note 7).

21. B. C. O'Brien, I. B. Harris, T. J. Beckman, et al., "Standards for Reporting Qualitative Research: A Synthesis of Recommendations," *Academic Medicine: Journal of the Association of American Medical Colleges* 89/9 (2014).

22. Government of Ireland, *Care and Welfare of Residents* (see note 13); Government of Ireland, *Care and Support of Residents* (see note 13); Government of Northern Ireland (see note 13).

23. McGrane et al. (see note 16); Amalberti et al. (see note 17); Cobos-Vargas (see note 17).

24. S. Porsdam Mann, V. J. Bradley, and B. J. Sahakian, "Human Rights-Based Approaches to Mental Health: A Review of Programs," *Health and Human Rights Journal* 18/1 (2016).

25. K. Murphy and E. Bantry-White, "Behind Closed Doors: Human Rights in Residential Care for People with an Intellectual Disability in Ireland," *Disability and Society* 36/5 (2021).

26. Ibid.

27. World Health Organization, *Global Priorities for Patient Safety Research* (Geneva: World Health Organization, 2009).

28. L. Dyer, "A Review of the Impact of the Human Rights in Healthcare Programme in England and Wales," *Health and Human Rights Journal* 17/2 (2015).

29. R. Newham, A. Hewison, J. Graves, and A. Boyal, "Human Rights Education in Patient Care: A Literature Review and Critical Discussion," *Nursing Ethics* 28/2 (2021).

30. United Nations Development Group, *The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding among UN Agencies* (New York: United Nations, 2003).

31. S. Every-Palmer, L. Kininmonth, G. Newton-Howes, and S. Gordon, "Applying Human Rights and Reducing Coercion in Psychiatry following Service User-Led Education: A Qualitative Study," *Health and Human Rights Journal* 23/2 (2021); P. Hunt, A. E. Yamin, and F. Bustreo, "Making the Case: What Is the Evidence of Impact of Applying Human Rights-Based Approaches to Health?," *Health and Human Rights Journal* 17/2 (2015); Dyer (see note 28).

32. T. Jessop and C. Peisah, 'Human Rights and Empowerment in Aged Care: Restraint, Consent and Dying with Dignity," *International Journal of Environmental Research and Public Health* 18/15 (2021).

33. Dyer (see note 28).

34. World Health Organization (see note 27).

35. S. Baxter and H. Carr, "Walking the Tightrope: The Balance Between Duty of Care, Human Rights and Capacity," *Housing, Care and Support* 10/3 (2007).

36. C. Cole, S. Wellard, and J. Mummery, "Problematising Autonomy and Advocacy in Nursing," *Nursing Ethics* 21/5 (2014); R. Griffith and C. Tengnah, "The Influence of Human Rights on District Nurse Practice," *British Journal of Community Nursing* 14/10 (2010).

37. Baxter and Carr (see note 35).

38. C. Macrae, "The Problem with Incident Reporting," *BMJ Quality and Safety* 25 (2015).

39. O'Regan et al. (see note 19); Health Information and Quality Authority, *Database of Statutory Notifications from Social Care in Ireland* (unpublished database).

40. Macrae (see note 38).

41. Health Information and Quality Authority (2019, see note 7).

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PERSPECTIVE

“Reducing the Treatment Gap” Poses Human Rights Risks

LISA COSGROVE, CRISTIAN MONTENEGRO, LEE EDSON YARCIA, GIANNA D’AMBROZIO, AND JULIE HANNAH

Introduction

The United Nations (UN) officially acknowledged the “global burden” of mental disorders in September 2015, when mental health was included in the UN Sustainable Development Goals (SDGs).[1] In so doing, the UN identified mental health as a priority for global development. The call to “close the treatment gap” was seen as a way to both uphold the right to treatment and integrate mental health into the SDGs, with many asserting that this is a human rights-based approach to transforming mental health.[2]

Although using the SDG framework is a sensible and necessary approach to catalyze action on mental health, the integration of mental health into the SDGs has sparked debates about the relevance and role of human rights frameworks in this area. For example, the latest draft resolution on mental health and sustainable development, presented by Mexico to the UN General Assembly, has been met with renewed calls to avoid the psychiatrization of the SDGs.[3] Psychiatrization, in this context, points to the process by which “psychiatric institutions, knowledge, and practices affect an increasing number of people, shape

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Lisa Cosgrove, PhD, is a professor in the Counseling Psychology Department and a faculty fellow at the Applied Ethics Center, University of Massachusetts Boston, United States, as well as co-founder of the Centre for Mental Health, Human Rights, and Social Justice, a multi-institutional platform dedicated to the study of rights-based approaches to mental health law, policy, and practices.

Cristian Montenegro, PhD, is a senior research fellow at the Wellcome Centre for Cultures and Environments of Health at the University of Exeter, UK, and a member of the Centre for Mental Health, Human Rights, and Social Justice.

Lee Edson Yarcia is a senior lecturer at the College of Law at the University of the Philippines Diliman, Manila, Philippines; a drug policy expert at the United Nations Joint Programme for the Protection and Promotion of Human Rights in the Philippines; and a member of the Centre for Mental Health, Human Rights, and Social Justice.

Gianna D’Ambrozio, LMSW, is a doctoral candidate in the Counseling Psychology Department at the University of Massachusetts Boston, United States.

Julie Hannah, LLM, is director of the International Centre on Human Rights and Drug Policy at the University of Essex, Colchester, UK, and co-founder of the Centre for Mental Health, Human Rights, and Social Justice.

Please address correspondence to Lisa Cosgrove. Email: lisa.cosgrove@umb.edu.

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more and more areas of life, and further psychiatry's importance in society as a whole."[4] Concerns about psychiatrization stem from the fact that the focus is predominantly on scaling up the diagnosis and treatment of mental disorders, without paying attention to how a biomedical approach is limited in addressing the environmental, social, economic, and political determinants of mental health.[5] Further, the emphasis on "closing the treatment gap" selectively deploys human rights in order to promote increased access to Western biomedical treatments. In so doing, there is a risk that the foundational principles of interdependence and indivisibility of international human rights will not be brought to fruition. What is needed is a holistic, rights-based approach that focuses not only on the clinical or individual interventions and outcomes but also on the *process and contexts* of implementation. That is why it is critical to ask "what type of evidence is valued (and devalued)."[6] Thus, any discussions about the meaning and logistics of including global mental health as a priority for global development must include the voices of those most affected.

Indeed, advocates for global mental health, including the Movement for Global Mental Health, should engage more deeply with the meaning and the consequences of a human rights framework, as well as the tensions surrounding the idea of a right to mental health. That is, conflating the right to health with increased access to treatment deflects attention away from questions about the validity and sustainability of "closing the treatment gap."[7] The purpose of this paper is to articulate what a human rights perspective in mental health and psychosocial disabilities could mean, and how a more nuanced approach to rights can provide an important challenge to mainstream approaches in global mental health. As individuals within the fields of critical disability and anticolonial studies have long argued, we need an approach to human rights that does not assume that increased diagnosis and treatment will always lead to improvements in population or individual mental health. Our paper builds on and consolidates prior literature in critical disability studies and anticolonial scholarship on mental health policy and human rights.[8]

After briefly describing a rights-based approach, we offer four suggestions for how to integrate such an approach into mental health policy and practice in a way that more fully addresses the social and structural determinants of emotional well-being.

Pillars of a human rights-based approach

A rights-based approach to health and development integrates the norms and principles of human rights into the planning, implementation, monitoring, and evaluation of policies and programs. This approach not only focuses on the delivery of health services but also emphasizes the broader determinants of health that impact individuals' well-being. In essence, a rights-based approach ensures that every aspect of health care and its determinants is imbued with respect for, and the realization of, human rights.

At the heart of a human rights-based approach to mental health lies the commitment to uphold and integrate specific fundamental human rights norms in both policy formulation and practical implementation. There is a convergence between the SDGs and human rights standards, and thus a rights-based approach embraces the following core principles:[9]

- *Participation*: Central to a rights-based approach is the principle that all individuals have the right to actively engage in, contribute to, and influence—in a way that is meaningful and inclusive—processes, decisions, and activities affecting their lives.
- *Nondiscrimination and equality*: This principle mandates the elimination of all forms of discrimination and the assurance of equality before the law, in rights, and in opportunities. It underscores the importance of creating an environment where all individuals, irrespective of their race, gender, socioeconomic status, or any other characteristic, enjoy equal rights and opportunities.

- *AAAQ framework*: The AAAQ framework—availability, accessibility, acceptability, and quality—represents a comprehensive and action-oriented approach to economic, social, and cultural rights, such as the rights to health, education, food, and housing. Each component of the AAAQ framework serves as a critical standard for assessing and ensuring the realization of these rights.
- *Transparency and accountability*: These principles advocate for clear, open, and accessible information regarding policies and practices, and they ensure that individuals and entities are held accountable for upholding human rights standards.
- *Interdependence and indivisibility*: This principle recognizes that all human rights are interconnected and interrelated. The improvement or deprivation of one right affects the others. Hence, a holistic approach that respects the interdependence and indivisibility of all human rights is essential for the full realization of each right.

Suggestions for a more robust integration of a rights-based approach into mental health policy and practice

Consider the lessons learned from social medicine and social epidemiology

> [S]*ocieties cannot improve the health status of their populations and reduce significant health inequalities solely or primarily by increasing the resources devoted to medical services. While necessary and significant, investments to improve availability of health services and enhance their quality and relevance cannot compensate for significant disparities in access to the social determinants of health.*[10]

In 2017, depressive disorders were ranked as the third leading cause of "years lost to disability."[11] The World Health Organization ranks depression as the single largest contributor to global disability.[12] Thus, it is unsurprising that policy makers are advocating for scaling up mental health diagnosis and treatment. However, following Audrey Chapman, we believe that focusing on intra-individual interventions and conflating access to psychiatric services with mental health equity often keeps the status quo intact and does little to animate our political imagination.[13] One of the most important lessons from the fields of social medicine and social epidemiology that is relevant to the mainstream agendas in global mental health is that we must guard against reducing rights to the right to receive treatment. Population-based health promotion is a fundamental human right that is as important as individual health treatment. As argued by the former UN Special Rapporteur on the right to health, child psychiatrist Dainius Pūras, mental well-being can be achieved only by *creating environments* that allow individuals, families, communities, and populations to live lives of dignity with the full enjoyment of all of the rights to which they are entitled.[14]

The capabilities approach (CA), a conceptual and normative framework developed by Amartya Sen, is consistent with the focus on creating environments that facilitate well-being.[15] According to the CA, rights and capabilities are interdependent: having a right to do or have something will not guarantee that people are *actually able* to do what they value and thus live a life of dignity and meaning. The opportunity to develop capabilities is central to human freedom and dignity. Rather than focus predominately on scaling up the diagnosis and treatment of mental health conditions, the CA shifts our attention toward the possibilities for well-being and, most importantly, the resources and rights needed to achieve well-being. In order for capabilities to be realized, for people to be able to lead meaningful lives worthy of human dignity, governments need to provide actual opportunities and political entitlements.[16] The 2007 United Nations Declaration on the Rights of Indigenous Peoples, which established a human rights framework to ensure "the survival, dignity and well-being of indigenous peoples," is relevant here. Specifically, article 24 requires states to take the necessary steps to achieve the full realization of the right to physical and mental health. As Laurence Kirmayer and colleagues note, strengthening the agency and dignity of Indigenous peoples through political activism (e.g., negotiating land claims) enhances mental health.[17]

Incorporate an epistemic injustice framework as part of a robust human rights approach

> [There are] *structural prejudices in the processes involved in knowledge production, use, and circulation in global health.*[18]

In global mental health research, it is crucial to acknowledge the presence of bias, prejudice, and power disparities that influence the creation, use, and dissemination of knowledge. A significant proportion of this bias stems from the dominance of Western perspectives in mental health research. When applied to non-Western contexts, Western theories and frameworks may fail to capture the cultural entanglements and drivers of mental health and illness.[19]

Power asymmetries exacerbate the issue.[20] Scholars from affluent countries typically have access to more resources and higher chances of getting published in high-impact journals, which inherently disadvantages researchers from lower- and middle-income countries. Language poses another barrier since high-impact academic journals publish in English, which may leave out valuable research and insights from non-English-speaking researchers. Additionally, the stigmatization associated with mental illnesses worldwide often results in the devaluation of lived experience as a legitimate source of knowledge in research, policymaking, and practical applications. The dominance of the biomedical model often neglects the social, economic, and cultural context of mental illnesses.

