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SPECIAL SECTION

Human Rights and the Social Determinants of Health

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Table of Contents

SPECIAL SECTION ON HUMAN RIGHTS AND THE SOCIAL DETERMINANTS OF HEALTH

In collaboration with the Lupina Foundation and the Dalla Lana School of Public Health, University of Toronto

EDITORIAL

1 Deepening the Relationship between Human Rights and the Social Determinants of Health: A Focus on Indivisibility and Power
Kristi Heather Kenyon, Lisa Forman, and Claire E. Brolan

11 Using Health Committees to Promote Community Participation as a Social Determinant of the Right to Health: Lessons from Uganda and South Africa
Moses Mulumba, Leslie London, Juliana Nantaba, and Charles Ngwena

19 Social Medicine in Practice: Realizing the American Indian and Alaska Native Right to Health
Lucas Trout, Corina Kramer, and Lois Fischer

31 Human Rights and Fracking in England: The Role of the Oregon Permanent People's Tribunal
Miriam R. Aczel and Karen E. Makuch

43 Challenging Neoliberalism: ILO, Human Rights, and Public Health Frameworks on Decent Work
Gillian MacNaughton and Diane Frey

PERSPECTIVE

57 Tax and the Right to Health
Bernadette Ann-Marie O'Hare

65 A Meta-Narrative Literature Synthesis and Framework to Guide Future Evaluation of Legal Empowerment Interventions
Katherine Footer, Michael Windle, Laura Ferguson, Jordan Hatcher, Carrie Lyons, Emma Gorin, Anne L. Stangl, Steven Golub, Sofia Gruskin, and Stefan Baral

GENERAL PAPERS

PERSPECTIVE

85 Human Rights in Public Health: Deepening Engagement at a Critical Time
Benjamin Mason Meier, Dabney P. Evans, Matthew M. Kavanagh, Jessica M. Keralis, and Gabriel Armas-Cardona

93 Engaging Human Rights Norms to Realize Universal Health Care in Massachusetts, USA
Gillian MacNaughton, Mariah McGill, April Jakubec, and Andjela Kaur

105 The Rohingya in Cox's Bazar: When the Stateless Seek Refuge
Abhishek Bhatia, Ayesha Mahmud, Arlan Fuller, Rebecca Shin, Azad Rahman, Tanvir Shatil, Mahmuda Sultana, K. A. M Morshed, Jennifer Leaning, and Satchit Balsari

123 Domestic and Family Violence in Post-Conflict Communities: International Human Rights Law and the State's Obligation to Protect Women and Children
Samantha Bradley

137 Human Subject Research: International and Regional Human Rights Standards
Andrés Constantin

149 Strategic Litigation to Advance Public Health
Tamar Ezer and Priti Patel

PERSPECTIVE

161 Contribution of the Health Ombud to Accountability: The Life Esidimeni Tragedy in South Africa
Ebenezer Durojaye and Daphine Kabagange Agaba

169 Does Information and Communication Technology Add Value to Citizen-Led Accountability Initiatives in Health? Experiences from India and Guatemala
Marta Schaaf, Shruti Chhabra, Walter Flores, Francesa Feruglio, Jashodhara Dasgupta, and Ana Lorena Ruano

185 Social Solidarity, Human Rights, and Collective Action: Considerations in the Implementation of the National Health Insurance in South Africa
Renate Douwes, Maria Stuttaford, and Leslie London

197 Gendered Power Relations and Informed Consent: The *I.V. v. Bolivia* Case
Martín Hevia and Andrés Constantin

205 Intersex Variations, Human Rights, and the International Classification of Diseases
Morgan Carpenter

215 Transsexuals' Right to Health? A Cuban Case Study
Emily J. Kirk and Robert Huish

223 Eradicating Female Genital Mutilation/Cutting: Human Rights-Based Approaches of Legislation, Education, and Community Empowerment
Beth D. Williams-Breault

235 Child Labor in Global Tobacco Production: A Human Rights Approach to an Enduring Dilemma
Athena K. Ramos

LETTER TO THE EDITOR

249 Malnutrition, Poverty, and Climate Change are also Human Rights Issues in Child Labor
Adele Jones

EDITORIAL

Deepening the Relationship between Human Rights and the Social Determinants of Health: A Focus on Indivisibility and Power

KRISTI HEATHER KENYON, LISA FORMAN, AND CLAIRE E. BROLAN

The social determinants of health and human rights describe where and how we live and thrive. They express our actual and optimal conditions of housing and nutrition; our social, cultural, and spiritual connections; our access to education, health, and social services; and our ability to be fully involved in our societies through expression, mobility, association, work, and engagement with the formal political process. Ultimately, they are different yet overlapping measures and languages of human well-being and self-actualization. The connection between these deeply related but, until recently, rarely linked conceptual frameworks was made explicit in the 2008 report of the WHO Commission on the Social Determinants of Health (CSDH). This seminal report comprehensively outlined the imperative to scale up the global focus on the social determinants as a matter of social justice, the absence of which was "killing people on a grand scale."[1]

The CSDH report prompted a special issue in *Health and Human Rights* in 2010 exploring the relationship between human rights and the social determinants of health.[2] Since then, there have been several critical global policy initiatives, including the Rio Declaration on the Social Determinants of Health (2011) and the Sustainable Development Goals (SDGs) (2015), which affirmed the links made by the CSDH locating the social determinants of health in relation to human rights and the right to health.[3] These complimentary frames are at last connected in rhetoric and policy, but what does this linkage mean in practice, and what progress has been made since 2009?[4]

As three human rights and right to health scholars, we are deeply engaged with the theoretical and practical implications of these concepts and their linkages. Yet none of us exists outside concepts or theory when it comes to human rights and the social determinants of health. This was made clear when one of us experienced a health crisis in the lead up to this special issue. A long night in the emergency room highlights how power is mediated through variables like place, race, age, class, gender, ethnicity, and disability to determine health care, and indeed health: watching nurses brush off valid questions from an older male patient of color; hearing a white male patient interrupt his female doctor repeatedly. While

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such actions are small and subtle, they suggest the broader dynamics that underlie inequitable disparities in health care treatment and health outcomes not only in low- and middle-income countries, but in high-income countries like Canada, the United States, and Australia.

Newspaper reports from 2018 exemplify these trends and their complexities: in April, *The New York Times* reported a CDC finding that black women in the United States are three to four times more likely than white women to die from pregnancy-related health issues.[5] In October, *The Sydney Morning Herald* reported on systematic and widespread bullying and harassment of public health workers in the Australian state of New South Wales, and the ensuing impact this has on quality of patient care and health worker mental health and well-being.[6] And in November, the Canadian Broadcast Corporation reported on a class-action lawsuit brought by almost 60 Indigenous women alleging a prolonged period of forced sterilizations over a 25-year period, including as recently as 2017.[7] No person, no community, and no country is exempt from the interaction of the social, economic, and political factors that determine health and health care.

This is the context from which this special section proceeds in its effort to deepen exploration of the relationship in theory and practice between human rights and the social determinants of health. It is inspired by and builds on a diverse series of conversations that took place at an international conference held in May 2017 at the University of Toronto. The conference, sponsored by the Lupina Foundation, the Dalla Lana School of Public Health, and the Canada Research Chair Program, began with a special keynote address on health and human rights by Amartya Sen.[8]

Unsurprisingly, the conference discussions were deeply influenced by Professor Sen's capabilities approach that considers the societal conditions in which individuals can become active agents of change rather than "passive recipients of dispensed benefit."[9] Conference discussions identified two key areas particularly in need of deeper scholarly and practitioner engagement: (1) expansions of the theoretical and evidence-based links between human rights and the social determinants of health, encapsulated in the human rights framing of "indivisibility," and (2) analyses that deepen our understanding of the constitutive role of power in the broader determination of health. We used these key areas to anchor this special issue. In our call for papers for this issue, we drew on these conference discussions to offer guiding questions elaborating on both themes. With regard to the indivisibility of human rights and the social determinants of health, we asked researchers to consider how to move beyond calling for access to health and related services only, towards health and health related policy capable of realizing the fuller vision of dignity and equal worth that underpins human rights. In this respect, health could be understood in line with its definition in international law not simply as the absence of disease, but as physical, mental, emotional, social, and cultural well-being. We asked whether this comprehensive vision of human rights could provide an alternative conceptualization of the social determinants of health, that moved beyond exclusively outcomes-based top-down measures towards process-oriented, agency-based empowerment that broaden the scope of health interventions. We asked whether and how social science research on the social determinants of health in areas such as intersectionality, anthropology, sociology, communications, and political science could help build the concept of the indivisibility of human rights into a richer operational concept in relation to the social determinants of health. Finally, we asked how we could build an evidence base to buttress the interdependence of human rights and the social determinants of health and show how systematic attention to rights could promote population health? And which disciplines and institutions should decide what constitutes such evidence?

With regard to our second key theme, we asked contributors to consider how the human rights community could better focus on structural drivers of health, including neoliberal policies that impact realization of the right to health and systematically enacted power differentials around

race, gender, sexuality, disability, and ethnicity.

How could human rights practitioners and health workers be more attentive to the way power consciously and unconsciously shapes both the definition and realization of human rights and the social determinants of health? And how does power influence the full vision of human rights as incorporating social, economic, civil, and cultural domains?

We are gratified to present six papers that responded to various aspects of this ambitious call. In our analysis, these papers highlighted four key themes in relation to the indivisibility of human rights and the social determinants of health, and the constitutive role of power therein.

(1) Participation as a determinant of health: Recognizing knowledge in communities. Linking practitioner experience and scholarly reflection, Mulumba et al., Trout et al., and Aczel and Makuch present case study analyses that highlight the importance of community involvement in the development and implementation of effective health systems and health protections. The right to participation is codified in Article 21 of the Universal Declaration of Human Rights and Article 25 of the International Covenant on Civil and Political Rights, which guarantee a right to participate in governance, public affairs, and access to services. Building on Human Rights Committee General Comment No. 25 and the Rio Political Declaration on Social Determinants of Health, Mulumba, London, Nantaba, and Ngwena argue that participation is not only an independent right but also an underlying positive determinant of the right to health. Recognizing the critical importance of participation, both South Africa and Uganda have developed specific structures to integrate community participation and represent their interests within the health care system. Drawing on a three-year study aiming to "develop and test models of good practice for Health Committees in South Africa and Uganda," Mulumba et al. examine the fora, structures, and timing of participation in this practice-oriented piece. They interrogate how to leverage community participation in a meaningful rather than perfunctory manner. They ask: if participation is essential, how do we do it right? One of their key findings is that the level of participation is critical. They note that community participation is too often limited to "the lowest rung of the health system," a strategy which is "manifestly disabling to community agency" because few possibilities exist at this level to address health system determinants. Conversely, forms of community participation that include "a voice that is able to articulate all the way up the system" can strengthen community engagement, provide meaningful substantive input, and allow it to be communicated at levels where it can have an impact.

Trout, Kramer, and Fisher examine a series of paradoxes in "Social Medicine in Practice: Realizing the American Indian and Alaska Native Right to Health." While Indigenous peoples in the United States were some of the first people to "hold an unambiguous state-conferred right to health," this recognition has not demonstrably improved the health of American Indian and Alaska Natives (AIAN). They identify two key obstacles. First, there has been "socialization for scarcity in tribal health" wherein deprivation of resources has become normalized and consequently not served as a catalyst for action. They ask if it is "possible to disrupt" community expectations of inferior infrastructure, care, and health outcomes. Is it possible to disrupt the American public's expectation of these disparities as "inevitable, immovable, and allowed"? Second, they highlight the lengthy delay by both health care workers and academics in linking social determinants of health and human rights. Trout et al. argue that existing literature articulating these links "tends towards historicized notions of social determinants" that rightly acknowledges the impact of colonialism as "social forces shaping the inequitable burden of disease in Indigenous communities" but neglects contemporary, concrete, and immediate conditions. Despite the lack of resources and a high burden of disease, Trout et al. recognize Alaskan Indigenous communities not as places of deficit, but of knowledge and opportunity. They recognize that while AIAN communities may benefit from support from global networks, "AIAN

health organizations, tribes, and community activists have much to offer the global movement toward health as a human right." They offer a detailed case study as one such example.

Trout et al. examine the Maniilaq Social Medicine center and their attempts to align the care they offer with a rights-based approach to health acknowledging social determinants. Using an integrated approach—connecting governance, social services, primary care, local knowledge, academic research, and policy advocacy around social determinants and human rights—Maniilaq Social Medicine aims not only to treat illness and injury but "ultimately to play a role in redressing structures of inequality that both produce and are propagated by poor health." In doing so, this project understands health as a broader social, cultural, and economic mandate of strength, health and resilience. This detailed case study concludes with concrete recommendations and "scalable strategies" for other AIAN communities.

Aczel and Makuch's paper considers the human rights dimensions of hydraulic fracturing ("fracking") —a method of natural gas extraction—arguing for a "human rights-based, participatory approach to regulation." This topical paper examines the intersection of politics, power, and participatory governance through the vehicle of an international People's Tribunal vis-à-vis the environmental determinants of health. Reflecting on findings from the May 2018 Permanent People's Tribunal on Human Rights, Fracking, and Climate Change, they examine how such a mechanism can support advocacy against the commencement of fracking activities in the north of England. They highlight international participatory governance mechanisms as key tools advocates can leverage to challenge a government's decision to begin fracking—particularly in the absence of compelling domestic laws and regulatory environments. Aczel and Makuch argue that the tribunal demonstrates "*why* human rights mechanisms are key in regulation of a new technology" and "*how* international human rights law and providing an open forum to present testimony can be an important tool to protect citizens' basic human rights." Although the paper is more nuanced in its thematic connection to the social determinants of health, it no less contributes to an important conversation around the role people's tribunals play in terms of implicitly promoting the right to health alongside social and environmental determinants in national and global landscapes.

Mulumba el at, Trout et al., and Aczel and Makuch each emphasize the importance of substantive and meaningful participation. Mulumba et al. and Trout et al. both highlight the expertise that lies in populations typically depicted as "service recipients" rather than policy contributors. Their papers speak to Sen's capability approach as they examine how people can engage with health care systems as active agents of change rather than "passive recipients of dispensed benefits." Aczel and Makuch identify participation as a critical advocacy tool through which to actively combat "dispensed harm." All three papers identify agency at a collective rather than individual level. Mulumba et al. and Trout et al. recognize local communities as assets and sites of expertise, while Aczel and Makuch identify local communities as agents of accountability. In different ways, Mulumba et al. and Trout et al. make the critical point that recipients can and should be participants, and that participation is not a nicety but an efficient and effective strategy to improve health care systems and services. In doing so, they challenge structures of power as well as prevalent assumptions of who is an expert, recognizing that community members are valuable resources and, unsurprisingly, experts on their own lives. Mulumba et al. and Aczel and Makuch highlight mechanisms and structures of participation. Mulumba et al. argue that structures of participation must be carefully considered for maximum impact, while Aczel and Makuch examine ways in which participatory mechanisms can provide alternatives to weak legal and regulatory structures.

(2) Power, neoliberalism, and economics as structural determinants of health. How do we negotiate the relationship between state-guaranteed human rights, underlying social determinants of health, and the economic systems in which we

work and through which we finance these systems? MacNaughton and Frey, and O'Hare address this question at different levels, examining the relationship between work and health, and the role of taxation in supporting health rights.

MacNaughton and Frey compare three frameworks addressing decent work: the CSDH, the Decent Work Agenda of the International Labour Organization, and the right to decent work in international human rights law. They argue that while the CSDH acknowledges fair employment and decent work as "components of daily living conditions that have powerful effects on health and health equity," it missed important opportunities to link to and strengthen existing frameworks and, in doing so, affirm decent work as a human right. This gap is one, they argue, that has been perpetuated at several junctures. The Millennium Development Goals "failed to include a goal or target on full employment and decent work for all until 2007" and the subsequent SDGs feature work only in Goal 8, a goal aimed at "economic growth, full and productive employment and decent work for all." MacNaughton and Frey argue that the SDG contextualization of work is problematic. In Goal 8, it is articulated not as a social determinant that could alleviate poverty (SDG 1) or hunger (SDG3), or provide a path to a healthy life (SDG3), but as a "means to or ends of economic growth unlinked to human rights of well-being." They note, "the resulting paradigm […] is that full employment and decent work are not recognized as human rights or social determinants of health but merely components of the neoliberal economy." MacNaughton and Frey argue that the CSDH "could have helped to ensure that full employment and decent work were recognized as human rights or health equity goals in the SDG framework." MacNaughton and Frey are concerned with how to build a strong and protective structure for decent work as a human right. Their piece is a conceptual analysis of how to place floors and walls upon foundations, which building blocks to place where, and which walls can bear weight. In this complex project, they note gaps in construction and the failure to capitalize on past investments, often resulting from an inability to learn across different fields of study and practice. MacNaughton and Frey posit that interdisciplinary and cross-institutional collaboration "may be the key to achieving the rights to decent work and health for all."

While social determinants of health are increasingly recognized as necessarily interdisciplinary, there continue to be dangerous blind spots. O'Hare shines light on one such gap examining the role of tax abuses on the right to health. She argues that while such abuses have a negative impact on core human rights obligations, including those under the right to health, outside of the ground-breaking work of scholars like Attiya Warris, "human rights scholars have largely ignored the need for revenue and tax scholars have not analyzed laws and policies through the lens of human rights." She observes that while human rights are extensively codified, less attention is paid to the practical financial mechanics of their fulfillment. O'Hare explains that the "pathways between government revenue, government expenditure, public services, and fundamental rights is known," as she traces the link from a 10% increase in tax revenue through increases in public health spending to decreases in under five mortality. Although there are sufficient global resources to meet shortfalls in low-income countries, O'Hare argues that meeting this gap domestically is preferable, as this is where the human rights obligation lies, the funding is more stable, there is an opportunity for greater citizen engagement, and priorities can be set locally. She examines the lower tax contribution in low-income countries, with a focus on domestic and international "tax avoidance," including waivers granted to international corporations.

Exploring the worlds of work and taxation, MacNaughton and Frey, and O'Hare bring new language into these fields while stretching the concept of social determinants of health to engage with new disciplines and sectors. Both pieces highlight the need for real, boundless interdisciplinarity in addressing these complex questions, including systematically interdisciplinary policy development processes to ensure that knowledge across fields is incorporated and reflected in new policies and laws.

These two pieces also illuminate the underexplored intersection of neoliberal economics, human rights, and social determinants.

(3) Law as a determinant of health: Learning from practice, improving research. The final paper, by Footer et al., aims to improve both research and practice through a systematic review of a particular mode of engagement. Legal empowerment holds real promise in improving the well-being of vulnerable people with respect to both social determinants of health and human rights. Footer et al. note that this approach, consisting of "the use of laws, legal systems/institutions and services for socio-structural change," has "gained prominence as a framework for strengthening individuals capacity to exercise their rights, with implications for their health and well-being." They argue however, that while significant literature explores how law can inhibit the right to health, particularly for vulnerable peoples, less research empirically examines the ways in which engagement with law can facilitate improved health. With a view to identifying patterns, gaps, and the evidence base supporting legal empowerment, Footer et al. undertake a meta-narrative literature review and synthesis. In doing so, they ask: How has legal empowerment been practiced in relation to health? How has it been studied? What is its impact? They find that there is a lack of "robust conceptualization," measurement, and analysis of the contexts in which legal empowerment initiatives function alongside insufficient study of interventions themselves, particularly those operating at the grassroots level. They identify a need for more thorough assessment of legal empowerment interventions drawing on a variety of methodological tools and approaches, noting, for example, that none of the examined studies follow a single cohort through time. The task of assessing the impact of legal empowerment either at the community, structural, or individual level is a complex and difficult one. Acknowledging these challenges and aiming to provide a structure to assist future research, they propose a framework that aims to clarify the different forms legal empowerment can take, the level of intervention, and suggest variables that can be measured.

(4) Reflections on context and categorization. The six papers in this special section draw on the experience of practitioners and the insights of scholars in the Global North and Global South, stretching the concept of social determinants to include new sectors and actors. While diverse in their focus and approach, the importance of context emerges in each. When we discuss and address social determinants and human rights in relation to health, what ideational and practical categories are we placing them in? Trout et al. note that an obstacle to improved health in AIAN communities is the context of expectations. Communities, providers, and the public anticipate substandard health care, health infrastructure, and health outcomes. Insufficient expectations can be self-perpetuating and can normalize the inequitable and unacceptable. Mulumba et al. argue that the context of participation—when, why, and at what level—is critical. The way participation is incorporated into policy development and consultative processes reflects beliefs about the value and utility of community participation and its expected impact on health systems and outcomes. Aczel and Makuch re-contextualize fracking by examining it through a human rights lens. In doing so, they also question the limits of the categories of human rights and health, blurring the lines between humans and their natural environment. MacNaughton and Frey critique the contextual placement of decent work in the SDGs, underlining the ways in which framing a right as an economic good undermines its content and positions it as a component in an economic equation rather than of a fulfilling life. O'Hare pushes for tax evasion to be considered a human rights abuse in addition to a financial crime, connecting the dots between lost revenue and investments in health. Footer et al. note that understanding of context is currently lacking from analysis on legal empowerment. Context and categorization are ways of structuring and understanding, guiding us in how to think about and act on particular topics. They are also, however,

actions of power that indicate priorities, urgency, and importance, that place ideas within institutions, ministries, and disciplines, and that shape who is (and who is not) expected to act.

Way forward

The papers in this special section illustrate ways in which the intersection of the social determinants of health and human rights can assist us to better understand and respond to the breadth of deeply embedded power differentials and structural disparities that persist in impacting health, even in settings of relative wealth. These papers outline some of the ways that these conceptual tools, when operationalized through their legal, policy, and advocacy dimensions, could enable effective action to realize a meaningful holistic right to health in many settings. However, we note that *de facto* realization of the transformative power of the social determinants and human rights nexus will depend on four key factors.

First, complex health issues and their political, economic, socio-cultural, environmental, and transboundary intricacies cannot continue to be addressed in silos. Multi-stakeholder partnerships that advance game-changing interdisciplinary, cross-sectoral right to health research and advocacy approaches will need to be leveraged, and a Health in All Policies approach persistently pushed.[10] Interdisciplinary teams and approaches must become standard practice, and education and training must be developed with this in mind.

Second, the social determinants and human rights nexus will need to be purposively advanced through formal integration of participatory governance mechanisms into policy and planning for health at national and subnational levels. The diversity of community and local actors, civil society, and the private sector that are causally impacted by health-related resources and investment should be an official part of interconnected decision-making and policy implementation, monitoring, and review processes. This is consistent with the international disability rights' mantra, "nothing about us without us." Certainly, the necessity to critically interrogate presumptions of expertise on both global and local scales was recognized by UN Member States in both the formulation and finalization of SDG content.[11] This is made clear in SDG 16 ("Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels") and its target 6 ("Develop effective, accountable and transparent institutions at all levels") and target 7 ("Ensure responsive, inclusive, participatory and representative decision-making at all levels").[12]

Indeed, when it comes to participatory governance and the social determinants, Article 4 of the landmark Alma-Ata Declaration (1978) is unequivocal: "people have a right and duty to participate individually and collectively in the planning and implementation of their health care."[13] The Ottawa Charter for Health Promotion (1986) and the Bangkok Charter for Health Promotion in a Globalized World (2005) also emphasize that communities and civil society organizations must play a central role in health promotion for achieving better health for all and for community empowerment.[14] The UN Committee on Economic, Social and Cultural Rights is similarly unequivocal in its 2000 General Comment No. 14, The Right to the Highest Attainable Standard of Health:

> *[T]he right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under [the right to health]… Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people's participation is secured by States.*[15]

The third factor that will bring to life the overlap between the social determinants of health and human rights is overt commitment on the part of countries to the realization of intergenerational health equity. Populist, polarizing politics and bigoted policy-making, often cobbled together

on the fly and without a sound scientific evidence base, is surely undermining the health of future generations across all five global regions. There is an urgent need for many countries to acknowledge and redress intergenerational trauma and its destructive health and well-being consequences among disenfranchised populations. This includes intergenerational trauma exacerbated by environmental abuse, degradation, and climate change, which can perniciously and disproportionately impact Indigenous communities.[16]

Countries should therefore formally commit to intergenerational health and well-being through regulatory measures that cut across short-term electoral cycles and partisan political divides. Such actions both complement and strengthen countries' SDG commitments, which are non-binding. For example, we commend the Welsh government's introduction of a Well-Being of Future Generations (Wales) Act (2015) that requires public bodies in Wales "to think about the long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change."[17] In fact, the Welsh Assembly is the "first legislature in the world to enshrine in law a duty, falling on public bodies, to safeguard the well-being of future generations."[18]

Fourth, while it is imperative to pay keen attention to funding, policy frameworks, and legal structures, we must not ignore the amorphous power of attitudes and beliefs, and the ways in which these intangible ideas yield concrete impacts on health. Attitudes and beliefs that reflect and perpetuate dominant structures of power such as economic and political systems, as well as forms of racial, cultural, gender, and class domination, systematically damage the health of marginalized communities. Such beliefs led to the shooting of multiple unarmed black men and boys in the United States and allowed Brian Sinclair, an Indigenous man, to be "ignored to death" in a Canadian hospital emergency waiting room because he was presumed to be drunk rather than suffering from a treatable bladder infection.[19] Beliefs rooted in inequality perpetuate violence against LGBT communities and promote violence against women worldwide. Fear-fuelled beliefs perpetuate stigma around health conditions as varied as HIV, mental illness, addiction, and lymphatic filariasis, which can in turn lead to social isolation, depression, and hesitation in seeking care. These intangible ideas are determinants of health that are as real as the lack of access to safe drinking water. We need to pay attention not only to perceptions and attitudes that result in overtly violent structures, but also "structures of indifference" that bring injury, illness, and death by neglect.[20] Finally, we must be alert to the ways in which attitudes, beliefs, and biases shape where and to whom we look for solutions, what expertise we recognize, which disciplines, professions and lived experience we deem relevant, and which parts of the world (and parts of town) we think we can learn from.