Conflating increased access to diagnosis and treatment with the fulfillment of a right to mental health is made possible because the epistemic injustice involved in mental health research is rendered invisible, and diverse voices and approaches are sidelined in order to promote a single dominant approach. Addressing these asymmetries thus requires an emphasis on epistemic justice and human rights. Implementing epistemic justice involves incorporating diverse perspectives in mental health research, policy, and practice, validating local knowledge systems, and recognizing the importance of the lived experiences of individuals affected by mental health issues.[21]

(Re)cast mental well-being in a moral, not economic, framework[22]

> *While it is uncontroversial to note that millions of people around the world are grossly underserved, the current "burden of disease" approach firmly roots the global mental health crisis within a biomedical model, too narrow to be proactive and responsive in addressing mental health issues at the national and global level.*[23]

The prevailing discourse on the "global burden" of mental disorders often deploys the disability-adjusted life year (DALY) metric as a gauge of economic loss. This composite measure—combining years of life lost from premature death and years lost due to disability—converts emotional distress into economic burden. Such quantification is not without its flaws. For example, a recent critical appraisal of the epidemiological evidence for the 2017 global burden of disease estimates for major depressive disorder found that the estimates were based on incomplete country and population coverage and used unclear methodologies. The authors concluded that there were critical flaws in the data underpinning the global burden of disease estimates and that "policymakers should interpret disease estimates with caution."[24]

Also, at an empirical level, the DALY model struggles with the heterogeneity of mental health conditions. For instance, depression manifests with varying severity, making it nearly impossible to quantify its economic impact accurately. Yet the DALY metric endeavors to compute the economic "loss" attributed to conditions such as depression, rendering the approach not just imprecise but arguably inappropriate. Derek Summerfield has pointed out that applying the DALY metric to depression is "epistemologically lamentable."[25] Such criticisms highlight the need to place emotional distress within its broader moral and political context, as an increasing number of psychiatrists argue. Indeed, a dominant view of mental health conditions is that dignity is not inherent. Rather, it is lost through the "disorder" and regained through specialist intervention. However, a rights-based approach to mental health rejects this view and instead asserts that "the absence of dignity and the power to restore it, is the absence of rights, and a license for unaccountable intervention."[26]

As a result, a human rights-based approach to mental well-being offers a different lens, facilitating a nuanced understanding of the relationship between human rights and the social determinants of health. By reconceptualizing human rights as "social ethics," we can better understand the psychosocial contexts from which symptoms emerge.[27] Specifically, we need to move away from reductive economic metrics and toward a framework that recognizes mental health as a complex interplay of individual, social, and systemic factors.

Create mechanisms for protecting fundamental liberties and human dignity when developing mental health policies and interventions

> *The current approach* [to global mental health] *emphasizes the development of mental health services and interventions in "silos," focusing on the treatment of mental illnesses at the exclusion of a holistic and contextualized approach to people's needs.*[28]

A rights-based approach to mental health recognizes that people with psychosocial disabilities and mental illnesses are often systematically made vulnerable by legal restrictions imposed by states on their capacity to decide for themselves. In many states, a diagnosis of a psychiatric disorder (e.g., schizophrenia) gives health care professionals the authority to deprive persons of liberty and subject them to in-patient admission treatments, which are otherwise sanctioned by next of kin who act as substitute decision-makers. In the Philippines, for example, persons diagnosed with drug dependency or disorders undergo court-ordered compulsory rehabilitation, which is often militaristic or centered on religious or spiritual frameworks.[29] Relapse is attributed to a personal failing of the person under treatment, and the power imbalance between the patient and the physician prevents accountability; there is no review of the treatment protocol in terms of whether it is evidence based or effective, or if the harms outweigh the benefits.

Indeed, the practice of court diversion to compulsory treatment in the community—often done with the best of intentions—is deeply problematic and raises important human rights considerations. As legal scholar Linda Steele cogently argues, court-mandated compulsory treatment exacerbates disability oppression.[30]

Human dignity, which in its core respects a person's autonomy and capacity to decide and give informed consent, is often lost when a label of psychosocial disability is medically introduced. Essentially, a state-sanctioned global policy directive that medicalizes mental health enables injustices that are then perpetuated (often unwittingly) by mental health service providers. It is therefore critical that safeguards and accountability structures be included in mental health policies and practices—structures that can ensure that human rights are being upheld in health care contexts. Human rights literacy of health care professionals and program implementers must be mainstreamed as the core prevention tool for violations of fundamental liberties. A rights-based mental health framework acknowledges the accountability of actors and provides effective remedies for the promotion and protection of liberties.

Conclusion: How might we build a decolonial politics of care?[31]

Current efforts to prioritize and embed mental health into the SDGs through the scaling up of evidence-based interventions can have the unintended effect of undermining the development of social, local, and structural interventions.[32] As we have shown here, a robust human rights approach to global mental health refuses one-size-fits-all solutions, is grounded in epistemic humility, and creates mechanisms and policies for protecting the liberties that allow for human dignity. Certainly, not all mental health obstacles are structural, but large-scale transformations and improvements in population health will not be achieved if we continue to view mental illness as a universal and technical problem that can be ameliorated by closing the treatment gap.[33]

As human rights scholar and activist Alicia Ely Yamin argues, we are at a critical inflection point in human rights, and what is needed is "epistemic disobedience."[34] This is because, as Yamin rightly notes, there is a complex and ambivalent relationship between biomedicine and human rights. Too often in health, the language of rights is invoked without critical reflection on what the experts are assuming constitutes a right to a healthy life. The call to "scale up the diagnosis and treatment of mental disorders" is an example of the seductive neutrality of the way in which the language of human rights is invoked in mental health. The assumption is that if everyone everywhere had the right to (Western) psychiatric assessments and treatment, the world would be a much better place and a human rights-based approach would be brought to fruition. However, as we have argued here, a genuinely transformative (and decolonial) human rights approach to mental health requires us to problematize the framing of the problem (e.g., "the global burden of mental disorders"). Problematizing the frame is the first step in animating our political imaginations and addressing the sociopolitical determinants of well-being.

References

1. N. Votruba and G. Thornicroft, "Sustainable Development Goals and Mental Health: Learnings from the Contribution of the FundaMentalSDG Global Initiative," *Global Mental Health* 3 (2016).
2. T. Izutsu, A. Tsutsumi, H. Minas, et al., "Mental Health and Wellbeing in the Sustainable Development Goals," *Lancet Psychiatry* 2/12 (2015); C. Mills, "From 'Invisible Problem' to Global Priority: The Inclusion of Mental Health in the Sustainable Development Goals," *Development and Change* 49/3 (2018).
3. S. Korac, "Joint Explanation of Position at the Adoption of a GA Resolution; 'Mental Health and Psychosocial Support for Substantiable Development and Peace,'" United States Mission to the United Nations (June 26, 2023), https://usun.usmission.gov/joint-explanation-of-position-at-the-adoption-of-a-ga-resolution-mental-health-and-psychosocial-support-for-substantiable-development-and-peace/; "#StoppsychiatrizingSDGs," TCI Global (April 2023), https://tci-global.org/stoppsychiatrizingsdgs/.
4. T. Beeker, C. Mills, D. Bhugra, et al., "Psychiatrization of Society: A Conceptual Framework and Call for Transdisciplinary Research," *Frontiers in Psychiatry* 12 (2021).
5. R. Jenkins, "Global Mental Health and Sustainable Development 2018," *BJPsych International* 16/2 (2019).
6. J. J. Amon, "Realizing the Right to Health: A Long and Winding Road," *Health and Human Rights Journal* 25/2 (2023).
7. C. Bayetti, P. Bakhshi, B. Davar, et al., "Critical Reflections on the Concept and Impact of 'Scaling Up' in Global Mental Health," *Transcultural Psychiatry* 60/3 (2023).
8. S. Fernando, *Mental Health Worldwide: Culture, Globalization and Development* (Basingstoke: Palgrave Macmillan, 2014); C. Mills, *Decolonizing Global Mental Health: The Psychiatrization of the Majority World* (London: Routledge, 2014); S. William and C. Lang (eds), *The Movement for Global Mental Health: Critical Views from South and Southeast Asia* (Amsterdam: Amsterdam University Press, 2021); G. Limenih, A. MacDougall, M. Wedlake, and E. Nouvet, "Depression and Global Mental Health in the Global South: A Critical Analysis of Policy and Discourse," *International Journal of Social Determinants of Health and Health Services* 54/2 (2024); S. Wildeman, "Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities," *Journal of Law, Medicine and Ethics* 41/1 (2013); S. Wildeman, "Disabling Solitary: An Anti-Carceral Critique of Canada's Solitary Confinement Litigation," in C. Spivakovsky, L. Steele, and P. Weller (eds), *The Legacies of Institutionalization: Disability, Law and Policy in the "Deinstitutionalised" Community* (Oxford: Hart, 2020).
9. ENNHRI, the European Network of National Human Rights Institutions, *Aligning Poverty Reduction & Measurement with Human Rights & SDGs* (2019), http://ennhri.org/wp-content/uploads/2019/09/Leaflet-Aligning-Poverty-Reduction-Measurement-with-Human-Rights-SDGs.pdf; United Nations Sustainable Development Group, "Human Rights-Based Approach," https://unsdg.un.org/2030-agenda/universal-values/human-rights-based-approach; United Nations Population Fund, "Human Rights Principles," https://www.unfpa.org/resources/human-rights-principles.
10. A. R. Chapman, "The Social Determinants of Health, Health Equity, and Human Rights," *Health and Human Rights Journal* 12/2 (2010).
11. R. Lyus, C. Buamah, A. M. Pollock, et al., "Global Burden of Disease 2017 Estimates for Major Depressive Disorder: A Critical Appraisal of the Epidemiological Evidence," *JRSM Open* 14/9 (2023).
12. World Health Organization, *Depression and Other Common Mental Disorders: Global Health Estimates* (Gene-

va: World Health Organization, 2017), p. 5.

13. D. Hodgetts, O. Stolte, C. Sonn, et al., *Social Psychology and Everyday Life* (London: Red Globe Press, 2020); G. Gombos, "Global Movement for Mental Health: A Well-Paved Road to Hell?" (September 3, 2008), https://gabor-in-india.blogspot.com/2008/09/global-movement-for-mental-health-well.html.

14. Human Rights Council, Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/41/34 (2019); C. Campbell and R. Burgess, "The Role of Communities in Advancing the Goals of the Movement for Global Mental Health," *Transcultural Psychiatry* 49/3–4 (2012); C. Williams and A. R. Chapman, "Impact of Human Rights Council Reports on Mental Health," *Health and Human Rights Journal* 24/2 (2022).

15. A. Sen, "The Idea of Justice," *Journal of Human Development* 9/3 (2008); T. Pfister, "Citizenship and Capability? Amartya Sen's Capabilities Approach from a Citizenship Perspective," *Citizenship Studies* 16/2 (2012).

16. A. R. Chapman, "Assessing the Universal Health Coverage Target in the Sustainable Development Goals from a Human Rights Perspective," *BMC International Health and Human Rights* 16 (2016); M. C. Nussbaum, "Creating Capabilities: The Human Development Approach and Its Implementation," *Hypatia* 24/3 (2009).

17. L. J. Kirmayer, S. Dandeneau, E. Marshall, et al., "Rethinking Resilience from Indigenous Perspectives," *Canadian Journal of Psychiatry* 56/2 (2011).

18. H. Bhakuni and S. Abimbola, "Epistemic Injustice in Academic Global Health," *Lancet Global Health* 9/10 (2021).

19. C. R. Montenegro and F. Ortega, "Thinking beyond Implementation: Context and Culture in Global Mental Health," *BMJ Global Health* 5/12 (2020).

20. S. Abimbola, S. Asthana, C. Montenegro, et al., "Addressing Power Asymmetries in Global Health: Imperatives in the Wake of the COVID-19 Pandemic," *PLoS Medicine* 18/4 (2021).

21. C. Okoroji, T. Mackay, D. Robotham, et al., "Epistemic Injustice and Mental Health Research: A Pragmatic Approach to Working with Lived Experience Expertise," *Frontiers in Psychiatry* 14 (2023); P. Stastny, A. M. Lovell, J. Hannah, et al., "Crisis Response as a Human Rights Flashpoint: Critical Elements of Community Support for Individuals Experiencing Significant Emotional Distress," *Health and Human Rights Journal* 22/1 (2020).

22. Bayetti et al. (see note 7).

23. Human Rights Council, Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/35/21 (2017).

24. Lyus et al. (see note 11).

25. D. A. Summerfield, "Western Depression Is Not a Universal Condition," *British Journal of Psychiatry* 211/1 (2017).

26. D. Barrett, J. Hannah, and R. Lines, "What Does It Mean to Adopt a Human Rights-Based Approach to Drug Policy?," *Health and Human Rights Journal* 22/1 (2020).

27. A. Sen, *Development as Freedom* (New Delhi: Oxford University Press, 2016).

28. Bayetti et al. (see note 7).

29. G. Lasco and L. E. Yarcia, "The Politics of Drug Rehabilitation in the Philippines," *Health and Human Rights Journal* 24/1 (2022).

30. L. Steele, *Disability, Criminal Justice and Law: Reconsidering Court Diversion* (New York: Routledge, 2020).

31. E. Reinhart, "Medicine for the People," *Boston Review* (November 14, 2022), https://www.bostonreview.net/articles/eric-reinhart-accompaniment-and-medicine/.

32. Bayetti et al. (see note 7).

33. L. Cosgrove and A. F. Shaughnessy, "Mental Health as a Basic Human Right and the Interference of Commercialized Science," *Health and Human Rights Journal* 22/1 (2020); A. Chapman, C. Williams, J. Hannah, and D. Pūras, "Reimagining the Mental Health Paradigm for Our Collective Well-Being," *Health and Human Rights Journal* 22/1 (2020); K. Applbaum, "Solving Global Mental Health as a Delivery Problem: Toward a Critical Epistemology of the Solution," in L. J. Kirmayer, R. Lemelson, and C. A. Cummings (eds), *Re-Visioning Psychiatry: Cultural Phenomenology, Critical Neuroscience, and Global Mental Health* (Cambridge: Cambridge University Press, 2015).

34. A. E. Yamin, "Struggles for Human Rights in Health in an Age of Neoliberalism: From Civil Disobedience to Epistemic Disobedience," *Journal of Human Rights Practice* 11/2 (2019).

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PERSPECTIVE

Their Body, Our Choice: Organized Medicine's Responsibility to De-medicalize Abortion

AMIRALA S. PASHA AND ROMA SONIK

Introduction

Overmedicalization describes the overreliance on medical terminology and frameworks to explain, assess, and address an issue.[1] There is consensus among some scholars that reproductive health care and, in particular, abortion have been overmedicalized, resulting in a devaluation of pregnant persons' autonomy and increasing health disparities in access to reproductive health care.[2] These scholars have also advocated for de-medicalizing abortion to protect reproductive health rights, including expanded access to self-managed abortion, by emphasizing bodily autonomy and emancipation.[3]

One likely contributing factor to this overmedicalization is organized medicine's improper overemphasis on the patient-physician relationship rather than patient autonomy as the focal point of its advocacy to preserve and expand reproductive health care rights. Consequently, organized medicine can play a central role in de-medicalizing abortion by focusing instead on the pregnant person's autonomy. We consider organized medicine to broadly encompass large physician organizations that advocate for physicians and patients, while observing that organized medicine is not solely to blame for this phenomenon.[4]

In this essay, we review the overmedicalization of abortion from a historical perspective. We outline how organized medicine has contributed to this phenomenon and why continued overmedicalization devalues legal rights, questions pregnant persons' autonomy, and hinders efforts to expand access to reproductive health care. Finally, we call on organized medicine to adopt policies to de-medicalize abortion and, ultimately, to recognize individuals' right to autonomy and personal decision-making independent of the medical establishment.

Amirala S. Pasha, DO, JD, is an assistant professor of medicine at the Mayo Clinic, Rochester, United States.

Roma Sonik is a medical student at the Mayo Clinic Alix School of Medicine, Rochester, United States.

Please address correspondence to Amirala Pasha. Email: pasha.amirala@mayo.edu.

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Discussion

A fundamental pillar of contemporary bioethics is respecting autonomy, which is defined as the duty to protect and foster a person's free and uncoerced choices.[5] Autonomy emphasizes the person's individual right to make decisions. Consequently, any attempt to subvert or dilute the right of the individual to make decisions is in direct conflict with the right to autonomy. As seen in reproductive health care, especially with the provision of abortion, one such dilution of individual rights occurs by *requiring* a clinician's input in what is ultimately supposed to be the pregnant person's decision.

From a historical perspective, the overreliance on the clinician for decision-making in the abortion context can be considered a relatively novel development. Before the 1820s, under common law in the United States, abortion was generally legal up until "quickening," a relative point in pregnancy during which the pregnant person feels fetal movement.[6] Although similar to current gestational limits on abortion, quickening was a different type of legal limit, the pregnant person was the sole decision-maker of whether that threshold had passed, in contrast to today, where the medical establishment makes that determination.

An egregious example of overreliance on the clinician's judgment over a pregnant person's autonomy can even be found in the *Roe v. Wade* decision. In *Roe*, Justice Blackmun wrote, "the attending physician, in consultation with his patient, is free to determine, without regulation by the State, that, in his medical judgment, the patient's pregnancy should be terminated."[7] *Roe* charged the "attending physician" with the role of the decision-maker and, at most, recognized the pregnant person as an advisor in the process.

As a society, we have progressed in how we frame a pregnant person's autonomy since *Roe*. Minnesota's Protect Reproductive Options Act—which was enacted as part of new sweeping legal protections for reproductive rights in response to the 2022 *Dobbs v. Jackson Women's Health Organization* decision that eliminated the right to abortion as a fundamental constitutional right—is one example.[8] The act states that "every *individual* has a fundamental right to make *autonomous* decisions about the individual's own reproductive health, including the fundamental right to use or refuse reproductive health care" and "every *individual* who becomes pregnant has a fundamental right to continue the pregnancy and give birth, or obtain an abortion, and to make *autonomous* decisions about how to exercise this fundamental right."[9] Another example is California's Proposition 1, which was overwhelmingly approved by voters in 2022 and amended the California Constitution to establish a right to reproductive freedom.[10] The amendment states, "The state shall not deny or interfere with an *individual's* reproductive freedom in their most intimate decisions, which includes their fundamental right to choose to have an abortion and their fundamental right to choose or refuse contraceptives."[11] The focus on the individual and their autonomy in both examples is to identify the rights holder as the individual (i.e., the pregnant person), notably without any reference to clinicians or the medical establishment.

Despite societal and legal advances in how autonomy is viewed, organized medicine continues to lag in its response. Organized medicine has been rightfully active in sounding the alarm over the consequences of *Dobbs* on reproductive health rights. However, for many decades, organized medicine has inappropriately advocated for the incorporation of clinicians' perspectives as a part of the calculus of an autonomous right of the pregnant person, contributing to the overmedicalization of abortion. It did so even in the framing of its *Dobbs* refutations, where organized medicine anchored its advocacy on the practice of medicine rather than the pregnant person's autonomous choice.[12] For illustration, Table 1 includes public statements issued in response to the *Dobbs* decision by three of the largest medical organizations in the United States, collectively with over 500,000 members.[13] The table also includes our analysis of these statements and our recommended modifications to reframe the right to an abortion as an autonomous choice rather than continuing to dilute this right by unnecessarily incorporating the medical establishment and contributing to overmedicalization.

Beyond public statements made immediately after the release of the *Dobbs* decision, the well-intended permanent policy changes in response to this decision also continue to perpetuate overmedicalization. For instance, post-*Dobbs*, the American Medical Association amended its Ethics Opinion 4.2.7 on abortion to read, "Like all health care decisions, a decision to terminate a pregnancy should be made *privately within the relationship of trust between patient and physician* in keeping with the patient's unique values and needs and the physician's best professional judgment"—again, demanding the incorporation of a physician's judgment into what should really be the pregnant person's decision.[14]

By toeing the line of placating advocates on both sides and morphing "women's choice" into a decision made under the watchful eye of a clinician, organized medicine may hope that abortion access will be viewed as a well-overseen, irrefutably ethical practice. However, this approach has diluted pregnant persons' autonomy by aggrandizing the role of clinicians in the decision-making process. Consequently, over the years, the clinician's role has transformed into an arbiter of legal rights and a required party to the decision-making process, in direct conflict with the bioethical view of autonomy and reproductive rights.

Previous successes

Organized medicine's focus on the practice of medicine and clinicians' rights rather than pregnant persons' autonomy may, in part, be due to its previous legal successes in protecting access to abortion. For instance, in *Stuart v. Camnitz*, state restrictions on abortion were successfully challenged by claiming violation of physicians' rights and corruption of medical practice.[15] However, the precedent it sets is "a legal ruling focused on only one person in the doctor-patient dyad, and it was not the pregnant woman."[16] Despite such limited physician-centric abortion protection wins, the more significant national abortion protections that ought to find a basis in autonomy are upended, as evidenced by the *Dobbs* decision. Organized medicine's current approach may have won some battles but lost the war.

By assuming that medicalizing abortion will force legislators to stay out of the exam room, not only has organized medicine fumbled the strategic importance of emphasizing autonomy for the long-term protection of all, but it has also effectively and paternalistically extolled the roles of clinicians in the process. Even prior to the *Dobbs* decision, schol-

TABLE 1. Analysis of statements released by three of the largest medical organizations in response to the Dobbs decision, along with recommended modifications to emphasize autonomy rather than contribute to overmedicalization

Organization	Original public statement*	Analysis	Recommended statement
American Medical Association	"[A]n egregious allowance of government intrusion into the medical examination room, a direct attack on the practice of medicine and the patient-physician relationship, and a brazen violation of patients' rights to evidence-based reproductive health services."	The statement emphasizes the medical profession and the clinician's role three times, rather than focusing on pregnant persons' autonomy.	"An egregious allowance of government intrusion into private and intimate decisions of individuals."
American Academy of Family Physicians	"[N]egatively impacts our practices and our patients by undermining the patient-physician relationship and potentially criminalizing evidence-based medical care."	The statement focuses on the patient-physician relationship and provision of medical care rather than pregnant persons' autonomy.	"Negatively impacts the ability of individuals to make private and intimate decisions."
American College of Physicians	"A patient's decision about whether to continue a pregnancy should be a private decision made in consultation with a physician or other health care professional, without interference from the government."	The statement appears to require a consultation with a "physician or other health care professional" for a pregnant person to make a decision about continuing their pregnancy.	"A pregnant person's decision about whether to continue a pregnancy should be private, without interference from the government."

* Source: M. K. Wynia, "Professional Civil Disobedience: Medical-Society Responsibilities after Dobbs," *New England Journal of Medicine* 387/11 (2022).

ars such as Lois Shepherd and Hilary Turner noted that "constitutional law vests the government and sometimes the medical profession with the power to protect women's health, not women themselves," and organized medicine is partially to blame.[17]

Practical implications

Beyond the bioethical implications of the overmedicalization of abortion, overmedicalization has real-life consequences for pregnant persons, especially as stakeholders seek to find legal pathways to rectify the negative impact of *Dobbs* on access to reproductive health care. It can hinder these efforts if personal decisions around pregnancy continue to be framed around the patient-clinician relationship rather than the pregnant person's individual autonomous choice. This is especially concerning for its potential to negatively impact self-managed abortions, defined as any action that is taken to end a pregnancy outside of the formal health care system.[18] For instance, in light of data clearly demonstrating that the use of mifepristone and misoprostol requires little to no intervention by clinicians at least until the 10th week of gestation, the Food and Drug Administration has been urged to approve over-the-counter (OTC) sale of these medications to enable safer and more effective access to self-managed abortions, especially in abortion-restrictive jurisdictions.[19] Moreover, the Food and Drug Administration approved the first daily oral contraception pill for use without a prescription in the summer of 2023.[20] However, the current framework for autonomy in reproductive health care adopted by organized medicine requiring clinician involvement is in direct conflict with OTC access to contraceptives and abortion pills despite ample evidence supporting their safety and effectiveness.[21] This is especially troubling since the pregnant persons who would benefit the most from OTC access are from marginalized communities, thereby resulting in adverse health equity implications.[22]

Additionally, restrictive states have used the overmedicalization of abortion to pass laws intending to restrict abortion access under the guise of regulating medicine, requiring medical evaluations when data clearly indicate that such evaluations may not be medically necessary. By contrast, if the focus remained on autonomy, such laws would be less likely to be introduced in the first place. Instead of providing accessible care, overmedicalizing this process has increased barriers to care.[23]

Conclusion

Perhaps organized medicine simply needs to be made aware that its attempts to interject the medical profession into conversations about pregnant persons' autonomy can be detrimental to the very ends it hopes to achieve. Maybe the medical community intentionally incorporates the clinician's role into their advocacy to "stay in their lane," even though autonomy is the cornerstone of bioethics, and safeguarding autonomy thus sits squarely in the realm of organized medicine. Or, possibly, previous one-off successes in outcomes of individual cases while employing a physician-centric approach have blinded organized medicine to the bigger battle over autonomy. None of these possibilities justify ignoring the importance of centering the efforts on individuals' autonomy.