Conclusion

One of the most powerful contributions of research into the social determinants of health is that it can enable us to identify consistent patterns of inequality and their impact on health. At the same time, research into the social determinants of health can elucidate the complex, bidirectional association between health and education or health and the environment so as to bring weight to cross-disciplinary advocacy for health. Human rights enables us to name and frame these issues and patterns as violations with clear legal obligations for state action. We are glad to offer this special section as an important contribution to the ongoing effort to elaborate the links between human rights and the social determinants of health, and to dig deeply into key aspects of this relationship. We hope that the research presented in this section offers answers, provocation, and inspiration in what we anticipate will be an ongoing dialogue between these areas of scholarship and practice.

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Using Health Committees to Promote Community Participation as a Social Determinant of the Right to Health: Lessons from Uganda and South Africa

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Abstract

Community participation is not only a human right in itself but an essential underlying determinant for realizing the right to health, since it enables communities to be active and informed participants in the creation of a responsive health system that serves them efficiently. As acknowledged by the Rio Political Declaration on Social Determinants of Health, participatory processes are important in policymaking and in the implementation of laws relating to health. Collective deliberation improves both community development and health system governance, resulting in more reasoned, informed, and public-oriented decisions.[1] More recently, attention has focused on the elements of health system governance that enable greater responsiveness to community needs. However, there is relatively little by way of interventions linking human rights approaches to governance in ways that recognize participation as a critical social determinant of the right to health. This paper provides perspectives from a three-year intervention whose general objective was to develop and test models of good practice for health committees in South Africa and Uganda. It describes the aspects that we found critical for enhancing the potential of such committees in driving community participation as a social determinant of the right to health.

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Introduction

With consensus being established that community participation is essential for the development, monitoring, and delivery of health services, there is a need for credible platforms through which communities can participate in health decision making to move beyond being passive recipients of health care to actively and effectively participating in health decision making.[2] These platforms, which transform community participation from a mere civil right to a social determinant of health, increase communities' engagement in accountability and monitoring processes that are able to raise priorities and concerns, and they facilitate the implementation of actions that support the achievement of better health outcomes.[3]

The international human rights framework is instructive on the right to participation. For example, article 21 of the Universal Declaration of Human Rights guarantees everyone's right to participate in the governance of their country, and article 25 of the International Covenant on Civil and Political Rights enshrines people's right to participate in the conduct of public affairs and to have access to public service.[4] The Human Rights Committee, in its General Comment 25, further sheds light on the right to participate in the conduct of public affairs, explaining that article 25 of the International Covenant on Civil and Political Rights requires states to adopt legislative and other measures to ensure that citizens have an effective opportunity to realize this right.[5] Meanwhile, General Comment 14 of the Committee on Economic, Social and Cultural Rights—which further interprets the right to health as laid out in the International Covenant on Economic, Social and Cultural Rights—notes that realizing the right to health requires that both individuals and groups be entitled to participation in all government decisions affecting their health, including agenda setting, accountability, and decision making.[6] These rights and obligations are similarly reflected in the African Charter on Human and Peoples' Rights, especially article 13, which guarantees everyone's rights to participate in governance and to have equal access to the public service of their country.[7]

In the context of primary health care, the 2018 Declaration of Astana underscores the importance of supporting the involvement of individuals, families, communities, and civil society in the development and implementation of policies and plans that have an impact on health.[8] The declaration outlines countries' commitment to "increase community ownership and contribute to the accountability of the public and private sectors for more people to live healthier lives in enabling and health-conducive environments."[9] It builds on the 1978 Declaration of Alma-Ata, which emphasizes people's "right and duty to participate individually and collectively in the planning and implementation of their health care" and requires the state to facilitate the participation of communities and individuals in the "planning, organization, operation and control of primary health care," including educating communities about their right to participate.[10] These declarations provide an opportunity to consider community participation not only as an underlying determinant of health but also as a social justice mechanism through which groups can take part in issues affecting them beyond health services.

Partly on account of these international human rights instruments that recognize a right to participate, a community participation movement that places value on involving communities in the provision of public health services has grown. This movement argues that community participation in the provision of health services increases a sense of responsibility and conscientiousness among the public, given a perceived increase in skills, information, and control over health resources.[11] The organization and delivery of health services also benefit from community participation due to a better determination of the need for health facilities, their ideal location and size, the number and types of health workers required, employment practices, and health worker policies.[12] Ana Ruano et al., in presenting findings from the research consortium Goals and Governance for Global Health, have also argued that through meaningful participation and community engagement, a more horizontal and inclusive approach replaces the top-down process

of decision making.[13]

To fully realize the value of community participation, there is a need for credible platforms that allow communities to effectively participate in the provision of health care services. Following the Declaration of Alma-Ata, health committees have been considered an effective mechanism to achieve this. However, constraints such as the failure to integrate these workers into national programs, socioeconomic and political barriers, bureaucracies, and a lack of support from health professionals at other levels have inhibited the ability of community health workers to effectively facilitate the participation of communities in health service provision.[14]

Interventions

Our interventions—one in South Africa and another in Uganda—aimed to enhance the potential of health committees (also known as health unit management committees) to drive community participation as a social determinant of the right to health. In both countries, such committees have been established as participatory structures to represent community interests in relation to the health system.

In South Africa, we had two intervention sites: one in the Eastern Cape (Nelson Mandela Bay Metro) and one in the Western Cape (Cape Metro). We chose these sites based on an audit of health committees in the Cape Metro that identified a number of key challenges facing effective health committee functioning.[15] A training guide and an instructor manual were developed, and trainings were conducted with 405 committee members from seven of the eight subdistricts in the Western Cape and 202 participants from 47 clinics in three subdistricts in the Eastern Cape.[16] Additionally, intensive mentoring was used in both sites. In the Western Cape, learning circles were set up to provide ongoing support for 92 participants, who in turn provided support to a further 300 health committee members. In the Eastern Cape, 474 health committee members were reached through a more intensive mentoring process involving 41 mentoring and 32 follow-up sessions at 10 facilities over 24 months. We relied heavily on experiential learning, with interactive activities and group work generating energetic discussions among health committee members that allowed them to learn both from their own experiences and from the experiences of others.

In Uganda, we also had two intervention sites: Kiboga and Kyankwanzi districts. At the start of the intervention, many health committees in these districts were reported to be inactive or, at best, partially active. The role of the committees was sometimes performed by just one or two committee members, who were called on about once every two months, in accordance with National Medical Stores' delivery cycle, to witness the delivery of medicines to health facilities. Our preliminary research also showed that committees were partially constituted, did not hold regular meetings, and did not keep records of their deliberations.

Our trainings of health committee members in Uganda were guided by findings from earlier capacity assessments, Ministry of Health Guidelines for health committees, a gender and human rights mainstreaming manual for health professionals, and training materials for health committees developed by the Learning Network for Health and Human Rights of the University of Cape Town.[17] Like the trainings in South Africa, our trainings in Uganda explored the concept of community participation in health, the right to health, the role of health committees, and strategies for creating partnerships with stakeholders. As a result of these trainings, two health facilities in Kiboga and Kyankwanzi—which had previously been dormant and whose former roles consisted largely of the ceremonial witnessing of medicine delivery to health facilities—were provided with the capacity to undertake their functions.

Our interventions sought to assess and enhance the ability of health committees to serve as a platform for communities to participate in health service provision at their local health facilities. Specific activities included training and capacity building for health committee members, engaging with health officials and policy makers, building civil society networks, training health workers, and producing and distributing educational materials that followed a human rights-based approach. The

relevance and impacts of these interventions were identified through a community mapping process.

Our interventions also involved two exchange visits in which health committee members and health workers from Uganda visited South Africa, and vice versa. Despite the contextual differences between the sites, the visits provided an opportunity for sharing learning and best practices. During these visits, for example, local leaders had the opportunity to share their experiences with members of the visiting delegations regarding how they thought health committees could work better. The health worker from Uganda who was part of the team that traveled to Cape Town described her experience in Cape Town as an eye-opener, especially concerning how to deal with tensions between committee members and health workers. Moreover, the local political leaders in Uganda were surprised that health committees were not unique to their districts and were a best practice across the region.

The resource-constrained nature of health systems in both Uganda and South Africa created a vital space for civil society organizations to facilitate the performance of health committees within the health system. In Uganda, a community-based organization in Kyankwanzi district (Action for Rural Women Empowerment) played an instrumental role, through the provision of technical and financial resources, in building the capacities of health committees, other health professionals, and women's groups to advocate for improved maternal health service delivery. In South Africa, the Learning Network for Health and Human Rights partnered with the People's Health Movement, another active civil society organization in health, to develop training materials and run workshops for the committees on national health policies (such as the introduction of a national health insurance scheme). These investments represented significant resources that would ordinarily have been unavailable to build the capacity of health committees.

Critical features

We found that several aspects of our interventions were critical for enhancing the potential of health committees to drive community participation as a social determinant of the right to health.

The human rights-based approach

In the Cape Metro, training grounded in a human rights-based approach helped revitalize flagging or defunct committees and gave trainees a sense of empowerment and agency to undertake various social and advocacy actions. This is reflected in many trainees' comments and in postgraduate students' evaluations that were done as part of our research process prior to the intervention. For example, committees were empowered to advocate for better-quality services and to raise questions around the conditions of treatment and respect for patients' rights, such as the right to privacy for HIV and tuberculosis patients. Similarly, in Uganda, the rights-based nature of the intervention enabled health committees to demand their right to health by challenging health worker shortages and the lack of water. In Kyankwanzi, for instance, the committee was able to petition the district health officer concerning the absence of water and a poor sanitation environment, which the community had raised as a key concern in a dialogue with committee members.

In both countries, health committees' increased assertiveness—as seen through the active and informed participation of empowered committee members—also elicited an unexpected backlash from service providers when they were confronted with committee members who were unafraid to insist on patients' rights and state obligations. In one instance in Cape Town, this nearly led the clinic manager to dissolve the committee. However, due to the responsiveness of upper-level management and facilitation from the Learning Network for Health and Human Rights, that conflict was turned into a learning opportunity. The network was asked to mediate between the committee and the facility manager, which resulted in a better mutual understanding of the situations and interests of health committees and facility managers. This strengthened and increased accountability between duty-bearers (and their agents) and rights-holders.

The notion of committees as part of the heath system

Our interventions also showed that health committees' integration into the wider health system has a positive impact on advancing community participation as an underlying determinant of the right to health. For instance, while the committees had been formally provided for in all four intervention sites, communities had not been participating through these committees prior to our involvement because they did not view health committees as part of the wider health system. The fact that our interventions approached health committees as part of the health system opened the doors for communities and local leaders alike to exploit committees as a community participatory structure.

In both countries, the health committees were designed to promote participation and accountability in the provision of health services and to create a platform for community members to directly contribute to the planning, design, and delivery of health services at their local health facilities. However, in all four sites, we identified structural and operational barriers standing in the way of this role, including ignorance of the roles of the committees, limited opportunities for communities to engage with the committees, and socioeconomic and cultural barriers that undermined the committees' abilities to facilitate community participation.

One of the key lessons from our interventions is that confining community participation to the lowest rung of the health system is manifestly disabling to community agency, since at the clinic level there is little scope for changing health system determinants. It is also a flawed view of health rights to imagine participation as located only at the local level, without integration upstream.

Committees bring social knowledge, experience, views on health problems, and solutions to health system plans and budgets at the primary care and community levels. This role in governance gives health committees the information, authority, and motivation to facilitate dialogue and consultation with communities; to mobilize social action; to build constructive partnerships and facilitate dialogue with different actors to ensure that problems are addressed; and to implement services and health actions. This, in turn, raises their oversight capacity.

Health committees need to be mainstreamed within the conceptualization of a health system. Their work should be seen as broad, including not just actions aimed at addressing health care quality and equity but also actions centered on the social determinants of health, many of which lie outside the health system. Central governments should therefore construe committees as being organized intersectorally in ways that can effectively mobilize resources and political will when required to address health systems issues, including social determinants. Our interventions underscore the need for central governments to incorporate health committees into their health systems in a way that maintains their role as autonomous agents for participatory democratic governance.

Support from civil society networks and partnerships

The sharing of experiences between South African and Ugandan committee members and civil society activists helped strengthen community leadership. The exchange visits and the cross-sharing of training materials enabled participants in our interventions to see that their challenges are shared across very different contexts and that the solutions to these challenges are not entirely dissimilar. Since our interventions, committee members have expressed openly the value of networking across the region and sharing best practices.

Partnerships have been found to add significant value to the capacity of health committees to engage with communities and duty-bearers alike. Exchanges at the grassroots level between committees from different facilities go beyond the exchange of knowledge and skills to create solidarity among agents of change who are generally highly isolated. This ensures that there is a shared diagnosis of existing problems and corresponding action plans, which improves cooperation and coordination among agencies and sectors. It also helps committees ensure that action plans and strategies are economically and physically accessible, as

well as acceptable (that is, socially and culturally appropriate), to communities. Therefore, enabling committees to build a movement may be the most important bottom-up strategy to pursue.

Our interventions revealed the importance of building knowledge networks related to health committees, expanding the scope of health committees into subnational and national levels through mobilization and resource pooling, and establishing regional linkages on best practices for community participation through the sharing of information and experiences. While building knowledge networks supports access to relevant information that committees need to effectively perform their roles, pooling resources contributes to making resources available to support the work of committees, an essential facet of the progressive realization of the right to health.

The legal and policy framework

It can be drawn from the research that prior to the formation of health committees, there is a need for a strong legal and policy framework that provides a solid foundation for duty-bearers to act on. In South Africa, the lack of a policy framework for committees meant that health facility managers did not feel compelled to involve committees in the handling of complaints. This was addressed through a series of public dialogues hosted by the Cape Metro District Health Council to ventilate concerns and expectations regarding health committee roles. Partly as a result of community pressure, a draft bill on health committees was introduced for public debate in the Western Cape, and national guidelines were issued by the National Department of Health that recognize the key role of health committees in South Africa. In Uganda, existing health committee guidelines provided some clarity on the roles of committees. While these guidelines lack legal force, they indicate a commitment from the Ministry of Health in terms of committees' integration into the health system.

For policy makers to be compelled to consider committees as community participation instruments, it is essential to have a clear regulatory framework that defines the roles and powers that committees have in their communities and how they feed into national processes. Legislation also contributes to the sustainability of committees within the health system. The survival of committees also calls for legal requirements on continued capacity building and empowerment, system design, community empowerment, health worker reorientation, and an appropriate policy framework.

The existence of a clear legal and policy framework ensures that state commitments are framed as actionable legal obligations on which rights holders can frame their demands.[18] Such a legal and policy foundation can also be utilized to ensure that community participation is not contrary to existing legal frameworks and can address critical issues such as representation, committee tenure, and allocation of responsibilities, among others. This helps transform community participation through committees from just a social determinant to a legally enforceable value within the health system.

Such a legal and policy framework should require that committees be constituted in ways that make them credible to the communities they represent—for example, through elections or representative appointments in genuinely democratic spaces. Mechanisms for the representation and protection of marginalized and vulnerable groups should be incorporated into their setup as well.

Conclusion

Our interventions in South Africa and Uganda indicate that community participation is not only a human right in itself but an essential social determinant of the right to health. It is clear from our interventions that health committees provide a mechanism that enables communities to be active and informed participants in the creation of a responsive health system that serves them efficiently. The results confirm the effectiveness of rights-based trainings and exchanges in strengthening committee members' sense of agency, their capacity to engage the health system, and their ability to exercise claims to health rights. They also contribute evidence of health committees' potential to play a critical role in advancing community participa-

tion as a social determinant of the right to health. These participatory spaces bridge the gap between communities and health facilities, making services responsive to community needs and contributing to the realization of health as a human right.

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Social Medicine in Practice: Realizing the American Indian and Alaska Native Right to Health

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Abstract

American Indians and Alaska Natives have long held a state-conferred right to health, yet Indigenous communities across the United States continue to experience significant health and health care disparities. In this paper we posit two contributing factors: socialization for scarcity in tribal health care, and a slowness among health workers and allied health and social scientists to make explicit and convincing linkages between social determinants of health and human rights. We then summarize one attempt to align tribal health care delivery in the Alaskan Arctic with a rights-based approach, highlighting both the role of social and structural determinants as causes of health disparities and the role of social and structural interventions in local efforts to chart a future of equal health for our home.

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Introduction

American Indians and Alaska Natives (AIAN) were among the first global citizens to hold an unambiguous state-conferred right to health.[1] Yet the burden of disease in AIAN communities remains staggering, and the language of rights, trust, and treaty has only at length begun to galvanize the political will necessary to drive parity in tribal health care appropriations, delivery, and outcomes.[2] In this paper we posit two contributing factors: socialization for scarcity in tribal health care, and a slowness among health workers and allied health and social scientists to make explicit and convincing linkages between social determinants of health and human rights. Broader strategic participation among tribal entities and advocates in the right to health movement may serve to buttress action to address both problems. Conversely, AIAN health organizations, tribes, and activists have much to offer the global movement toward health as a human right.

The paper then summarizes one attempt to align tribal health care delivery in the Alaskan Arctic with a rights-based approach, highlighting both the role of social and structural determinants as causes of health disparities and the role of social and structural interventions in local efforts to chart a future of equal health for our home. The Maniilaq Social Medicine Program (SMP) is a center for health care innovation in Northwest Alaska working with regional, state, and national partners to build systems of care around the principles of health as a human right, social determinants as primary drivers of health, and social medicine as a key framework for realizing the AIAN right to health. SMP houses a clinical staff tasked with linking tribal government and social services to the regional primary care system; education programs designed to promote biosocial analysis of health and health care delivery; a tribally governed research division working at the intersection of social science and medicine; clinical partnerships with an academic medical center to address staffing and complex care challenges; and a policy advocacy mission to partner with regional stakeholders to advocate for policies that advance Alaska Native cultural, economic, health, and social rights. The paper concludes by highlighting strategies that other Native communities, governments, and health systems may find useful in forwarding the AIAN right to health.

Trust and treaty establish the American Indian and Alaska Native right to health

American Indians and Alaska Natives have long held a state-conferred right to health.[3] Beginning in the early 19th century, a trust relationship and numerous treaties with the United States government—alongside case law, American Indian activism and advocacy, and various executive orders and acts by Congress—have progressively defined and incrementally strived to realize this right, though complex and competing agendas often saw these obligations subverted, ignored, or otherwise failed.[4]

An 1832 Supreme Court case defined the federal government's trust relationship with Indian nations and consequent responsibility for the care and protection of American Indians, with the first Congressional appropriations specifically for health care made the same year.[5] By 1849, Indian health was transferred to the purview of civilian law from the War Department to the Department of the Interior.[6] Over the coming half-century, meager appropriations for American Indian health care allowed the establishment (and subsequent termination) of a medical division within the Bureau of Indian Affairs, as well as piecemeal programs directed, under different agendas and administrations, at varied combinations of assimilation, containment, care delivery, extirpation, education, political domination, and tribal sovereignty.[7] Finally, in 1921, the Snyder Act provided a clear and formal mandate for expenditures related to the "conservation of health" in American Indian communities, with ongoing appropriations for the "benefit, care, and assistance of the Indians throughout the United States."[8]

The post-Second World War years witnessed an acceleration of federal AIAN health policy efforts and tribal advocacy and activism. As "the highest attainable standard of health" became preamble to the World Health Organization (WHO) constitution in 1946, and as the United Nations adopted the Universal Declaration of Human Rights

two years later, an era of progressive change began in Indian health policy.[9] Following the transfer of responsibility from the Bureau of Indian Affairs to the Public Health Service in 1954 and the formation of the Indian Health Service in 1955, a level of political organization was accomplished which, through the Indian Self-Determination and Education Assistance Act of 1975, transformed into the progressive right of tribes to directly administer health services under contracts with the Indian Health Service.[10] The following year, the Indian Health Care Improvement Act boldly promised "all proper care and protection" to "ensure the highest possible health status" for tribal members—unequivocal statements pre-empting the call for universal primary care at Alma Ata by two years, and prophetizing still-unfolding elements of the contemporary right to health movement.[11] In the four decades following the formation of the Indian Health Service, AIAN life expectancy increased by nearly 15 years.[12]

Despite these successes, significant health care disparities persist across AIAN communities.[13] Per capita expenditures for AIAN health services remain less than half those for the US population as a whole.[14] More local challenges, including health professional shortages and attrition, continue to plague AIAN health organizations, which tend also to be rural or remote—areas already prone to staffing shortages and poor access to specialty care.[15] Finally, the complexity of organizing culturally safe, accessible, and effective care systems in communities where colonialism remains an ongoing structural force—and health care one of its most noteworthy tools—remains a further challenge.[16] This issue tracks a broader tension at the heart of global health, perhaps near its most visible in the context of American welfare colonialism in Native communities, between medicine as a social practice and political tool, and health care as an unequivocal human right.[17]

Though important gains have been made since the advent of the Indian Health Service, there remains a long road ahead.[18] In the following sections, we posit two related factors contributing to the persistence of inequities in AIAN health and care delivery: socialization for scarcity in AIAN health systems, and a slowness among health workers and allied health and social scientists to make explicit and convincing linkages between social determinants and the right to health. Broader strategic participation among tribal entities and advocates in the global right to health movement may serve to buttress action to address both problems.

Health professionals, policy workers, and community stakeholders are socialized for scarcity in American Indian and Alaska Native health care

AIAN health disparities have become an entrenched fixture of the American social imaginary; that is, much to the detriment of tribal health care, they have become normalized.[19] Matters of Indian health have historically entered public consciousness in patterned ways, from the overtly racist (for example, in portrayals of AIAN life in film) to the seemingly necessary (for example, in health disparities research meant to galvanize policy action).[20] While recent decades have seen a proliferation of more nuanced and varied media portrayals through local activism, AIAN journalism, research focused on community strengths and resilience, and greater autonomy in the production of public narratives in Native communities, it appears true that Americans in general—and perhaps health workers in particular—expect Indigenous people, far more than others, to be sick.

Paul Farmer's concept of 'socialization for scarcity' is familiar to many working at the intersection of health and human rights. Socialization for scarcity indexes how limited health resources for the socially marginalized are normalized in a global health policy and care delivery. The concept points to the widespread narrative that (presumably) inherent resource scarcity translates to a lower standard of care for the world's poor.[21] Socialization for scarcity frames a calculus of health resources, disease burden, and political order that concludes that there is simply no way that health care for the world's rural, poor, and minority populations can equal health care for its urban, wealthy, and white. In the context of tribal health systems,

this translates to an expectation that we (as Americans, as a federal government, or as local health systems) simply lack the resources to systematically redress health inequities across Native America.

Working for a tribal health system in Alaska, we have come to appreciate this concept for several reasons. First, 'scarcity' acknowledges the basic reality of resource poverty. For tribal health workers, it is generally not unwarranted to make claims about an actual, material shortage of the resources needed to provide perfect—or even very good—care.[22] Second, it relates this status to a field of beliefs and ideas that, though reflective of material reality, are fundamentally social in nature. 'Socialization' implies that notions of scarcity are acquired, un-tame, unfixed—and therefore modifiable. Socialization is an event, albeit a subtle one, that allows for the maintenance of a state of affairs through the twin vehicles of narrative and expectation. It comes to rest in the minds of those engaged with problems of inequity, as both an anesthetic to suffering and a barrier to broad and systemic change.

So the question arises: Is it possible to disrupt the socialization of tribal health care workers, policymakers, and community stakeholders to resource-poor health care infrastructure, enduring health disparities, and a lower standard of care for American Indians and Alaska Natives? And is it possible to disrupt the expectation on behalf of the American public that these disparities are inevitable, immovable, and allowed?