Attempts to include clinicians as a necessary part of the decision-making process detract from the moral authority of the decision-maker herself. Predicating personal decision-making on decisional expertise does not protect our vulnerable patients—it infantilizes them. It justifies questioning and stripping away an individual's autonomy, which may hinder efforts to expand access to those who most need it. This is not to say that clinicians cannot or should not play a role in their patients' important medical decisions, nor is it intended to eliminate the clinician's agency. Rather, it is to shift the debate to recognize the autonomous choices of the individual. This recognition is crucial to establishing the individual as the central authority of decision-making in the clinical setting and the rights holder in the legal domain. Finally, this is not a call to adopt new bioethical policies but a call to adopt positions that are in line with current bioethical principles and understandings of autonomy.

Therefore, it is imperative that organized medicine reevaluate its approach to autonomy, especially in reproductive health care. Both in court and in public, organized medicine must adopt stances in line with the bioethical principle of respecting autonomy that focus on the individual's autonomy rather than the patient-clinician relationship or the provision of medical care alone.

References

1. D. H. Broom and R. V. Woodward, "Medicalisation Reconsidered: Toward a Collaborative Approach to Care," *Sociology of Health and Illness* 18/3 (1996); M. Bul, "Secularization and Medicalization," *British Journal of Sociology* 41/2 (1990).
2. B. J. Hill, "De-medicalizing Abortion", *American Journal of Bioethics* 22/8 (2022).
3. Ibid.
4. M. J. Kahn, N. Baum, and M. S. Ellis, "Organized Medicine," in N. Baum and M. Kahn (eds), *The Business Basics of Building and Managing a Healthcare Practice* (Cham: Springer Nature, 2020), p. 53.
5. L. S. Sulmasy, T. A. Bledsoe, and ACP Ethics, Professionalism and Human Rights Committee, "American College of Physicians Ethics Manual: Seventh Edition," *Annals of Internal Medicine* 170/2_Suppl (2019); Whalen v. Roe, 429 U.S. 589 (1977).
6. M. J. O'Dowd and T. M. O'Dowd, "Quickening: A Re-evaluation," *British Journal of Obstetrics and Gynaecology* 92/10 (1985).
7. Roe v. Wade, 410 U.S. 113, 163 (1973).
8. Minn. Stat. § 145.409 (2023); Dobbs v. Jackson Women's Health Organization, 597 US _ (2022).
9. Minn. Stat. § 145.409 (see note 8) (emphasis added).
10. M. Gutierrez, "Californians Vote to Protect Abortion Rights with Prop. 1," *Los Angeles Times* (November 9, 2022), https://www.latimes.com/california/story/2022-11-08/2022-california-election-proposition-1-abortion-rights-results.
11. Cal Const, Art. I § 1.1 (emphasis added).
12. M. K. Wynia, "Professional Civil Disobedience: Medical-Society Responsibilities after Dobbs," *New England Journal of Medicine* 387/11 (2022).
13. American College of Physicians, "Four Leading Medical Organizations Urge Congress to Protect Patients' Access to Health Care" (2023), https://www.acponline.org/acp-newsroom/four-leading-medical-organizations-urge-congress-to-protect-patients-access-to-health-care; American Medical Association, "AMA Fact Sheet on Its Decade of Membership Growth" (2021), https://www.ama-assn.org/system/files/2021-06/ama-10-years-2021-fact-sheet.pdf.
14. American Medical Association, *AMA Code of Medical Ethics*, opinion 4.2.7, https://code-medical-ethics.ama-assn.org/ethics-opinions/abortion (emphasis added).
15. Stuart v. Camnitz, 774 F.3d 238 (4th Cir. 2014).
16. L. Shepherd and H. D. Turner, "The Over-Medicalization and Corrupted Medicalization of Abortion and Its Effect on Women Living in Poverty," *Journal of Law, Medicine and Ethics* 46/3 (2018).
17. Ibid.
18. N. Verma and D. Grossman, "Self-Managed Abortion in the United States," *Current Obstetrics and Gynecology Reports* 12/2 (2023).
19. A. R. A. Aiken, E. P. Romanova, J. R. Morber, and R. Gomperts, "Safety and Effectiveness of Self-Managed Medication Abortion Provided Using Online Telemedicine in the United States: A Population Based Study," *Lancet Regional Health: Americas* 10 (2022); L. A. Grossman, "Freedom Not to See a Doctor: The Path toward Over-the-Counter Abortion Pills," *Wisconsin Law Review* 4 (2023).
20. US Food and Drug Administration, "FDA Approves First Nonprescription Daily Oral Contraceptive" (July 13, 2023), https://www.fda.gov/news-events/press-announcements/fda-approves-first-nonprescription-daily-oral-contraceptive.
21. Aiken et al. (see note 19).
22. Verma and Grossman (see note 18).
23. Aiken et al. (see note 19).

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VIEWPOINT

Drone Attacks on Health in 2023: International Humanitarian Law and the Right to Health

JOSEPH J. AMON AND LEONARD RUBENSTEIN

In May, the Safeguarding Health in Conflict Coalition (SHCC) and Insecurity Insight issued their 2023 report on attacks on health.[1] The report identifies 2,562 incidents of violence against or obstruction of health care in conflicts in 2023, a 25% increase from 2022, and the highest ever since the coalition began reporting on attacks in 2014.

The incidents documented—arrests, kidnappings, and killings of health workers, damage to or destruction of health facilities, and targeting of ambulances—occurred in 30 countries or territories, with the most intense violence occurring in conflicts in Gaza, Sudan, Myanmar, Ukraine, and Haiti. Countries in the Sahel region of Africa also experienced ongoing attacks and insecurity.

Overall, more than 480 health workers—doctors, nurses, ambulance drivers, pharmacists, lab technicians, paramedics, and psychologists—were killed in 2023, almost double the number reported in 2022. Both government forces and nonstate armed groups were responsible for attacks. In addition, in violation of international humanitarian law, health facilities were frequently occupied or repurposed for military use.[2]

Drone attacks

As drones are increasingly used in conflict globally, they are increasingly being used to target health facilities. The 2023 SHCC report documents and describes drone attacks in eight countries: Burkina Faso, Ethiopia, Myanmar, the Occupied Palestinian Territory, Sudan, Syria, Ukraine, and Yemen.

In Burkina Faso, in April, the Sabouna Health and Social Promotion Center in Nord region was hit in a government military drone strike. The following month, an ambulance evacuating a pregnant woman was

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Joseph J. Amon, PhD, MSPH, is director of the Office of Global Health and a clinical professor at Drexel University Dornsife School of Public Health, Philadelphia, United States; editor-in-chief of *Health and Human Rights*; and a member of the Safeguarding Health in Conflict Coalition's Steering Committee.

Leonard Rubenstein, JD, LLM, is distinguished professor of the practice, Johns Hopkins Bloomberg School of Public Health, Baltimore, United States, and chair of the Safeguarding Health in Conflict Coalition.

Please address correspondence to Joseph J. Amon. Email: jja88@drexel.edu.

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hit in another government drone strike on a JNIM checkpoint in Centre-Est, which killed her and three health workers. In both strikes, Turkish-made Bayraktar TB2 drones, which often use munitions with wide-area effects, were used, resulting in damage to health targets and neighboring structures, including homes, schools, and businesses.

In Ethiopia, in November, the Ethiopian National Defense Force carried out two drone strikes in the Amhara region. The first strike hit an ambulance transporting medicine, killing an ambulance driver and pharmacist, wounding the head administrator of a hospital, and destroying the ambulance. The second drone strike hit Goshiamba Kebele, not far from the scene of the first incident. These attacks followed five strikes conducted by the Ethiopian National Defense Force in Tigray between December 2021 and October 2022, which killed two health workers, injured seven, damaged one hospital, and destroyed another.

In Myanmar, 418 incidents of violence against or obstruction of health care were documented in 2023, resulting in 37 health worker deaths; 102 health worker arrests; 53 incidents where health facilities were occupied; and 133 damaged or destroyed health facilities. Included in these incidents were 26 drone attacks on health facilities. Unlike most other conflicts, in Myanmar, local resistance forces were identified using drones armed with explosive weapons to attack Myanmar armed forces occupying health facilities. For example, the Ye-U Traditional Medicine Hospital in Ye-U township, Sagaing region, which was occupied by the Myanmar armed forces, was damaged on seven separate occasions in July, September, October, and November, with all of these incidents attributed to armed resistance groups.

In the Occupied Palestinian Territory, in 2023, there were at least 309 incidents of violence against health care by the Israeli Defense Forces, including 61 involving ground-launched missiles, rockets, and shelling and four drone attacks occurring between November 6 and December 24, damaging Al-Shifa Hospital, Kamal Adwan Hospital, and the Palestine Red Crescent Society Al-Amal Hospital.

In Sudan, 257 incidents of violence against or obstruction of health care were documented in 2023, compared to 54 in 2022. In these incidents, 56 health workers were killed, medicines were looted, and health facilities were damaged, destroyed, and occupied. Nine cases were recorded of air-launched explosive weapons impacting health care in Khartoum. Seven involved Sudan Air Force military aircraft dropping explosive weapons in residential areas that damaged hospitals and medical centers, and two cases involved drones armed with explosives. Both drone attacks targeted hospitals and were attributed to the Rapid Support Forces, a Sudanese paramilitary group.

In Syria, incidents involving explosive weapons use affecting health care doubled in 2023 compared to 2022. Most incidents involved air-launched explosive weapons use, but Turkish forces also used drones armed with explosives, destroying and damaging health facilities, including Meshtanour Medical Centre and a pharmacy, and killing a doctor.

In Ukraine, 109 health workers were killed, health facilities were damaged or destroyed on at least 192 occasions, and Russian military forces occupied health facilities 36 times in 2023. Russian forces used drones armed with explosives in 17 documented incidents, compared to two in 2022, and attacks were recorded in Khersonska, Kyivska, Odeska, Zaporizka, and Kharkivska oblasts.

In Yemen, five cases recorded the use of drones armed with explosives in attacks on health care in Al Dali, Al Hudaydah, Dhamar, Sanaa, and Ta'izz governorates in 2023. Previously, only one case, in Marib governorate in 2021, had been documented. Three cases recorded Houthi rebels using drones to drop mortar bombs that damaged two clinics and a Southern Transitional Council military ambulance.

Addressing attacks on health

Comprehensively documenting attacks on health is complicated by many challenges, including insecurity, limited access and communication in conflict settings, and lack of reporting. The numbers reported in the 2023 SHCC report are undoubtedly an undercount.

Some authors have suggested that the problem should be tackled like any other public health issue—by improving our understanding of the scale and scope of the problem, identifying those most vulnerable, and developing effective interventions to prevent the risks.[3] While undoubtedly each of these steps should be taken, other steps to strengthen respect for international humanitarian law and end impunity are critically important as well. The SHCC report includes several recommendations toward ending attacks on health, and impunity for attacks, including the following:

- The International Criminal Court and national courts, through principles of universal jurisdiction, should initiate prosecutions for war crimes and crimes against humanity involving attacks on the wounded and sick and on health facilities.
- Governments should cease arms transfers to parties to conflict that engage in grave breaches of international humanitarian law.
- Ministers of health should engage with their own military and security forces and armed groups to protect health care from violence and strengthen mechanisms to mitigate the impacts of attacks on communities, health workers, and health systems.
- Regional bodies and the United Nations humanitarian cluster system should expand initiatives to protect health care in conflict and mitigate the impact of violence against it.

In addition, prosecutors domestically and internationally should bring cases of war crimes and crimes against humanity against those who commit attacks on health, and special tribunals should be established to hear cases of attacks on health—and to circumvent United Nations Security Council members' vetoes of referrals to the International Criminal Court.

Attacks on health facilities, personnel, and transport also have an impact on the right to health broadly, as the destruction of health facilities, the killing of health workers, and other impacts on health systems interrupt the ability of people to access care and prevention services and to realize the highest attainable standard of physical and mental health.[4] Equally important, as Katherine Footer and Leonard Rubenstein point out, attacks on health can occur in the absence of formally identified conflict settings, limiting the reach of international humanitarian law.[5] In these settings, and in the aftermath of conflict, health care workers may nonetheless face hostility and physical and psychological injury, which limits their ability to provide care, and individuals may avoid seeking care in health facilities because of the history or threat of violence.