Social determinants of health shape enduring American Indian health disparities

AIAN health disparities have persisted across 500 years of colonial history and into contemporary American life, although the kinds of illness experienced have changed significantly over time.[23] Replacing infectious disease epidemics are rates of suicide, diabetes, cardiovascular disease, substance use disorders, and cancer in present-day AIAN communities that far exceed US averages.[24] Witnessed against both this history and contemporary economic and political realities, it is difficult to contest that social forces shape the distribution and burden of disease.[25] This highlights one central argument of this paper: that although AIAN health disparities are ubiquitous and well-discussed, their solutions have not commonly been brought to light within analytic frameworks that make explicit, meaningful, and convincing linkages between social determinants of health and the AIAN right to health. Work that does acknowledge these connections, though valuable, tends often toward historicized notions of social causation that fail to draw attention to the concrete and immediate social, political, and economic conditions of life in Native America—and the human rights these conditions fail to realize.[26]

Rittel and Webber hypothesized that when dealing with inherently ambiguous social problems, "The choice of explanation determines the nature of the problem's resolution"; that is, an intimate and morally charged relationship exists between defining a problem and invoking its solution.[27] Bearing witness to inequalities in the distribution and burden of disease, we invoke explanations with real-world consequence—be they providence, social agency, or simply inadequate health care.[28] The explanatory models invoked in making sense of health disparities direct and conscribe the strategies elected for their remediation, garnering public attention (or not), mobilizing resources (or not), selecting the level and type interventions (or not), and placing blame (or not) based on models of health and illness rooted in various social expectations. As medical historian David Jones writes:

> *[Health] disparities can be seen as proof of natural hierarchy, as products of misbehavior, or as evidence of social injustice. These assessments motivate or undermine interventions, influencing whether observers prevent an epidemic's spread, treat its victims, or exploit its opportunities. Even as epidemics emerge as the product of specific social structures, they enable actions that reproduce those structures.*[29]

'Social determinants of health' (SDH) is a broad and amorphous concept—and the fields of social medicine, social epidemiology, public health, and medicine have suffered for lack of a shared framework to advance a health equity agenda through

action on this theme. SDH simultaneously invokes social causation and, in the Anglo-American context, often bypasses more meaningful levels of analysis by framing health events within the discursive registers of medicine and public health; that is, within systems of surveillance and intervention that relate outcomes primarily to more proximate, behavioral causes.[30] In the United States, the term has often been associated with notions of social agency and personal choice instead of broader social and structural drivers of health.[31] A core contention of SMP is that these levels of analysis—the proximate or behavioral, historical, and structural—are intimately and inherently connected, and that effective interventions can be structured across multiple levels of social causation. For example, alcohol abuse is often stereotyped as a social determinant of American Indian health, yet the morbific social and historical contexts that give rise to alcoholism—the intergenerational impacts of structural violence, poverty, and cultural genocide, perhaps—are more rarely cited in meaningful, actionable terms.[32]

Conversely, colonialism itself is often and rightly indexed as a social force shaping the inequitable burden of disease in Indigenous communities.[33] This has brought much-needed focus to the movements of power and privilege through history, and has yielded important analytic frameworks for understanding and representing subjugation, marginalization, and simply human evil. Yet colonization as a historicized event can easily shift focus away from the enduring inequities and dispossessions that characterize contemporary AIAN life. Similarly, culture and its loss has become a highly pressurized trope in framing AIAN health disparities. Within this imaginary, culture also becomes (again, rightly) relevant as a factor touching more or less every dimension of health and health care.[34] As with colonialism, though, this treatment can obscure a more situated "materiality of the social," that is, notions of culture that encompass political economy and history alongside the better-known idioms of social life.[35] In the context of academic preoccupations with Indigenous distress in postcolonial and trauma theory, care must be taken to situate theory within meaningful, locally engaged, and actionable frameworks that direct attention and resources toward the real and immediate social contexts of contemporary life.[36] As Kirmayer, Gone, and Moses note,

> *By obscuring the ongoing forms of material dispossession and political domination, the discourse linking Indigenous culture and historical trauma may deflect attention from the fundamental structural causes of distress. Healing then is framed in terms of therapy for psychic wounds…rather than in terms of how people might find meaningful livelihoods within increasingly difficult constraints and imagine a viable future rooted in the material realities necessary for reproducing thriving communities at the local level.*[37]

American Indians and Alaska Natives have been among the more convincing scholars to understand and articulate how specific social forces shape health outcomes.[38] Additionally, Native communities have begun to occupy increasingly sovereign roles as administrators of their own health services.[39] This opens up a wide space for innovation in tribal health care that foregrounds the local social context of health disparities, outcomes, and care delivery, and which promotes action across multiple strata of social determinants of health.[40] This, we suggest, will be a central concern in the coming decades of AIAN health policy: to define problems and elect strategies for their remediation based on thorough, multidisciplinary biosocial analysis that links broader understandings of human experience and action to health systems and care. In other words, social medicine.

Maniilaq Social Medicine Program (SMP)

Envisioned in 2015 and formally inaugurated by Northwest Alaska's regional tribal health organization in January 2017, SMP forwards an advocacy and equity agenda in tribal, health, and social services to promote the Alaska Native right to health. SMP's mission is to wed regional health care delivery to an actionable equity plan by building strong, sustainable, and scalable systems of care grounded in social medicine theory and practice. Within the context of Northwest Alaska, the region

discussed in the rest of this paper, SMP has proven an effective platform for organizing resources to address the social determinants of health on several levels. By linking tribal health care delivery to the global right to health movement, SMP has grown in two years from an unstaffed, unfunded concept to an impactful program operating across clinical, education, policy, and research divisions. The remainder of this paper documents SMP's early efforts and highlights scalable strategies for other health systems facing health disparities borne of social inequity.

Regional context

Maniilaq Association is the sole health care and social services provider for 12 circumpolar Inupiat (Alaska Native) villages spread across 38,000 square miles of the Alaskan Arctic (See Figure 1). The Maniilaq service area (MSA) encompasses the entirety of Alaska's Northwest Arctic Borough and the North Slope village of Point Hope, with a total population of 8,391, 83% of whom are Alaska Native. Kotzebue is the regional hub city, with a population of 3,201. The 10 additional MSA villages are Ambler, Buckland, Deering, Kiana, Kivalina, Kobuk, Noorvik, Noatak, Selawik, and Shungnak. As there is no road system connecting these communities to each other or to the rest of the state, travel is accomplished by small aircraft or, seasonally, by snowmobile or boat.

A vibrant subsistence culture has carried Inupiat through 10,000 years of Northwest Alaska residence, through a century of colonial settlement, and into the fold of modern American life—where life remains deeply rooted to this heritage. Communities settled at the sites of mandatory mission schools throughout the 20th century are now sites of year-round residence, organized as independent tribes with (in most cases) additional city and borough governance. In contrast to American Indians in the 'Lower 48' contiguous United States, few reservations were established in Alaska, and none in the Northwest reaches of the state. Instead, the Alaska Native Claims Settlement Act, signed into law by President Nixon in 1971, established for-profit corporations out of tribal entities, conceding cash payouts and 40 million acres of land claims with the stipulation that the settlement be administered through this corporate structure.[41] Within this broader framework for self-determined corporate

Figure 1: Map of Alaska

leadership, the Alaska Tribal Health Compact established with the Indian Health Service fostered a number of nonprofit entities across the state, which assumed responsibility for regional administration of health services.[42] Maniilaq Association has assumed these responsibilities since the early 1970s. Increasingly, some tribes in the Lower 48 have followed suit.[43]

A full account of historical, social, and political forces shaping the health and health care of Inupiat far exceeds the scope of this paper, yet several critical elements bear mention. Colonization of the Alaskan Arctic must be understood as a recent development within a regional history over 10 millennia old; similarly, colonialism in this context must be understood as a contemporary social force continuing to play out in the day-to-day existence of Alaska Natives and the social, political, and health care systems that shape their worlds.[44] Missionary settlement of Northwest Alaska began in earnest in the last years of the 19th century, with forced settlement at the sites of mission schools occurring over the following decades.[45] Health, education, and human services infrastructure was developed in multiple, rapid waves throughout the 20th century, invoking both welfare colonial logic and responding to real and pressing health needs.[46] An expressly assimilationist agenda saw physical and cultural violence become colonial mainstays of Alaska Native communities through forced residential schooling, imposed political systems, and profound revisions to livelihoods, family structures, and cultural life.[47]

Within this context, unprecedentedly steep grades of social inequality were accompanied by new health care infrastructure, significant improvements in average life expectancy, and rising rates of suicide, cancer, chronic liver disease, and cardiovascular disease.[48] Economic development, though rapid and impactful, has not been inclusive or evenly distributed between individuals and families or across communities, and has been heavily predicated on the extraction of natural resources. Of the 12 villages served by Maniilaq Association, seven have recently been listed as distressed communities by the Federal Denali Commission, indexing severe economic hardship.[49] Unemployment, though an unreliable indicator for subsistence economies, is approximately four times the national average.[50] A quarter of the population lives below the federal poverty level, a figure double that of the US white population.[51] While significant gains were seen in average life expectancy throughout the 20th century, Alaska Natives today have higher rates than US whites for nine of the 10 leading causes of death (cancer, heart disease, unintentional injuries, suicide, chronic obstructive pulmonary disease, cerebrovascular disease, chronic liver disease, pneumonia/influenza, and alcohol abuse), with an age-adjusted cancer mortality rate 80% higher than that of US whites.[52] The suicide rate among Alaska Native males ages 15–24 is approximately eight times that of US white peers.[53]

Economic development, climate change, and tactical assimilation have applied a wide range of competing structural forces within Inupiat communities.[54] To take one example, contradictory pressures to enter the wage labor economy or to continue traditional subsistence practice are mediated by an exceptionally high cost of food, limited educational and employment opportunities, rapid environmental change, exploitation of natural resources impacting subsistence foods availability, and public moral stands against the ongoing structural pressures of colonialism.[55] Dependence on subsistence foods relates on each of these levels to both culture and economy.[56] In a region where rapid social change and culture loss are indexed locally as drivers of poor health, subsistence practice retains incredible power as an anchor to shared cultural life. In addition, availability of fresh foods is limited throughout the region; where supply exists, extreme cost further limits access. Yet existing outside of a wage labor economy has grown increasingly difficult. Cost of living is higher than in many major US cities, and social and climate change place significant barriers to subsistence practice. This one facet among many in which highly pressurized, competing forces vie to define the Arctic's future.

Planning the Maniilaq Social Medicine Program

In creating SMP, Maniilaq aimed to create a re-

gional community of practice which foregrounds the lived, local social context of health disparities, outcomes, and care delivery, and which promotes action across multiple strata of social determinants of health.[57] The program serves as a vehicle for long-term planning, policy, education, clinical care, research, and community advocacy by collaborating with local agencies and stakeholders, developing academic and clinical partnerships, and integrating tribal and social services into the regional primary care system. SMP applies a human rights framework to action on social determinants of health by organizing services around a preferential option for those without ready access to care; by organizing its priorities and strategy around an equity plan, taking for granted that the same standards of health and health care apply to rural Alaska Natives as anyone else; and by seeking to bring tribal health care delivery into the fold of the broader global right to health movement by working with activists, academic and clinical partners, and policymakers working at the intersection of health and human rights. The program's four key divisions are highlighted in the following sections.

Clinical practice: Addressing social determinants of health through primary care

SMP's initial mandate from its board of directors was to create an integrated primary care system linking social, tribal government, behavioral health, and general medical services. In organizing our early efforts, we drew on Diderichsen's model of the social production of disease, later adopted by WHO as a framework for action on social determinants of health.[58] This framework posits that social stratification fosters differential exposure to conditions that impact health, differential vulnerability to those conditions based on material and social resources, and differential consequences of injury and disease based on access to health care, material support, and other socially determined factors. In addition, poor health circularly propagates social inequality by reducing economic security, mobility, and access to social supports. Therefore, primary care systems that address the proximate social determinants of health help to shape a world where the distribution of these causes is more just. Conversely, addressing the social causes of health fundamentally requires addressing the social causes of their distribution by redressing (for example, through SMP's policy vehicles) larger structures of inequity that both produce and are propagated by poor health.

To fund its early work, SMP applied for and received several federal grants to support care system planning, infrastructure development, and service expansion. In 2017 and 2018, Maniilaq Health Center created three new clinical roles, deemed social medicine counselors, in its outpatient and women's health clinics. Operating as integrated members of the primary health care team, these health workers address a wide range of social needs through emergency assistance programs, housing and food subsidies, education and job training, Medicaid assistance, tribal doctors, legal counsel, a traditional foods program, chore support and transportation for elders, nutrition and diabetes counseling, childcare assistance, tobacco cessation programs, tribal vocational rehabilitation, disability services, and other key social programs. As licensed clinical social workers, the social medicine counseling team also serves to improve access to mental health care, focusing in particular on expectant mothers, infants and children, and medically complex patients with behavioral health comorbidities.

Clinical partnership

Health professional shortages across rural America are well remarked-upon, and numerous federal programs have been built to address this problem.[59] Less thoroughly investigated is the concrete impact on health outcomes wrought by high turnover, chronic understaffing, poor continuity of care, and limited resources for complex care management in rural tribal health systems. Sustainable staffing models are an urgent need in Indian Health Service facilities and tribally operated health care organizations, and were noted as a high priority by Maniilaq leadership.

To address the primary care workforce itself as a social determinant of health, SMP established a clinical partnership with the Massachusetts General Hospital (MGH) Fellowship Program in Rural

Health Leadership (RHL), a post-residency fellowship program that supports primary care providers in developing clinical and health leadership skills in rural communities. Utilizing a staffing model developed in Rosebud, South Dakota, RHL fellows and affiliated clinicians will maintain 'institutional continuity' (that is, sourcing clinicians from a consistent program) while rotating between Maniilaq Health Center and MGH. These providers will maintain a dedicated patient panel, handing off care as they rotate between MGH and MHC. The first RHL-affiliated physician arrived in Kotzebue in October 2017, and its first cohort of five mid-level providers is anticipated in January 2019.

Education division: A regional hub for learning and action on social determinants of health

SMP's second aim was to create a regional hub for learning and action on social determinants of health to train health workers, learn from community experts, deliberate on clinical and policy decisions, and build relationships between community members, health care providers, tribal government and social services workers, and other stakeholders. In 2017, SMP established two education programs at Maniilaq Health Center, both jointly administered with the MGH Department of Medicine.

Social Medicine Grand Rounds is a program aimed at building coordinated clinical, organizational, and community capacity to address social determinants of health.[60] Grand rounds bring tribal, health, and social service workers together for monthly meetings in which a range of social medicine topics are used to drive health planning, focused on priority health disparity areas. In addition to its local utility, the program aims to demonstrate a scalable process model for moving social medicine education beyond the preclinical curriculum into practice, policy, and health systems, and for building and leveraging shared training infrastructure with academic partners to increase the capacity of rural health centers.

The second program, Project ECHO, is a case-based tele-mentoring program directed at building capacity among rural primary care providers to deliver best practice specialty care in community settings. Developed by Sanjeev Aurora at the University of New Mexico Health Sciences Center, the model links specialist teams with local clinicians through videoconference-based clinics, in which brief didactic presentations and longer case-based discussions are used to support clinical mentorship, guided and reflective practice, and practical gains in knowledge.[61] The first SMP clinic is focused on psychiatry and addiction medicine in rural Alaska, with a particular focus on culture, resilience, and social determinants of mental health. The core faculty for the inaugural clinic includes a local community health worker (Tanya Kirk), a medical anthropologist and psychiatrist (Arthur Kleinman), and an Alaskan clinical psychiatrist (Mark Erickson).

Policy division: Engaging community experts to forward the right to health

A central premise of SMP is that health-impacting polices should be authored by and for their beneficiaries, and that effective community governance is at the heart of responsive health care systems. SMP works with a range of local, regional, and national organizations (regional corporations, academic health systems, local and state politicians, village wellness coalitions, tribal governments) and community stakeholders to shape strategy, and to promote broader social policies that advance the right to health. Practical and conceptual frameworks from global health and social medicine have bolstered many of these efforts. For example, the concepts of accompaniment, structural violence, social suffering, and structural barriers to care—each of which emerged at the intersection of global health and human rights—have informed many policy decisions and programming efforts at SMP. For example, the concept of accompaniment has guided the development of practice guidelines for regional community health worker programs, and identifying and reducing structural barriers to care has been a core project of the social medicine counseling staff. These frameworks have also proven useful in staking out and articulating policy positions that advance health and social rights.

One of SMP's primary non-clinical collabo-

rations is with Maniilaq Wellness, a village-based program utilizing the framework of decoloniality to promote cultural, social, and physical wellness. The two programs work together to advance a framework similar to Amartya Sen's capability approach, which holds that human development can be supported through initiatives that remove social and structural obstacles to realizing basic human freedoms, agency, and health.[62] SMP and Maniilaq Wellness host learning circles to engage community members as health planners, discuss and develop community protective factors, promote culture as prevention, and develop strategies for addressing social determinants of health.

Research division: Driving a tribally governed health research agenda

A persistent challenge in tribal health care delivery is the lack of research evidence to guide policy decisions. While it is true that American Indian and Alaska Native communities are often geographically distant from universities and academic medical centers where such projects are often housed, there is also a history of extractive research with little tangible benefit for participating communities, and in the worst cases, unethical medical experimentation on American Indians.[67] Mistrust of researchers is justifiably common, though the need for research agendas responsive to local need is also acute.

Tribal entities have responded in some cases by establishing forms of review boards and other processes for governing health research. Maniilaq Association has navigated this terrain through its governing board, comprised of elected representatives from each of the 12 service area tribes. This board reviews and makes decisions on all research proposals, processes, and publications. Consequently, it has produced a large volume of health research through university and health center partnerships.

SMP has expanded the scope of the Maniilaq research program through collaboration with partners at Harvard Medical School and MGH, ongoing partnerships with the University of Massachusetts-Amherst, and by supporting an active cohort of co-researchers in Northwest Alaska. Where possible, the framework of community-based participatory research has been employed to lateralize research authority and gear efforts toward catalytic validity.[63] This methodology reframes research as a local and participatory process, and acknowledges the shortcomings of traditional research methods in Indigenous communities, including failure to meaningfully account for the local delivery context when designing programs and interventions, the marginalization of Indigenous voices and knowledge, and the perpetuation of power imbalances between researchers and participants.[64]

SMP's research agenda aims to create long-term partnerships that drive knowledge production directed at action of specific, measurable utility, focused on mobilizing health systems and other community supports to reduce health disparities by addressing the social determinants of health. In this sense, the SMP's efforts center on creating an evidence base for the indivisibility of social, economic, and cultural rights, and the right to health. Active studies in 2018 include community-level outcomes from a suicide prevention intervention, provider practice pattern outcomes tied to SMP's clinical education programs, and service utilization and health outcomes related to the integrated primary care model. Each project is designed with clinical and programmatic quality improvement efforts in mind, and is meant to translate to meaningful recommendations to improve regional services.

Conclusion

The need is great to shape local and national platforms for advocacy and activism to promote the AIAN right to health; to develop research programs linking social, economic, and cultural rights to the right to health; and to build capacity within primary care systems to address the social determinants of health as part of the basic purview of care. The community-based/academic-partnered SMP approach weds local knowledge and experience to the clinical and training infrastructure, resources, and reach of a leading academic medical center, and serves to link diverse perspectives on human health to a unified equity program in Alaska Native communities. Social medicine itself

as a moral and intellectual scaffolding for this work suggests a blending of perspectives from community stakeholders, social science, public health, and clinical medicine, and prioritizes both a preferential option for the marginalized and a focus on the ways in which SDH frameworks can inform care.

The history of the AIAN right to health can serve as a point of leverage to increase public awareness and policy action to promote AIAN health equity. It may also serve as a meaningful case study for those working to realize this right in other contexts. Unfortunately, this history also demonstrates that a number of steps follow the establishment of a state-conferred right to health, not the least of which is making a case for research, policy, and clinical care to address the social determinants of health. Though a small-scale effort, we hope that the Maniilaq Social Medicine Program can contribute on both conceptual and practical levels to the critical intersection of social determinants, human rights, and health.

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Human Rights and Fracking in England: The Role of the Oregon Permanent People's Tribunal

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"The dictates of public conscience can become a recognized source of law and a tribunal emanating directly from the conscience of the people reflects an idea that is bound to grow. It is claimed that institutions derive their power from the people, but actually these two have moved further and further apart and only a major public initiative can try to build a bridge between the people and power."

—Lelio Basso[1]

Abstract

The potential impacts of fracking on the environment and health, as well as impacts on local communities and their "quality of life," are well documented. This paper outlines the potential human rights impacts of fracking and argues for a human rights-based, participatory, and justice-based approach to regulation. In particular, it discusses the findings of the recent Permanent Peoples' Tribunal session on human rights, fracking, and climate change, held in Oregon, United States, and the potential impact of the tribunal's decision on other jurisdictions where fracking takes place, particularly England.

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Introduction

The government of the United Kingdom (UK) is promoting the development of its unconventional natural gas resources in England, following the United States' commercial success employing horizontal drilling combined with hydraulic fracturing ("fracking") to extract shale gas.[2] The potential impacts of fracking on the environment and health, as well as impacts on local communities and their "quality of life," are well documented.[3] The UK commenced commercial drilling in the North of England on October 15, 2018, despite community concerns and legal challenges that suggest potential harm to human health, impacts on environmental quality, inadequate procedural fairness, and limited distributive justice.[4] The UK does not have a written environmental constitution or any explicit environment-related provisions in the Human Rights Act of 1998, which draws its content from the European Convention on Human Rights. This lack of explicit recognition of environmental rights arguably makes it easier for the UK government to promote a pro-fracking agenda in England aligned with a political agenda rather than broader societal and environmental standards and safeguards. Despite calls for human rights impact assessments in relation to fracking, the UK government is resisting the development of further legislation largely on the grounds that it is confident the current regulatory regime is "more than robust enough" and due to its strong desire to promote technological development and industrial growth through the extraction of shale gas using fracking.[5]

This paper outlines the potential human rights impacts of fracking and argues for a human rights-based, participatory, and justice-based approach to regulation. In this context, the paper discusses the findings of the recent Permanent Peoples' Tribunal session on human rights, fracking, and climate change, held in Oregon, United States, and the potential impact of the tribunal's decision on other jurisdictions where fracking takes place, particularly England.[6]

An argument for a human rights framework

In 1945, the United Nations General Assembly adopted the Universal Declaration of Human Rights as a "common standard of achievement for all peoples and all nations," setting the scene for the normative landscape and codifying the basis for parameters in relation to the roles of states in the lives of their citizens.[7] Here, human rights were codified to allow an individual to "be" and to "live" a fundamentally "free" life, subject to the social contract norms of civil society (criminal law and so on), with dignity and without arbitrary interference. A useful normative standard in interpreting the application of human rights law, particularly in an environmental context, operates around notions of consent, contract, capacity, and causation. Did I agree ("contract") to be "interfered" with in this way? Do I have the capacity (including the opportunity) to make a decision (mentally or procedurally) about the way I am being affected by the decisions of others, and thus did I "consent" to the effects of said action or inaction? Where there is a lack of compromise, it is fair to say that there is likely to be an injustice or potential breach of human rights, or procedural unfairness. We attempt to explore these ideas in this paper within the context of fracking, analyzing certain notions of environmental rights and pollution.

Central to our argument is the notion that pollution, caused by the acts of others, may cause harm to humans, their health, and their environment. There are obligations on states to uphold human rights, including rights related to the environment and the global commons, in order to prevent harm and interference in such instances.

International human rights law recognizes the "interdependence between human rights and the integrity of the environment."[8] In other words, "to enjoy human rights fully, it is necessary to have a safe and healthy environment; and to have a safe and healthy environment, it is critical to protect human rights."[9] We posit that the regulation of fracking requires a robust framework that addresses environmental and public health impacts, as well as the

related potential impacts on human rights. To date, this appears not to have been the case in England.

There are myriad human rights and environmental agreements, but varying degrees to which they are implemented and enforced. The Permanent Peoples' Tribunal (PPT) was set up to "quality control" the responsibilities of states, to audit and monitor their (in)actions, and to issue advisory opinions. As indicated by the apostrophe in the tribunal's name, this forum is for and on behalf of all *peoples*, and it acts independently of political and other vested interests of states:

> The importance and strength of decisions by the PPT rest on the moral weight of the causes and arguments to which they give credibility, as well as the integrity and capability to judge of the Tribunal members." The goal of PPT Sessions is "recovering the authority of the Peoples when the States and the International Bodies failed to protect the right of the Peoples.[10]

The PPT, comprising 10 experts in human rights and environmental law, was co-hosted by the Spring Creek Project for Ideas, Nature, and the Written Word and took place on May 14–18, 2018, in Oregon, United States.[11] The session, which was also live-streamed globally, was convened to address four questions from petitioners (who in this case were legal experts representing "nature's rights"):

1. Under what circumstances do fracking and other unconventional oil and gas extraction techniques breach substantive and procedural human rights protected by international law as a matter of treaty or custom?
2. Under what circumstances do fracking and other unconventional oil and gas extraction techniques warrant the issuance of provisional measures, a judgment enjoining further activity, remediation relief, or damages for causing environmental harm?
3. What is the extent of responsibility and liability of states and non-state actors for violations of human rights and for environmental and climate harm caused by these oil and gas extraction techniques?
4. What is the extent of responsibility and liability of states and non-state actors, both legal and moral, for violations of the rights of nature related to environmental and climate harm caused by these unconventional oil and gas extraction techniques?