International human rights law obligates states to respect, protect, and ensure the right to health for all, including in conflict settings. The Committee on Economic, Social and Cultural Rights, which provides authoritative interpretation of the International Covenant on Economic, Social and Cultural Rights, has recognized the impact of conflict and violence on health and thereby states' obligations to take steps to address violence among other determinants of health, to protect health workers and patients from harm, and to ensure that health facilities are available and accessible to all.[6]

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References

1. Safeguarding Health in Conflict Coalition and Insecurity Insight, *Critical Condition: Violence against Health Care in Conflict 2023* (Baltimore: Safeguarding Health in Conflict Coalition, 2024).

2. International Committee of the Red Cross, "International Humanitarian Law Databases: Rule 28; Medical Units," https://ihl-databases.icrc.org/en/customary-ihl/v1/rule28#.

3. K. Blanchet, L. Rubenstein, B. Taithe, and L. Fast,

"Have Attacks on Healthcare Become the New Normal? A Public Health Call to Action for Armed Conflicts before It Is Too Late," *Conflict and Health* 17/1 (2023).

4. K. H. Footer and L. S. Rubenstein, "A Human Rights Approach to Health Care in Conflict," *International Review of the Red Cross* 95/889 (2013).

5. Ibid.

6. Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000), para. 10.

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VIEWPOINT

Psychological and Social Suffering of Another Generation of Palestinian Children Living under Occupation: An Urgent Call to Advocate

TANIA BOSQUI, SAWSAN ABDULRAHIM, RIMA A. AFIFI, ALASTAIR AGER, THERESA S. BETANCOURT, ALAN CARR, KRISTIN HADFIELD, GHENA ISMAIL, MARK J. D. JORDANS, SALAM JABBOUR, ZEENA KHAZENDAR, BASSAM MARSHOUD, AND EVE PUFFER

Palestinian children today are the fifth generation to have lived under Israeli occupation, characterized by violence, restricted movement, and displacement. Children in Gaza, referred to as the world's largest "open-air prison" by Human Rights Watch, have been suffering from a decades-long land, air, and sea blockade. In the first 100 days of the most recent Israeli bombardment of Gaza following the October 7 Hamas attack

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Tania Bosqui is at the American University of Beirut, Lebanon, and the Trinity Centre for Global Health, Trinity College Dublin, Republic of Ireland.

Sawsan Abdulrahim is at the Harvard T.H. Chan School of Public Health, Boston, United States, and the American University of Beirut, Lebanon.

Rima A. Afifi is at the University of Iowa, Iowa City, United States.

Alastair Ager is at Queen Margaret University, Edinburgh, UK, and the Mailman School of Public Health, Columbia University, New York, United States.

Theresa S. Betancourt is at the Boston College School of Social Work, United States.

Alan Carr is at University College Dublin, Republic of Ireland.

Kristin Hadfield is at the Trinity Centre for Global Health, Trinity College Dublin, Republic of Ireland.

Ghena Ismail is at the American University of Beirut, Lebanon.

Mark J. D. Jordans is at the War Child Alliance and the University of Amsterdam, the Netherlands.

Salam Jabbour is at the Trinity Centre for Global Health, Trinity College Dublin, Republic of Ireland.

Zeena Khazendar is at Stanford University School of Medicine, United States.

Bassam Marshoud is a freelancer.

Eve Puffer is at the Duke Global Health Institute, Durham, United States.

Please address correspondence to Tania Bosqui. Email: tb33@aub.edu.lb.

Competing interests: None declared.

on Israel, over 20,000 Palestinians were killed, half of them children.[1] In direct contradiction to international human rights law and the Convention on the Rights of the Child, 300,000 homes have been destroyed and over 90% of children under two have been pushed into severe food poverty.[2] Israel's bombardment of Gaza has been called a "children's graveyard" by the United Nations Secretary-General, and the International Court of Justice has ruled that it is "plausible that Israel's acts could amount to genocide."[3] Health care and pathways for humanitarian aid have been systematically blocked, with almost 500 health care workers killed, 26 hospitals damaged or destroyed, and border crossings closed.[4] At the same time, Israeli violence in the West Bank has escalated, including settler attacks, night-time military raids, and detentions. Amidst this horror—and set against a background of accumulated and intergenerational trauma over decades of occupation, settler colonialism, and apartheid—the physical and mental health of the population, particularly children, will inevitably take a devastating hit. This urgent call to *advocate*, written by a group of mental health and public health practitioners and researchers with experience in war-affected settings, is in response to this devastation.

Epidemiological research has identified extremely high rates of anxiety and traumatic stress, as well as externalizing and internalizing symptoms, distress, and "pressure" (known as *daghet nafsi* in Arabic) in Palestinian child populations. Research has directly linked these high rates to exposure to violence, poverty, and insecurity.[5] Prolonged and daily exposure has led Palestinian psychologists to push back against simplified conceptualizations of post-traumatic stress disorder. Samah Jabr, chair of the mental health unit at the Palestinian Ministry of Health, has said that "there is no 'post' because the trauma is repetitive and ongoing."[6] The mass steadfastness (*somoud*) of the Palestinian people, and the remarkable resilience of parents and children, is also well documented. Such resistance in the face of prolonged adversity has been sustained through mechanisms like community cohesion, nurturing families, faith, and active patience (*saber*).[7] However, the transgenerational cyclical patterns of violence exposure, distress, and affected parenting capacity underpin a major contributor to the continuing transmission of suffering across multiple generations.[8] This demonstrates clearly that *there can be no mental health without respect for human rights*.

The protracted nature of adversity suffered by Palestinian children has led to a level of collective and individual suffering that is poorly matched with existing systems of mental health support. Inter-Agency Standing Committee Guidelines on Mental Health and Psychosocial Support in Emergency Settings recommends strengthening protective factors (e.g., coping skills) and addressing risk factors (e.g., exposure to violence), building on existing systems, and integrating across sectors (e.g., health, education).[9] Basic mental health and psychosocial support (MHPSS) interventions in the midst of ongoing violence—such as psychological first aid—have a growing evidence base, including evidence of previous effectiveness in Palestine.[10] However, such interventions cannot be delivered, nor are they likely to be effective, in the context of the extreme conditions of violence currently placed on Palestinian children and their families. Mental health professionals in Palestine have consistently reported the need for a mental health approach focused on human rights and social justice rather than only individual-level coping.[11]

A call to advocate

The psychological and social suffering of Palestinian children and families can never be addressed without *a ceasefire and cessation of occupation*, full protection of human rights, and social equity. As mental health professionals, global citizens, and parents, we must advocate for the human rights of Palestinians and an end to occupation. Anything less will continue to perpetuate generations of individual and collective pain. This is in line with the Inter-Agency Standing Committee's statement of action to avoid worsening the catastrophe.[12] While that is the only acceptable outcome for protecting children, in the immediate term we must advocate for the protection of children under international humanitarian law and the Convention on the Rights of the Child. This call is an urgent request to our international community to advocate for meeting the immediate and long-term needs of children and their families. This includes advocating for the following actions, framed within the human rights-based SAFE model of child protection.[13]

1. **Safety and protection.** At its most basic, respect for children's human rights requires ceasing bombing of schools, residential areas, and hospitals; removing restrictions on humanitarian aid; ending settler violence; and freeing Palestinian children from detention. A sense of security, predictability, and consistency are the most basic emotional needs for healthy child development, essential for cognitive and socio-emotional functioning, and massively impacted by violence and displacement.
2. **Access to basic physiological needs and health care**. Access to water, nutrition, hygiene, shelter, and health care requires access to humanitarian aid, the protection of health care staff and facilities, and freedom of movement. There is no health without mental health, but equally no mental health without health. Sleep, food, and shelter are the most basic human rights and needs, essential for child survival and thriving. Poverty is strongly associated with poor child mental health and development globally, in some cases stronger even than other major contributing factors like trauma exposure.[14]
3. **Family and connection to others.** Protecting and restoring children's family links is essential, particularly for children separated through detainment and military isolation. Family functioning, parent-child relationships, and attachment are strong protective factors for children during armed violence but are also directly affected by displacement and violence.[15]
4. **Education and livelihoods**. The interruption of livelihoods and schooling causes immeasurable harm for parents and children. Poor access to education has been associated with significantly poorer health, mental health, and livelihood outcomes all the way into adulthood.[16] Children must have access to uninterrupted education and vocational opportunity.
5. **Investment in developing a system that responds to the collective long-term mental health needs of children and their families**. Donors must prioritize investment in mental health and psychosocial well-being as central to immediate *and* long-term responses. Following international guidance, contextually relevant mental health systems of support that address the collective needs of the population have never been more pressing.[17] Given population-wide, long-term, transgenerational suffering, it is now that we need to plan and fund a sustainable care system across sectors, integrate MHPSS into schools and health care, ensure adequate referral options, and support civil society organizations offering MHPSS.

By advocating for these urgent actions, we stand in solidarity with children and families in Palestine. We urge readers to stand with us, voice the impact of human rights violations, and call for the urgent end to occupation and violence. The time for focusing on individual frameworks to achieve mental health is over. This means recognizing how ending violence and promoting social justice are intricately and irrevocably tied to the flourishing of mental health.

References

1. Human Rights Watch, "Gaza: Israel's 'Open-Air Prison' at 15" (June 14, 2022), https://www.hrw.org/news/2022/06/14/gaza-israels-open-air-prison-15#:~:text=For%2015%20years%2C%20Palestinians%20in,Gaza%20and%20the%20West%20Bank; Save the Children, "Gaza: 10,000 Children Killed in Nearly 100 Days of War" (January 11, 2024), https://www.savethechildren.net/news/gaza-10000-children-killed-nearly-100-days-war.

2. UNICEF, "Gaza Has Become a Graveyard for Thousands of Children" (October 31, 2023), https://www.unicef.org/press-releases/gaza-has-become-graveyard-thousands-children.

3. Ibid.; Office of the United Nations High Commissioner for Human Rights, "Gaza: ICJ Ruling Offers Hope for

Protection of Civilians Enduring Apocalyptic Conditions, Say UN experts" (January 31, 2024), https://www.ohchr.org/en/press-releases/2024/01/gaza-icj-ruling-offers-hope-protection-civilians-enduring-apocalyptic.

4. Médecins Sans Frontières, "Strikes, Raids and Incursions: Seven Months of Relentless Attacks on Healthcare in Palestine" (May 14, 2024), https://www.msf.org/strikes-raids-and-incursions-seven-months-relentless-attacks-healthcare-palestine.

5. B. El-Khodary and M. Samara, "The Relationship between Multiple Exposures to Violence and War Trauma, and Mental Health and Behavioural Problems among Palestinian Children and Adolescents," *European Child and Adolescent Psychiatry* 29 (2020).

6. Z. Asad, "When There Is No "Post-" to the Trauma: Exploring Continuous Traumatic Stress in Refugee Populations," Gators for Refugee Medical Relief (September 21, 2021), https://www.grmruf.org/blog/2021/9/20/when-there-is-no-post-to-the-trauma-exploring-continuous-traumatic-stress-in-refugee-populations.

7. V. Nguyen-Gillham, R. Giacaman, G. Naser, and W. Boyce, "Normalising the Abnormal: Palestinian Youth and the Contradictions of Resilience in Protracted Conflict," *Health and Social Care Community* 16/3 (2008).

8. K. Qamar, T. Hashmi, T, M. Sadiq, et al., "Mental Health of Children in Palestine: An Intergenerational Crisis," *Asian Journal of Psychiatry* 75 (2022).

9. Inter-Agency Standing Committee, *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings* (Geneva: Inter-Agency Standing Committee, 2007).

10. C. Barbui, M. Purgato, J. Abdulmalik, et al., "Efficacy of Psychosocial Interventions for Mental Health Outcomes in Low-Income and Middle-Income Countries: An Umbrella Review," *Lancet Psychiatry* 7 (2020).

11. M. Diab, G. Veronese, Y. Abu Jamei, et al., "Psychosocial Concerns in a Context of Prolonged Political Oppression: Gaza Mental Health Providers' Perceptions," *Transcultural Psychiatry* 60/3 (2022).

12. Inter-Agency Standing Committee, *Statement by Principals of the Inter-Agency Standing Committee: Civilians in Gaza in Extreme Peril while the World Watches On; Ten Requirements to Avoid an Even Worse Catastrophe* (New York: Inter-Agency Standing Committee, 2024).

13. R. O'Connor, T. S. Betancourt, and N. V. Enelamah, "Safeguarding the Lives of Children Affected by Boko Haram: Application of the SAFE Model of Child Protection to a Rights-Based Situation Analysis," *Health and Human Rights Journal* 23/1 (2021).