In addressing these four questions, the tribunal considered the following six areas of concern:

1. Human physical and mental health
2. Climate change, including both the human and earth rights dimensions
3. Environmental, ecosystem, atmospheric, hydrologic, and seismicity concerns relevant to both human rights and earth rights
4. Public participation concerns related to decision-making on oil and gas exploration, extraction, and policy
5. Fuels infrastructure concerns related to human and earth rights, including exploration, drilling, extraction, transport, and end-use processes, as well as infrastructure needed for transport, storage, and export of product and waste (for example, pipelines, storage facilities, waste treatment facilities, compressor stations, and so forth)
6. Social and cultural impacts on individuals, families, and communities that affect their human rights.

The tribunal received a range of expert evidence and testimony, which it found to

> clearly demonstrate that the processes of fracking contribute[s] substantially to anthropogenic harm, including climate change and global warming, and involve[s] massive violations of a range of substantive and procedural human rights and the rights of nature. Thus the industry has failed to fulfil its legal and moral obligations. The evidence also shows that governments have, in general, failed in their responsibility to regulate the industry so as to protect people, communities and nature. In addition, they have failed to act

> promptly and effectively to the dangers of climate change that fracking represents.[12]

We do not go into depth in discussing the tribunal's findings but instead raise some salient points in relation to the current situation in England.

The need for rights-based regulation

There have been many opportunities to develop a *sui generis* human rights impact assessment for fracking in the UK (and perhaps this is on the to-do lists of Scotland, Wales, and Northern Ireland's devolved administrations, which do not currently permit fracking), but it does not seem forthcoming from the UK Parliament. The England and Wales regulatory framework for fracking emphasizes petroleum regulation and, to a lesser extent, planning (where construction of the well site requires planning permission, which may be linked to environmental impact assessments and public consultations that might provide space for procedural human rights considerations). There is arguably little scope for the consideration of environmental human rights concerns under current regulations, which are based largely on petroleum, minerals, and energy.

There are many existing human rights agreements at the international and regional levels, including the 1948 Universal Declaration of Human Rights, the 1969 American Convention on Human Rights, the 1950 European Convention on Human Rights, the 1987 African Charter on Human and Peoples' Rights, and the United Nations Convention on the Rights of the Child. Related mechanisms for accessing justice include the Inter-American Court of Human Rights, the European Court of Human Rights, and the African Court on Human and Peoples' Rights. Some of these human rights agreements explicitly recognize a right to environment in some form (such as article 24 of the African Charter), while others do not (such as the Convention on the Rights of the Child)—however, the latter "allow" us to argue that the fulfillment of existing human rights is contingent on certain standards of environmental protection and other rights such as the right to health.[13]

In the UK context, it can be argued that a technology such as fracking, which has the potential to adversely affect environmental and public health, should be evaluated through a human rights impact assessment and regulated under a framework of human rights protections.[14] Questions posed in relation to the above are manifold and are largely equity based: Who benefits from the technology and who is set to suffer adverse impacts? What are the adverse impacts likely to be and how can they be mitigated or avoided, particularly when the technology and techniques are new to the UK? And has there been an open and public decision-making procedure that takes account of a variety of framings and views on the issues? Complementary to a human rights impact assessment approach would be the application of the precautionary principle—before fracking can be allowed to proceed—requiring that proponents of this technology undertake risk assessments to demonstrate what the related health, environmental, and other impacts might be. These processes encourage accountability and the halting of any activities that may damage the environment and human health.

The current UK regime and England's experience with fracking has highlighted a lack of accountability, gaps in access to public information and participation, and an erosion of local powers in light of "national interest," evidenced in the recent overturning of the Lancashire County Council's decision *not* to grant planning permits for shale gas drilling.[15] John Whitton et al. maintain that public opposition to shale gas in the UK is exacerbated by a convoluted planning and regulatory framework, which arguably further leads to public mistrust and additional power disparity issues.[16] In the North of England, homeowners and community residents have expressed concern over the undermining of their rights to property, to health, and to private and family life due to the lack of a legally required human rights impact assessment. The UK government has recently approved commercial extraction at the Preston New Road sites in Lancashire, England. It can be argued, however, that the regulatory regime does not address stakeholder concerns with respect

to social rights and health risks, as it is concerned mainly with licensing, infrastructure, site health and safety, and the mechanics of drilling.

Further, the public's lack of trust in the fracking industry in England could be linked to the way that companies have historically interacted with communities. Acknowledging the lack of trust in decision makers—and developing ways to remedy the problem—has not been considered in environmental impact assessments or other relevant legal mechanisms.[17] Thus, assessing and regulating shale gas through a human rights framework may help manage issues related to accountability, trust, and power and the disparity between local concerns, national interest, and industry needs.[18]

Substantive human rights issues related to fracking

It can be argued that a benchmark for environmental human rights would ideally require a zero-tolerance approach to pollution.[19] This way, there would be no impact on the rights to health, life, or water, for example. We refer to the previous section, however, where we mention consent, capacity, and compromise. Societies and communities cannot function without economic input (the economic arguments in favor of fracking have been discussed at length in the academic literature), and a compromise is needed.[20] If we are to reach a compromise, we need consultation, dialogue, and consideration of all issues and stakeholder views and concerns. One way to achieve this compromise (even if it tells us that fracking should not proceed in certain locales) is through a human rights impact assessment. We are aware of the variance in semantics and standards surrounding environmental rights discourse and take the following position in relation to fracking and human rights:

1. The natural environmental needs to be "healthful" in that it must be intrinsically robust and giving of health to humans, flora, and fauna.
2. If we require compromise on an issue, such as fracking, we need to set environmental standards at a level that accounts for the most vulnerable in our communities, including children, those with illnesses, pregnant women, and marginalized groups (such as those living in comparatively less affluent communities) in order to ensure that human rights objectives are fulfilled.
3. International and regional human rights and environmental treaties that the UK has signed and ratified can be drawn on to leverage action on particular human rights standards related to fracking in England.

The right to water is enshrined in several international conventions, including the Convention on the Rights of the Child, which "tak[es] into consideration the dangers and risks of environmental pollution," and a 2010 resolution of the United Nations General Assembly that states that "safe drinking water and sanitation is a human right, essential for the full enjoyment of life and all other human rights."[21]

The right to water is relevant for our purposes because shale gas extraction has the potential to contaminate groundwater, streams, rivers, and lakes through the migration of chemicals used in fracking fluids to underground water sources; spillage during "frackfluid" handling; improper disposal of wastewater; and underground injection of wastewaters.[22] All stages of the fracking water cycle have a potential impact on the quality of water resources, including drinking water supplies and, in turn, health. Furthermore, given that fracking fluid contains a mixture of chemicals, often not fully known, there is a risk of water contamination due to accidental surface spills and leaks.[23] Moreover, during the flowback stage, fracking fluid returns to the surface along with any injected chemicals, but it can also bring to the surface toxic materials that occur naturally underground, including radioactive materials.[24] Additionally, large quantities of water are required in the fracturing process, which can be particularly problematic in areas where water sources are already stressed (such as areas that suffer frequent droughts), affecting humans both directly and indirectly (for example, via impacts on the surrounding flora and fauna, which can have effects on the local area).[25]

Studies have found that chemicals in fracking fluids may have dangerous health and environmental effects in sufficient concentrations and exposures.[26] However, if the chemical mix is recognized as a "proprietary blend," the company may not be required to disclose its composition. Additionally, fracking activities may use chemical quantities that are below required thresholds but without accounting for cumulative effects, or the techniques and technology may not be included in legislation on account of being relatively new or being regulated under the umbrella of other processes that do not require such disclosure.

According to the United Nations Human Rights Committee, states are required to "proactively put in the public domain Government information of public interest" and ensure that access to information is "easy, prompt, effective and practical."[27] In Europe, the public's right to information is codified in the United Nations Economic Commission for Europe's Convention on Access to Information, Public Participation in Decision-Making and Access to Justice in Environmental Matters (Aarhus Convention).[28] The Aarhus Convention lays out the rights to access information and to participate in decision-making in environmental matters. In the United States, the right to information is recognized in the Convention on the Rights of the Child, the International Covenant on Civil and Political Rights, and other documents.[29] Although there are cases where information about chemical constituents, such as the proprietary formula for Coca-Cola, are not made public, the case of fracking fluid is more problematic because of the notion of consent. Thus, although the chemicals in something such as a food product may cause harm to human health, individuals can arguably decide if they want to ingest the product, as opposed to exposure to fracking fluids, which may happen regardless of an individual's choice. Also, negative publicity and media scare-mongering may make public perceptions of fracking's impacts even more egregious.[30]

Moreover, the fulfillment of other human rights, including the right to life, is contingent on the right to water. While it may seem extreme to invoke the right to life in the case of fracking in the UK, we have yet to know what the long-term cumulative effects of fracking fluid in the environment are, which could justify calls for precaution in this regard. Also, it is possible to claim that the right to life has a wider reach beyond communities in the UK. If we accept that fracking has a carbon footprint, the effects of fracking will affect the environment in other countries, thereby affecting the right to life of persons outside the UK who are suffering the life-altering effects of global climate change.[31]

The right to food is enshrined in the International Covenant on Economic, Social and Cultural Rights; the Convention on the Rights of the Child; and other conventions.[32] According to the Committee on Economic Social and Cultural Rights, this right ensures the accessibility and availability of food "free from adverse substances."[33] Food supply may be at risk from fracking activities as a result of depleted water resources and the degradation of soil or water quality.[34]

The right to health is recognized in the Convention on the Rights of the Child and the International Covenant on Economic, Social and Cultural Rights. According to the Committee on Economic Social and Cultural Rights, the right to health includes access to "safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, [and] healthy occupational and environmental conditions," in addition to "reduction of the population's exposure to harmful substances such as radiation and harmful chemicals or other detrimental environmental conditions that directly or indirectly impact upon human health."[35]

Other potential impacts of fracking include effects on property values and risk from induced seismicity, the latter of which could affect the right to safe shelter, recognized in the International Covenant on Economic, Social and Cultural Rights.[36]

Standard of living and basic human rights

The human rights framework also protects the right to an adequate standard of living. A 2017

NAACP report calls for "the establishment of a universal right to uninterrupted energy service."[37] Therefore, decisions about whether and how to proceed with fracking activities and how to regulate them should include an evaluation of the need for energy balanced against potential risks to the rights to a healthy environment and to adequate housing. Concerns expressed with respect to fracking include distrust of both the industry and government, the use of potentially risky chemicals, land access, and community impacts from the shale gas boom-bust-recovery cycle.[38] On the other hand, fracked natural gas may reduce atmospheric pollution and potentially reduce greenhouse gas emissions, as compared to other sources of energy, such as coal. In this way, fracking may ameliorate the very threats to health and the environment that are arguably caused by the practice.[39] Thus, accepted rights frameworks may conflict with one another. Decisions about these sorts of tradeoffs can often be facilitated by an external third party, underscoring the potentially significant role of a body such as the PPT.

When local and national environmental legislation prove inadequate to ensure communities' protection from the potential impacts of fracking, we have the option of triggering human rights-based obligations enshrined in international law. This approach may offer a means of attaining some form of legal accountability and standard setting while waiting for the UK's legal framework for fracking to be more fully developed. In addition, using internationally recognized human rights protections may relieve concerns regarding the demise of European Union standards and the obsolescence of European Union law in the UK once "Brexit" has been concluded.

While a human rights framework, when appropriately invoked, can be a useful mechanism to evaluate the potential risks that fracking poses to humans and the environment, what happens when international legal bodies fail to provide adequate remedies for the risks and impacts—whether material or procedural—experienced by individuals and communities? The PPT is one example of a mechanism that can be used to identify potential transgressions and issue declaratory opinions as a civil society initiative.