14. A. Chen, C. Panter-Brick, K. Hadfield, et al., "Minds under Siege: Cognitive Signatures of Poverty and Trauma in Refugee and Non-refugee Adolescents," *Child Development* 90/6 (2019).

15. S. R. Qouta, M. Vänskä, S. Y. Diab, and R. L. Punamäki, "War Trauma and Infant Motor, Cognitive, and Socioemotional Development: Maternal Mental Health and Dyadic Interaction as Explanatory Processes," *Infant Behavior and Development* 63 (2021).

16. H. Clark, A. M. Coll-Seck, A. Banerjee, et al., "A Future for the World's Children? A WHO–UNICEF–Lancet Commission," *Lancet* 395/10224 (2020).

17. T. Bosqui, "The Need to Shift to a Contextualized and Collective Mental Health Paradigm: Learning from Crisis-Hit Lebanon," *Global Mental Health* 7 (2020).

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VIEWPOINT

US Clinicians Face a "Dual Loyalty" Crisis over Reproductive Health Care

RANIT MISHORI, PAYAL K. SHAH, KAREN NAIMER, AND MICHELE HEISLER

> *As a provider, I am supposed to counsel my patients on risks and benefits, alternatives, and help them navigate through making a decision. And I can't do that ... because it's not allowable and I can go to jail.*[1]

Since the 2022 US Supreme Court decision in *Dobbs v. Jackson Women's Health Organization*, which overturned *Roe v. Wade*, clinicians have been struggling to provide routine medical care and to manage situations where well-established standard practices for patient care are in conflict with new state laws that have expanded legal restrictions on sexual and reproductive health care. This dilemma is known as "dual loyalty."

A growing number of states have imposed restrictions on abortion care, including 14 that have introduced abortion bans with limited or no exceptions and severe civil and criminal penalties against clinicians.[2] Some states are also considering or passing laws that could restrict gender-affirming care and assisted reproductive technologies such as in vitro fertilization.[3]

Clinicians in these states are experiencing an expanding array of dual loyalty conflicts as they attempt to practice patient-centered health care.[4] Clinicians are being forced to choose between providing evidence-based care or obeying new legal prohibitions when treating pregnant patients, including those facing pregnancy-induced medical emergencies or with severe comorbidities. The resulting delays or denial of care is causing devastating harm to patients, moral distress to clinicians, and expanding health inequities.[5]

Ranit Mishori, MD, MHS, MSc, FAAFP, is former senior medical advisor at Physicians for Human Rights (PHR) and currently serves on PHR's Advisory Council. She is an adjunct professor of family medicine at Georgetown University Medical Center, Washington, DC, United States.

Payal K. Shah, JD, is the director of PHR's Program on Sexual Violence in Conflict Zones, New York, United States, and a fellow of the International Reproductive and Sexual Health Law Program, Faculty of Law, University of Toronto, Canada.

Karen Naimer, JD, LLM, MA, serves as PHR's director of programs, New York, United States.

Michele Heisler, MD, MPA, is PHR's medical director and a professor of internal medicine in the Department of Internal Medicine and the Department of Health Behavior and Health Equity at the University of Michigan, Ann Arbor, United States.

Please address correspondence to Ranit Mishori. Email: rmishori@phr.org.

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The concept of dual loyalty encompasses situations in which clinicians and other health care workers find their medical and ethical obligations to their patients in direct conflict with their obligations to a third party, be it a state or employer.[6] Throughout history, powerful state actors have created situations that mandate clinicians to betray their professional ethics. These include participating in or supporting torture, withholding medical care from some individuals and groups, partaking in executions or research studies based on nonconsensual medical experimentation, and forcibly feeding hunger strikers, among other human rights-violating actions.[7]

The challenges faced by clinicians to provide their patients with standard and evidence-based health care also contributes to violations of human rights.[8] These include the rights to life, health, nondiscrimination and equality, freedom from torture and ill-treatment, privacy, reproductive self-determination, and the benefits of scientific progress.[9] Dual loyalty also affects medical specialists who may be forced by current bans to withhold urgently needed care: for example, an oncologist considering chemotherapy for a pregnant cancer patient, a pediatrician assessing a transgender patient for hormone treatment, or an internist treating women for autoimmune disease.[10]

International bodies focused on professional ethics overwhelmingly agree that patients' interests must be centered in the imperative to "do no harm." For example, the World Medical Association's Declaration of Geneva urges physicians to pledge that "the health of my patient shall be my first consideration" and upholds the principle that physicians provide medical services in "full technical and moral independence."[11] The World Medical Association's International Code of Medical Ethics includes the pledge not to use "medical knowledge to violate human rights and civil liberties, even under threat."[12]

To do otherwise risks violating professional and ethical obligations as well as being complicit in violations of a wide range of internationally recognized human rights standards and treaties.[13]

Physicians for Human Rights and other experts have highlighted physicians' responsibility to respect and promote human rights as part of "a social pact in which society and its institutions accord the health professional status, power and prestige in exchange for a guarantee that [physicians] will meet certain standards of practice."[14]

Clinicians have long faced dual loyalty dilemmas and conflicts in their provision of sexual and reproductive health care. Clinician participation—sometimes coerced—in state or institutionally mandated actions such as forced sterilization, forced abortion, forced contraception, forced pregnancy, denial of contraception, and mandatory reporting of pregnant people with evidence of substance use has been extensively documented around the world.[15]

Current dual loyalty challenges in the United States range from limiting, delaying, or denying medical treatment to an individual because of unclear or non-evidence-based state laws to withholding critical services or even information about evidence-based therapeutic interventions and treatments because of state laws.[16]

Clinicians—even those practicing outside restrictive states—face the fear of civil or criminal charges, fines, and loss of medical licensure, among other possible penalties. The threat of violence is also real: US sexual and reproductive health care providers faced significant physical attacks even prior to *Dobbs*. And 2022 saw a 20% increase in death threats and a 229% increase in stalking incidents compared to 2021.[17]

Criminalizing, harassing, abusing, and physically harming health workers create downstream violations of the rights of the patients being served. Such laws, however, endanger the rights of health professionals themselves, including their rights to work, to life, to health, to liberty and security, and to receive and impart information. In addition, such laws may promote moral distress or moral injury among clinicians, with adverse mental health consequences.[18]

Governments have an obligation to create an environment where clinicians can provide health care effectively and safely. Currently, legislators and other officials in some states that respect abortion rights have adopted or are contemplating measures to protect clinicians providing sexual and reproductive health care. Examples include "shield laws" that create protections for clinicians who provide, recommend, or assist others in obtaining abortion services from civil actions of another state; the enforcement of the Freedom of Access to Clinic Entrances Act, which prohibits threats of force, obstruction, and property damage intended to interfere with reproductive health care services; efforts to monitor the impact of abortion bans on the provision of reproductive health care and on health disparities; and the implementation of legislative measures such as federal guidance on the Emergency Medical Treatment and Active Labor Act (EMTALA) that is aimed to secure access to abortion in life-threatening situations even in states where abortion is banned.[19] Yet these protections are continually under attack. For example, EMTALA's protection against prosecution under states laws will be reviewed by the Supreme Court in June 2024.

As efforts to impose restrictions on clinicians' ability to provide evidence-based sexual and reproductive health care continue to expand, it is essential to advocate for greater protections for clinicians and patients at the federal level.[20]

Additionally, and equally critical, the medical, public health, and human rights communities must work to end laws creating the current dual loyalty crisis.[21]

References

1. Center for Reproductive Rights, Lift Louisiana, Reproductive Health Impact, and Physicians for Human Rights, *Legal Retrogression and the Harms of Louisiana's Near Total Abortion Bans: A Report to the Human Rights Committee 139 Session (09 Oct 2023 - 03 Nov 2023), United States* (2023), https://phr.org/wp-content/uploads/2023/10/ICCPR-LA-FF-Shadow-Report_Final.pdf.

2. Center for Reproductive Rights, "After Roe Fell: Abortion Laws by State," https://reproductiverights.org/maps/abortion-laws-by-state/.

3. Human Rights Campaign, "Map: Attacks on Gender Affirming Care by State," https://www.hrc.org/resources/attacks-on-gender-affirming-care-by-state-map; J. Glenza, "Doctors Shocked and Angry as Alabama Ruling Throws IVF Care into Turmoil," *Guardian* (February 23, 2024), https://www.theguardian.com/society/2024/feb/23/fertility-doctors-reaction-alabama-embryo-ruling.

4. Physicians for Human Rights, Oklahoma Call for Reproductive Justice, and Center for Reproductice Rights, *No One Could Say: Accessing Emergency Obstetrics Information as a Prospective Prenatal Patient in Post-Roe Oklahoma* (April 2023); Center for Reproductive Rights et al. (see note 1).

5. N. Westman, J. Brownstein, and B. Rader, "Maternal Care Deserts Overlap with Lack of Abortion Access, Analysis Shows," *ABC News* (August 1, 2023), https://abcnews.go.com/Health/abortion-access-restrictions-affect-maternity-care-access-research/story?id=101770115.

6. Physicians for Human Rights, *Dual Loyalty and Human Rights in Health Professional Practice: Proposed Guidelines and Institutional Mechanisms* (Boston: Physicians for Human Rights, 2002).

7. Ibid.

8. C. Mallory, M. G. Chin, and J. C. Lee, "Legal Penalties for Physicians Providing Gender-Affirming Care," *JAMA* 329/21 (2023).

9. Office of the United Nations High Commissioner for Human Rights, "Access to Safe and Legal Abortion: Urgent Call for United States to Adhere to Women's Rights Convention, UN Committee" (July 1, 2022), https://www.ohchr.org/en/statements/2022/07/access-safe-and-legal-abortion-urgent-call-united-states-adhere-womens-rights; Office of the United Nations High Commissioner for Human Rights, "Sexual and Reproductive Health and Rights," https://www.ohchr.org/en/node/3447/sexual-and-reproductive-health-and-rights.

10. M. Suran, "Treating Cancer in Pregnant Patients After Roe v Wade Overturned," *JAMA* 328/17 (2022); A. S. Wyckoff, "AAP Reaffirms Gender-Affirming Care Policy, Authorizes Systematic Review of Evidence to Guide Update" (August 4, 2023), https://publications.aap.org/aapnews/news/25340/AAP-reaffirms-gender-affirming-care-policy; B. Frederiksen, M. Rae, T. Roberts, and A. Salganicoff, "Abortion Bans May Limit Essential Medications for Women with Chronic Conditions," KFF (November 17, 2022), https://www.kff.org/womens-health-policy/issue-brief/abortion-bans-may-limit-essential-medications-for-women-with-chronic-conditions/.

11. World Medical Association, WMA Declaration of Geneva (2017).

12. Ibid.

13. International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI) (1966); Office of the United Nations High Commissioner for Human Rights, "Committee on the Elimination of Discrimination against Women," https://www.ohchr.org/en/treaty-bodies/cedaw; Office of the

United Nations High Commissioner for Human Rights, "Committee on the Elimination of Racial Discrimination," https://www.ohchr.org/en/treaty-bodies/cerd; Center for Reproductive Rights, *Reproductive Rights Violations as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment: A Critical Human Rights Analysis* (New York: Center for Reproductive Rights, 2010).

14. Physicians for Human Rights (2002, see note 6).

15. Ibid.

16. L. Sánchez, "Abortion Restrictions Force Medical Personnel to Commit Grave Ethical Violations," *Current Affairs* (June 30, 2022), https://www.currentaffairs.org/2022/06/abortion-restrictions-force-medical-personnel-to-commit-ethical-violations.

17. US Department of Justice, Civil Rights Division, "Recent Cases on Violence against Reproductive Health Care Providers" (September 17, 2021), https://www.justice.gov/crt/recent-cases-violence-against-reproductive-health-care-providers; National Abortion Federation, "Violence against Abortion Providers Continues to Rise Following Roe Reversal, New Report Finds" (May 11, 2023), https://prochoice.org/violence-against-abortion-providers-continues-to-rise-following-roe-reversal-new-report-finds/.

18. A. Desai, R. Holliday, M. Wallis, et al., "Policy Changes as a Context for Moral Injury Development in the Wake of Dobbs v Jackson Women's Health Organization," *Obstetrics and Gynecology* 141/1 (2023); E. L. Sabbath, S. M. McKetchnie, K. S. Arora, and M. Buchbinder, "US Obstetrician-Gynecologists' Perceived Impacts of Post-Dobbs v Jackson State Abortion Bans," *Jama Network Open* 7/1 (2023).

19. D. S. Cohen, G. Donley, and R. Rebouché, "Abortion Shield Laws," *NEJM Evidence* 2/4 (2023).

20. L. Dawson, J. Kates, and M. Musumeci, "Youth Access to Gender Affirming Care: The Federal and State Policy Landscape," KFF (June 1, 2022), https://www.kff.org/other/issue-brief/youth-access-to-gender-affirming-care-the-federal-and-state-policy-landscape/.

21. K. Gilmore and V. Boydell, "Defending Frontline Defenders of Sexual and Reproductive Health Rights: A Call to Action-Oriented, Human Rights-Based Responses," *BMJ Global Health* 7/4 (2022).

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BOOK REVIEW

Fighting the (Mis)fortunes in Global Health

REBECCA RIDDELL

When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality, by Alicia Ely Yamin (Stanford University Press, July 2023)

These are difficult days for hope in the struggle for health justice. A United Nations expert, condemning an "unrelenting war" on health systems in Gaza, declared this "the darkest time for the right to health in our lifetimes."[1] Four years after the emergence of a devastating global pandemic, rich countries continue to champion pharmaceutical interests over access to care, and a much-needed pandemic treaty is off track, leading the World Health Organization's Director General to warn that "future generations may not forgive us."[2] Medical breakthroughs that should offer solace are out of reach for many. Consider the sticker price of two new cutting-edge treatments for sickle cell disease—reportedly US$3.1 and US$2.2 million each—unthinkable sums for most, but especially the estimated three-quarters of the world's sickle cell patients who live in Sub-Saharan Africa.[3]

It's quite a moment to pick up Alicia Ely Yamin's excellent book *When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality*. The recently released second edition is an informed, engaging, and deeply insightful stocktaking of limited but real advancements in the right to health, understood in the context of skyrocketing inequality and a prevailing global economic order that has rendered the fulfillment of that right all but impossible.

Yamin starts with the genesis of multilateral rules and institutions following World War II, including the Universal Declaration of Human Rights, but also the Bretton Woods Institutions—designed to entrench US and Western European control over multilateral economic authority. From there, the book moves at a fast clip, canvassing the creation of human rights treaties and developments in the conceptualization and application of the right to health, as well as the simultaneous and relentless march of neoliberal policies and ideas that have undermined the realization of so many rights.

The reader is transported through time and through the world, from Argentina—where Yamin's mother is from—to the United States, Tanzania, Costa Rica, and beyond, meeting the patients, health workers, and advocates whose struggles for care and for justice constitute the heart of the book. Yamin describes her work as a "historical account told through human stories," observing that the stories we tell define the future we create. With her deep expertise in law and public health, and decades of experience as a leading scholar and practitioner, it's hard to imagine a better storyteller.

Rebecca Riddell is the policy lead for economic and racial justice at Oxfam America and counsel to the Human Rights and Privatization Project at New York University School of Law's Center for Human Rights and Global Justice, New York, United States.

When Misfortune Becomes Injustice is a damning critique of the political economy that got us here—the rounds of structural adjustment, austerity, privatization, and financialization that have weakened states' capacity to provide public health care and embedded deeply unequal systems that segregate access to care.

Again and again, communities and researchers have shown how heavily privatized and commodified systems stratify, exclude, and impoverish. Globally, catastrophic spending on health care has been rising for two decades, and according to the latest data, health costs pushed 1.3 billion people into poverty in 2019.[4] This book is yet more evidence of the challenge of reconciling our status quo, where access to health care is often dependent on access to resources, with human rights guarantees of nondiscrimination and affordable care for all.[5]

Large companies also come in for rebuke, with good reason. For many of world's biggest companies, health care is an asset, not a right.[6] These are major players in the global economy who charge massive markups, avoid taxes, exert undue influence over politics, and funnel extreme profits to those who own shares (shares that are, of course, highly concentrated among the very richest—consider that the world's richest 1% owns 43% of global assets).[7] As I have written elsewhere, such companies have been aided and abetted by high-income countries shamelessly promoting their own private sector as a development solution, despite the poor and tragic outcomes associated with this approach.[8]

The book's interdisciplinary lens speaks to the virtues of the human rights framework, with its demand to look beyond individual biology and behavior and toward the systems—health care but also economic, political, social, and legal—that shape our health. Yamin vividly captures the grave injustice of inequalities in health, including along lines of race, class, and gender. She compares, for example, the decades-wide gap between average life spans in Swaziland and those in Japan, but also between those in a predominantly white Boston neighborhood and those in a Black one less than a half mile away. The unacceptably high levels of maternal mortality, and its concentration in low- and lower-middle-income countries, provides another chilling example, especially given the preventability of most maternal deaths.

Yamin is also a critical thinker about human rights and their connection to law, which she describes as "at best" a conservative tool for social change. She notes that human rights are also "more than law" and can serve as valuable tools for mobilization. The book is in dialogue with other recent commentators about the role of rights standards and actors.

Yamin's approach is neither to condemn nor to blindly extol. She criticizes how the political interests of the United States and Western Europe shaped the development of human rights, including the privileging of civil and political rights over economic, social, and cultural ones. But she also pushes back against the caricature of human rights as a mere foot servant to capital, insisting we pay attention to the "diverse set of practitioners, scholars and movements" who have used these rights to address social and economic injustice.

Further demonstrating this ability to be nuanced but not neutral, she offers a clear-eyed qualification of every positive example. Even the boldest victories and greatest verdicts are only partial and take place within a long, iterative fight. Quoting Philip Alston on human rights, she reminds us that "dejection and despair are pointless and self-defeating. It's assuredly not a lost cause, but we should not be fooled into thinking that it's ever going to be a winning cause; it's an ongoing struggle." She captures an ambivalence toward human rights that I recognize in myself, and I enjoyed the discussion, but others may find that it too closely resembles an insider's self-defense.

The book is a history and not a road map for the future, but Yamin offers guidance for the types of regulatory and legal changes needed at both the national and international level, and calls for addressing the "political determinants of health," including by reigning in large corporations. She also shares her reflections on how to achieve a transformative human rights practice, including by tackling all forms of inequality, not just poverty, as well as democratizing knowledge and authority.

Four years ago, amid our heartache, many of us dared to hope that the pandemic might be a catalyst for positive change. But now we know, in so many ways, it was an accelerant for a world on fire. Amid hardship and loss, the richest countries largely looked after their own—providing financial support and snapping up access to medicines as only the highest-income countries could do—and the biggest firms reaped record profits that in turn turbocharged the portfolios of the super-rich. And now many countries face a debt crisis that further threatens their ability to invest in care and the social determinants of health.

It is easy to feel despair. But Yamin's book, with its personal, thoughtful account of what has been achieved and what is left to do, gives me hope—which is, I believe, precisely what it is meant to do.

References

1. Office of the United Nations High Commissioner for Human Rights, "Gaza: UN Expert Condemns 'Unrelenting War' on Health System amid Airstrikes on Hospitals and Health Workers" (December 7, 2023), https://www.ohchr.org/en/press-releases/2023/12/gaza-un-expert-condemns-unrelenting-war-health-system-amid-airstrikes.
2. C. Paun, "Biden's Got Pharma's Back in Global Pandemic Treaty Negotiations," *Politico* (January 29, 2024), https://www.politico.com/news/2024/01/29/bidens-got-pharmas-back-in-global-pandemic-treaty-negotiations-00138133; Reuters, "World Risks Missing Deadline for Pandemic Accord, Says WHO Chief" (January 22, 2024), https://www.reuters.com/business/healthcare-pharmaceuticals/who-chief-worried-about-missing-deadline-pandemic-accord-2024-01-22/.
3. R. Robbins and S. Nolen, "New Sickle Cell Therapies Will Be Out of Reach Where They Are Needed Most," *New York Times* (December 8, 2023), https://www.nytimes.com/2023/12/08/health/casgevy-lyfgenia-sickle-cell-africa.html.
4. World Health Organization and World Bank Group, *Tracking Universal Health Coverage: 2023 Global Monitoring Report* (Geneva: World Health Organization and World Bank, 2023).
5. International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966); Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000).
6. N. Shaxson and C. Godfrey, *Taken, Not Earned: How Monopolists Drive the World's Power and Wealth Divide,* (UK: Balanced Economy Project, 2024).
7. N. Dearden, "Case Study: Big Pharma," Global Justice Now (January 17, 2024), https://www.globaljustice.org.uk/wp-content/uploads/2024/01/Taken-Not-Earned-Big-Pharma-case-study.pdf; P. Krugman, "Wonking Out: Attack of the Pharma Phantoms," *New York Times* (May 12, 2023); Oxfam International, *Inequality Inc.: How Corporate Power Divides Our World and the Need for a New Era of Public Action* (Oxford: Oxfam International, 2024).
8. R. Riddell, "Why Is the U.S. Trying to Export Its Flawed Health-Care Policies around the World?," *Washington Post* (January 10, 2022), https://www.washingtonpost.com/opinions/2022/01/10/usaid-private-health-systems-kenya/; Center for Human Rights and Global Justice and Economic and Social Rights Centre – Hakijamii, *Wrong Prescription: The Impact of Privatizing Healthcare in Kenya* (Nairobi: Economic and Social Rights Centre –Hakijamii, 2021); Oxfam International, *First, Do No Harm: Examining the Impact of the IFC's Support to Private Healthcare in India* (Oxford: Oxfam International, 2023); A. Marriott, "Sick Development: How Rich-Country Government and World Bank Funding to For-Profit Private Hospitals Causes Harm and Should Be Stopped," Oxfam Briefing Paper (June 2023), https://policy-practice.oxfam.org/resources/sick-development-how-rich-country-government-and-world-bank-funding-to-for-prof-621529/.

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BOOK REVIEW

To Achieve a Healthier World, Global Health Law and Policy Must Be Grounded in Human Rights

DAVID PATTERSON

Global Health Law and Policy: Ensuring Justice for a Healthier World, edited by Lawrence O. Gostin and Benjamin Mason Meier (Oxford University Press, 2024)

Global Health Law and Policy: Ensuring Justice for a Healthier World is an up-to-date, comprehensive, and accessible overview of global health law, policy, and governance. The editors, Lawrence O. Gostin and Benjamin Mason Meier, have provided the reader with a sound foundation for understanding the legal dimensions of the major global health challenges we face today. In this review, I first describe the context of the book, its structure, and contents. I then discuss some current limitations of global health law and how they could be addressed. I conclude with an appeal for greater collaboration between legal experts, public health professionals, and civil society organizations in addressing global health challenges.

Global health law is an expanding field of academic and professional interest to all working in global health. The role of the law, and human rights law, in responding to health challenges first came to global prominence with the HIV epidemic. In the 1990s, treatments for AIDS-related conditions were becoming more effective. Yet many people at risk of HIV infection avoided testing because of the associated stigma and discrimination. Legislation prohibiting discrimination against people living with HIV, and those most at risk, came to be seen as a vital component of a comprehensive national HIV response. These laws were grounded in international human rights law, with the prohibition of discrimination on the grounds of "other status" affirmed by the then United Nations Commission on Human Rights to include HIV status. In 1996, the commission endorsed guidelines for states on HIV/AIDS law and policy, published as the *International Guidelines on HIV/AIDS and Human Rights*.[1] This had not been done for any health condition before HIV/AIDS, nor has it been done since.

The 2010s saw increased attention to the growing global burden of noncommunicable diseases (NCDs), in part due to the epidemiological transition from infectious diseases to NCDs in low- and middle-income countries. This stimulated awareness of the role of the law in addressing the commercial determinants of NCDs beyond tobacco (where the role of law was already well recognized). In 2017, the World Health Assembly updated World Health Organization (WHO) guidance on "best buys" and other interventions for addressing the four major NCD risk factors: tobacco use, the harmful use of alcohol, unhealthy diet, and physical inactivity.[2] Many of the WHO best buys and other recommended interventions—such as

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David Patterson, LLM, MSc, HonMFPH, is a PhD candidate in the Groningen Centre for Health Law, Faculty of Law, University of Groningen, Netherlands.

taxes; regulation of production and marketing, including packaging, advertising, and sales; and prohibition—have a regulatory aspect.[3]

Since 2020, the COVID-19 pandemic has heightened awareness of the importance of national and international law in preventing and responding to infectious disease pandemics. Thus, all global health challenges have legal dimensions: it is increasingly accepted that responding to these health challenges requires understanding not only national and international health systems but legal systems as well.

In his foreword, WHO Director-General Tedros Adhanom Ghebreyesus flags key themes that appear throughout *Global Health Law and Policy*. He highlights the reference in the preamble of the WHO Constitution to the enjoyment of the highest attainable standard of health as one of the fundamental rights of every human being without distinction. Echoing the obligations in the International Covenant on Economic, Social and Cultural Rights (art. 2), Tedros notes that the COVID-19 pandemic revealed the continuing lack of international assistance and genuine collaboration to build public health capacities in low- and middle-income countries. He also emphasizes the importance of civil and political rights, noting that restrictions on civil society and political freedoms subvert social participation and universal rights. Tedros suggests that since the creation of WHO, global health law and policy have become crucial to addressing major health threats. *Global Health Law and Policy*, he writes, provides "an academic foundation for the next generation of global health leaders."

The book contains 20 chapters, each addressing an aspect of global health—either a substantive health issue such as infectious diseases, NCDs, and mental health, or aspects relevant to disease prevention and treatment, such as the commercial determinants, intellectual property law, funding, and universal health coverage. There is an important discussion of the *process* of developing global health law and policy, as well as of global health actors and of governance. Each chapter is written by two leading scholars in the respective field. Chapters follow a standard format: a review of the historical evolution and current state of the field followed by case studies and questions for discussion. There is minimal overlap: the editors have helpfully cross-referenced material that is discussed in earlier chapters.

A wide readership is envisaged: each chapter is written to be accessible to readers without formal training in law or public health. The book is divided into four sections: frameworks and institutions; global health governance in disease prevention and health promotion; the economic institutions that influence global health; and international legal responses to rising global health threats. The reader is advised to read these sections sequentially, as each chapter builds on the previous material. The sequence is generally logical, except that climate change, noted to be "the greatest threat to health faced by humanity," appears as the penultimate chapter. I suggest that climate change may soon be considered a cross-cutting concern for all global health challenges, along with gender and, increasingly, decolonization, and will be given far greater prominence.

I will now discuss three ways in which the contribution of health law to global health could be strengthened, and which lead me to the following recommendations:

- International human rights treaties should always be considered part of the legal framework for global health.
- Civil society and affected communities must be adequately consulted and engaged in health law and policy reform.
- Technical expertise in health law should be strengthened, as should collaboration between health and legal scholars and civil society organizations.

International legal frameworks

In their introduction to the book, the editors remind us that "global health law is guided by values of social justice, mutual solidarity and human rights." This is certainly true, yet it is important to reiterate that "human rights" offer more than ethical exhortations because they are backed by international and national frameworks and legislation. Legal scholars should be familiar with these frameworks; however, many public health scholars remain unaware of the scope and content of human rights law.[4]

These frameworks can help strengthen compliance with WHO technical guidance. It is well understood that WHO's guidance is nonbinding on World Health Assembly member states. But the international human rights legal framework offers accountability mechanisms, which can be used to assess states' implementation of WHO guidance. For example, WHO's Model List of Essential Medicines is now considered part of the core content of the right to health.[5] By drawing on WHO guidance, greater use could be made of international and regional human rights mechanisms in holding states to account for their obligations to promote and protect the right to health.

However, Global South criticisms and "decolonial" critiques of these frameworks should also be noted. Certainly, the struggle to achieve universal recognition of state responsibility for regulating the social determinants of health is far from won. In their overview of global health determinants, global governance, and global law in Chapter 1, Lawrence Gostin and Alexandra Finch suggest that "governments have come to accept responsibility to address the underlying conditions that affect public health." Yet this is still very much a contested view in some states. For example, in 2019, Health Policy Watch reported that representatives of Italy and the United States pressed WHO to remove information on the impact of taxes on sugar-sweetened drinks from its latest progress report on tackling NCDs.[6]

Public health experts often query what can be done if a state fails to meet its treaty obligations. In Chapter 2, Sharifah Sekalala and Roojin Habibi assert that states will incur sanctions if they breach the binding obligations in "hard" international law. However, this is not always the case. For example, the International Health Regulations (2005) are binding on all WHO member states. Compliance is assessed through "joint external evaluation" assessment missions. Yet there are no provisions for sanctions if states have not adequately implemented the International Health Regulations. Similarly, United Nations human rights treaties, although binding, contain no sanctions mechanisms for noncompliance.

Civil society engagement

In Chapter 2, Sekalala and Habibi fairly note that UNAIDS' use of "soft law" in the context of HIV and AIDS has been "revolutionary." The high rate of national compliance with monitoring and reporting commitments has been aided since 2001 by the placement of a UNAIDS monitoring expert with the Ministry of Health in countries that may otherwise lack the resources and technical capacity to respond. Also revolutionary is the design of the monitoring tool, which includes a two-part "national commitments and policy instrument." Part A is to be completed by national authorities, and Part B is to be completed by civil society, communities, and other nongovernmental partners involved in the national AIDS response. The participation of civil society organizations in the periodic monitoring of the national AIDS response demonstrates how a rights-based approach can be applied in this context.[7]

In the absence of civil society support, governments are less likely to make the hard policy choices needed to address the social determinants of health. Yet the case study of HIV/AIDS, intellectual property law, and access to medicines in Chapter 2 fails to acknowledge the pivotal role of civil society organizations in highlighting the inequalities inherent in access to HIV treatments at that time. Beginning in 1998, the Treatment Access Campaign in South Africa used a combination of human rights education, HIV treatment literacy, public protests, and litigation to advocate for access to more effective HIV medications. These were increasingly available in the Global North and produced in generic form in countries such as Brazil and India. When the South African government amended the Medicines Act to facilitate importation of these generic medications, some 40 multinational pharmaceutical companies took legal action to block its implementation. If the Treatment Access Campaign had not mobilized in front of the courthouse and the world's media, as well as joining the case as amicus curiae, the case may well have dragged on for many months, if not years. Instead, the pharmaceutical lobby dropped its legal action.[8]

The role of civil society in global health governance is also worth examining. UNAIDS and the Global Fund to Fight AIDS, Tuberculosis and Malaria each have representatives of nongovernmental organizations on their governing boards. This is not the case for the World Health Assembly, and there is a notoriously difficult procedure for accrediting nonstate actors in official relations with WHO. As a result, there were a mere 218 nonstate actors in official relations with WHO (as of February 2022), compared to over 6,000 organizations with United Nations Economic and Social Council (ECOSOC) consultative status (as of January 2024). These ECOSOC-accredited organizations can observe, and in some cases intervene, in United Nations General Assembly debates on health issues in New York, but not World Health Assembly debates on the same topic in Geneva! In 2023, WHO launched a separate Civil Society Commission to facilitate dialogue with civil society—this may prove useful but cannot replace meaningful civil society participation in the World Health Assembly.

Funding is a key aspect of obligations of international assistance and cooperation. Human rights obligations arise not only in determining the amount of funding but in determining how it is spent. The Global Fund has included "health equity, gender equality and human rights" as one of its three "mutually reinforcing contributory objectives" of its *Strategy Framework (2023–2028)*. Reflecting the human rights principle of the participation of affected communities, the Global Fund requires local civil society participation in funding applications through the so-called country coordination mechanism. Following UNAIDS technical guidance, the Global Fund has identified and supports key program areas to address human rights-related barriers to HIV and tuberculosis services. These include building the legal literacy of affected populations to "know their rights," strengthening access to legal services, and supporting related law and policy reform.

In their discussion of preventing, detecting, and responding to pandemic threats under international law in Chapter 6, Pedro A. Villarreal and Lauren Tonti review the historical development of, and weaknesses in, international legal frameworks. Critically, they note the emergence of advocacy for human rights in responses to HIV/AIDS, with lessons for broader policy responses to infectious diseases. In 2020, UNAIDS published rights-based guidance on lessons from HIV/AIDS for the response to COVID-19.[9] The guidance suggested that the response to COVID-19 must be grounded in the realities of people's lives and focused on eliminating barriers that people face in being able to protect themselves and their communities. This guidance was largely overlooked in the COVID-19 response.

Encouragingly, the draft pandemic treaty includes the obligation to develop and implement "policies to respect, protect and fulfill the human rights of all people."[10] However, it is unclear whether the treaty will be ratified by the larger and more powerful states such as China, India, Russia, and the United States. It is a trade-off: in general, the more a treaty aims to oblige states to act or refrain from acting, the less likely it is to be ratified. For example, the optional protocol to the Framework Convention on Tobacco Control to eliminate elicit trade in tobacco products was opened for signature in 2012. Although, as of December 2023, there were 183 parties to the convention, the optional protocol had only 68 ratifications, which did not include China, Russia, or the United States. By contrast, regulations adopted under article 21 of the WHO Constitution are binding on World Health Assembly member states, unless they opt out. Although the issues for which regulations can be adopted are limited, the list can be expanded through amendment to the WHO Constitution, which requires only a two-thirds vote for amendments to be adopted.

Technical expertise and collaboration between disciplines of law and public health

The good news for students of global health law is that there is a strong and growing demand for technical expertise in this field. For example, many countries have not reformed their legal frameworks as required by the International Health Regulations. The reasons for noncompliance are multiple and include a lack of technical assistance to support related law and policy reform. The same is true for national legal frameworks to address falsified and substandard medicines, although the challenge here may be the need for greater capacity to prosecute under existing criminal laws, rather than for law reform. WHO does not have unlimited funds to pay for the travel and fees of international legal experts to respond to state requests for technical assistance. Nor has technical assistance in health law been a top priority for development donors. Further, experts often have academic teaching and research obligations. They cannot allocate the time needed in-country for a participatory capacity-building process, which should include representatives of affected communities, consistent with the principle of participation in human rights law.

Another model of public health law capacity-building is needed, including through South-South collaboration. For example, in East Africa, a human rights-based research initiative provides technical assistance and regional networking between legal and public health scholars to improve diets and address NCDs.[11] And an initiative of the Faculty of Public Health (UK) and global public health organizations aims to support greater collaboration between public health professionals, legal experts, and affected communities to support climate litigation.[12]

Conclusion

Global Health Law and Policy is an invaluable, timely resource. It demonstrates the breadth, potential power, and utility of health law to address major health challenges. All have a legal dimension requiring an understanding of national and international legal as well as health systems. International legal frameworks, including human rights treaties, are crucial tools, but their power to oblige state action is limited. Civil society engagement in health law and policy reform is essential, including in supporting state action to address the commercial determinants of health. Collaboration between legal experts, public health professionals, and civil society organizations is needed to identify and support rights-based health law and policy reforms to address health challenges. Today, climate change is the greatest health threat faced by humanity. It may soon be considered a cross-cutting theme for all global health challenges, and hence global health law and policy.

References

1. UNAIDS and Office of the United Nations High Commissioner for Human Rights, International Guidelines on HIV/AIDS and Human Rights, UN Doc. HR/PUB/06/9 (2006).
2. World Health Organization, *“Best Buys” and Other Recommended Interventions for the Prevention and Control of Noncommunicable Diseases* (Geneva: World Health Organization, 2017).
3. R. S. Magnusson, B. McGrady, L. Gostin, et al., “Legal Capacities Required for Prevention and Control of Noncommunicable Diseases,” *Bulletin of the World Health Organization* 97/2 (2019).
4. D. W. Patterson, “Human Rights-Based Approaches and the Right to Health: A Systematic Literature Review,” *Journal of Human Rights Practice* (2024).
5. X. Seuba, “A Human Rights Approach to the WHO Model List of Essential Medicines,” *Bulletin of the World Health Organization* 84/5 (2006).
6. E. R. Fletcher, “Italy and United States: Remove Reference to Sugary Drink Tax from WHO NCDs Report,” *Health Policy Watch* (January 30, 2019), https://healthpolicy-watch.news/italy-united-states-remove-reference-to-sugary-drink-tax-from-who-ncds-report/.
7. T. Alfven, T. Erkkola, P. D. Ghys, et al., “Global AIDS Reporting – 2001 to 2015: Lessons for Monitoring the Sustainable Development Goals,” *AIDS and Behavior* 21/Suppl 1 (2017).
8. M. Heywood, “South Africa’s Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health,” *Journal of Human Rights Practice* 1/1 (2009).
9. UNAIDS, *Rights in the Time of COVID-19: Lessons from HIV for an Effective, Community Led Response*, UN

Doc. UNAIDS/JC2988E (2020).

10. World Health Organization, Proposal for Negotiating Text of the WHO Pandemic Agreement, UN Doc. A/INB/7/3 (2023), art. 16.

11. A. Garde and S. Abdool-Karim, *Human Rights and Healthy Diet Research Support Initiative: Synthesis Report* (Human Rights and Healthy Diet Research Support Initiative, 2022).

12. D. W. Patterson and F. Tahzib, *From Analysis to Action: Climate Change Litigation; A Guide for Public Health Professionals* (Faculty of Public Health and Aletta Jacobs School of Public Health, 2023).