Permanent Peoples' Tribunal: Session on human rights, fracking and climate change

The PPT is a "civil society public opinion tribunal" founded on the principles contained in the 1976 Algiers Charter (the Universal Declaration of the Rights of Peoples).[40] The tribunal was established in 1979 in Bologna, Italy, as a direct extension of the Russell Tribunals on Vietnam (1966–1967) and Latin America (1973–1976).[41] Lelio Basso, an Italian democratic socialist politician and lawyer, suggested that the PPT become a permanent institution and an "instrument and platform to give recognition, visibility and a voice to the peoples suffering violations of their fundamental rights."[42] The PPT thus engages citizens and communities and, employing internationally established human rights law, enables judges to render advisory opinions on the human rights impacts of various issues.[43]

Independent of state governments and authorities, the PPT hears cases where "*prima facie* evidence suggests abridgement of basic rights of ordinary people."[44] Recent cases heard by the tribunal include Canadian mining in Latin America (2014) and agrochemical transnational corporations (2011).[45]

On May 14–18, 2018, the PPT held a session on human rights, fracking, and climate change, which was hosted by the Spring Creek Project at Oregon State University in the United States and was live-streamed globally. At this session, the tribunal heard oral testimony and examined evidence from submitted reports and briefs with the aim of issuing an advisory opinion on key legal questions regarding the potential impacts of hydraulic fracturing and climate change:

> Under what circumstances do fracking and other unconventional oil and gas extraction techniques warrant the issuance of either provisional measures, a judgment enjoining further activity, remediation relief, or damages for causing environmental harm?

> What is the extent of responsibility and liability of States and non-state actors for violations of human rights and for environmental and climate harm caused by these oil and gas extraction techniques.
>
> What is the extent of responsibility and liability of States and non-state actors, both legal and moral, for violations of the rights of nature related to environmental and climate harm caused by these unconventional oil and gas extraction techniques?[46]

Prior to the tribunal's May 2018 session, four preliminary hearings were held: one in Virginia, United States; two in Ohio, United States; and one in Australia. These initial hearings gathered testimony for review by judges and legal experts in advance of the main PPT session in May.[47] The international body of judges included scientists with expertise in geology, hydrology, toxicology, and environmental science; experts in economics and resource extraction; and legal scholars with experience in criminal justice, international law, and water and environmental law.[48]

The tribunal's preliminary statement

On June 4, 2018, the judges issued a preliminary statement based on the testimony regarding fracking, its impact on climate change, and its impacts on the rights of nature and humans collected during the five-day session. The statement explained that because of the "overwhelming volume and comprehensiveness" of the evidence received, the 10 judges comprising the tribunal's panel would need several months to complete their comprehensive opinion and recommendations. Due to the "great significance and public concern" regarding the issues considered, the judges issued the preliminary statement to encourage "public discussion and action to abate the negative effects of fracking."[49] Based on evidence from hundreds of independent publications, this preliminary statement noted that

> The evidence clearly demonstrates that the processes of fracking contribute substantially to anthropogenic harm, including climate change and global warming, and involve massive violations of a range of substantive and procedural human rights and the rights of nature. Thus the industry has failed to fulfil its legal and moral obligations.
>
> The evidence also shows that governments have, in general, failed in their responsibility to regulate the industry so as to protect people, communities and nature. In addition, they have failed to act promptly and effectively to the dangers of climate change that fracking represents.
>
> Finally, this particular Session of the PPT has been an experiment of collaboration and communication. It has sought to overcome the economic constraint of limited resources which impede what should be a permanent, timely exercise of assessing, monitoring, preventing and transforming the universe of violations which occur in the present global scenarios, where the decisions on policies which go against the fundamental rights of nature and of human communities are taken, imposed and directed centrally by those who have unlimited resources.[50]

The judges' preliminary statement concluded that the successful "experiment" of the tribunal could be turned into a "flexible and powerful tool which could allow the struggles of the communities of the world" to be globally communicated and could promote effective solutions and justice.[51] Therefore, although the judges' final advisory opinion has yet to be rendered, the recent PPT session on human rights, fracking, and climate change provides an example of both why human rights mechanisms are key for the regulation of a new technology—particularly one with significant potential impacts—and how international human rights law and an open forum for presenting testimony can be an important tool for protecting citizens' basic human rights. Furthermore, the literature demonstrates the role of civil society associations in bringing greater public accountability to global governance.[52] In this manner, civil society bodies such as the PPT have the potential to enhance the transparency of

global governance, encourage compliance by monitoring and reviewing global regulations, facilitate redress for evidenced harms and transgressions, and encourage the development of additional accountability mechanisms.[53] The PPT is recognized and respected by the various interested parties—communities living near fracking, urban activists, government regulators, oil and gas companies, and others. For example, the third session of the PPT addressed industrial and environmental hazards and human rights and was held in 1992 in Bhopal and Bombay, India. The session, which built on earlier hearings in the United States and Thailand, was held in Bhopal—the site of the chemical disaster—in order to enable access to justice for the aggrieved parties.[54] The tribunal can thus play a crucial role in ensuring access to justice and redress for aggrieved parties, as well as publicizing human rights transgressions and promoting justice.[55]

Conclusion

In the case of hydraulic fracturing to extract shale gas, where there is a potential for human rights violations as evidenced from cases in the United States and other countries, there is an important role for the long-established and respected PPT in promoting justice and ensuring human rights protections to the fullest extent. Particularly regarding the potential impacts of fracking on people's health and the environment, as well as the rights to social inclusion and access to participation, the expert opinion of a civil society body such as the PPT can help promote procedural justice and fairness by highlighting potential rights transgressions and acting as a global forum to promote redress. In this manner, the tribunal can fill crucial gaps in the regulation of contentious issues such as shale gas extraction and can set an important precedent for promoting and protecting international human rights.

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Challenging Neoliberalism: ILO, Human Rights, and Public Health Frameworks on Decent Work

GILLIAN MACNAUGHTON AND DIANE FREY

Abstract

In the 2008 report *Closing the gap in a generation*, the Commission on the Social Determinants of Health (CSDH) described "fair employment and decent work" as components of daily living conditions that have "powerful effects on health." The CSDH therefore proposed far-reaching structural changes to bring about decent work and health for all. Crucially, however, it failed to acknowledge two relevant international legal frameworks, the Decent Work Agenda of the International Labour Organization (ILO) and the right to decent work in international human rights law. This article compares the three frameworks for decent work—CSDH, ILO, and human rights—and makes two arguments. First, it contends that the CSDH, as a creation of the World Health Organization (WHO) and therefore part of the UN system, should have grounded its report—including the section on decent work—in the applicable international law, including the UN Charter and human rights treaties. Second, had the CSDH linked its report to established international law, it would have strengthened all three frameworks, bringing coherence to international law and policy and bolstering the power of the ILO, WHO, and the human rights mechanisms to counter neoliberalism toward achieving their common goal of decent work and health for all.

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Introduction

In the 2008 report *Closing the gap in a generation*, the Commission on the Social Determinants of Health (CSDH) describes "fair employment and decent work" as components of "daily living conditions" that have "powerful effects on health and health equity."[1] By including fair employment and decent work in its agenda on the social determinants of health, the CSDH recognized the interdependency of work and health. Work (or lack of work) impacts on health, and health (or lack of health) impacts on ability to work. The CSDH also recognized the interdependency of work with several other social determinants of health—including nutritious food, safe housing, clean water, and improved sanitation—as these social determinants are more easily accessible to those who have fair employment and decent work.[2] Yet the CSDH fell short of advancing the conceptual understanding and framework for implementation of fair employment and decent work by failing to explicitly incorporate the international law on the Decent Work Agenda of the International Labour Organization (ILO) or even recognize the human right to decent work.

"Full employment and decent work"—in contrast to "fair employment and decent work" — are international human rights recognized in the Universal Declaration of Human Rights, which is applicable to all members of the United Nations.[3] It is not surprising that work is a human right. It is key a source of self-fulfillment, identity, and dignity.[4] It is also instrumentally important to bring in income to satisfy basic needs, such as food, housing, education, and health care.[5] Additionally, it provides opportunities for social relations and community participation.[6] Indeed, unemployment contributes to social exclusion, loss of self-confidence, and poor health, and also impacts negatively on families, by, for example, increasing divorce rates, and on communities, by, for example, increasing crime rates.[7] The CSDH recognized that work "can provide financial security, social status, personal development, social relations and self-esteem," but did not recognize that full employment and decent work are human rights.[8] Moreover, the CSDH did not acknowledge that the intricate web of interconnected social determinants of health—linking food, water, housing, sanitation, and decent work, among other factors—is enshrined in international human rights law in, for example, the International Covenant on Economic, Social and Cultural Rights (ICESCR), as well as other international treaties.[9]

Unfortunately, work rights are not widely respected around the world, and work can be low paying, demeaning, dangerous, and tedious, leaving workers and their families in multi-dimensional poverty.[10] The dominance of neoliberal ideology and policymaking suggests that substantial change is not on the horizon.[11] The ILO, the UN specialized agency responsible for global governance on labor and social justice, estimates that more than 190 million people are currently unemployed.[12] This number is expected to increase over the next year by 1.3 million as more people seek to enter the work force.[13] Further, the ILO estimates that 1.4 billion workers are in vulnerable forms of employment.[14] This number is also expected to increase by 17 million in 2018 and again in 2019.[15] In developing and emerging countries, 300 million workers live in extreme poverty on less than US$1.90 (PPP) per day.[16] The CSDH recognized that these daily living conditions impact negatively on health and health equity.

The ILO has also conceptualized, promoted, and mainstreamed "full employment and decent work" throughout the UN and the world.[17] Indeed, the ILO Decent Work Agenda (1999) provides the main framework for all ILO work.[18] Consequently, it is odd that the CSDH sidelines the Decent Work Agenda—and the enormous body of work promulgated under this soft law initiative—in its chapter on "fair employment and decent work," and removes the term "full employment" from its chapter title, adding a new term "fair employment" with merely a footnote to explain the concept.[19] In contrast, Mary Robinson, former UN High Commissioner for Human Rights, speaking at the launch of the CSDH report in November 2008, highlighted "the importance of human rights as an ethical and legal framework" for action on the social determinants of health, addressing the connections between work as a social determinant of health, the ILO Decent Work Agenda, and the human right to decent work.[20]

Despite the centrality of full employment and decent work to human well-being, they have been overlooked or marginalized in international development agendas. The Millennium Development Goals (2001–2015), for example, failed to include a goal or target on full employment and decent work for all until 2007.[21] This may be because this social determinant of health (and human right) conflicts so directly with neoliberalism, the dominant global ideology and policymaking framework. Neoliberalism is an ideology of market fundamentalism, which posits that economic growth is the sole avenue to development and social progress and requires reducing labor protections, among other actions that result in exploitation of workers, to successfully compete in the global marketplace.[22] This neoliberal approach is now encompassed in Sustainable Development Goal (SDG) 8, which aims to promote "economic growth, full and productive employment and decent work for all."[23] Had full employment and decent work been linked with ending poverty (SDG 1), ending hunger (SDG 2), or ensuring healthy lives (SDG 3), it would be recognized as a social determinant of health in the global development agenda. But instead, full employment and decent work are merely *means* to or *ends* of economic growth, unlinked to human rights, health, or well-being.[24]

This article presents three approaches to conceptualizing and implementing the goals of full employment and decent work for all: (1) the ILO's Decent Work Agenda, (2) the International Bill of Human Rights, and (3) the CSDH 2008 report *Closing the gap in a generation*. Previous literature has examined the WHO, ILO, human rights, and neoliberal approaches to decent work from public health perspectives.[25] Generally, this literature has grouped WHO, ILO, and human rights approaches together and contrasted them with neoliberal approaches of, for example, the World Bank, International Monetary Fund (IMF), and World Trade Organization (WTO).[26] We bring a legal lens to this project. The three approaches we examine all recognize full employment and decent work as important conditions for health and wellbeing. However, the ILO Decent Work Agenda and human rights treaties also recognize full employment and decent work as (soft or hard) law, imposing legal obligations on states. This article argues first that the CSDH, as a creation of the World Health Organization and therefore part of the UN system, should have grounded its report—including the section on decent work—on the applicable international law, including the UN Charter, human rights treaties, and the ILO Decent Work Agenda. Second, had the CSDH linked its report to established international law, it would have strengthened all three frameworks, bringing coherence to international law and policy and bolstering the power of the ILO, WHO, and human rights mechanisms to counter neoliberalism toward achieving their common goal of decent work and health for all.

Three frameworks for full employment and decent work

International Labour Organization

The ILO, established in 1919, is the oldest international organization focused on improving employment and working conditions.[27] It is unique among international governance institutions because each of its 187 member states has worker, employer, and government representatives.[28] It was founded on an ideology of social justice, recognizing that improved employment and working conditions are necessary for sustained peace and that the failure of any country to adopt humane labor conditions creates obstacles for others to do so. The ILO's social justice mission aligns with work-related social determinants of health such as: work time limits, prevention of unemployment, adequate living wages, protection against sickness, old age, disease and injury arising from employment, and equal remuneration for work of equal value. The ILO's mission also implicitly acknowledges the role of power by recognizing the principle of freedom of association, specifically for worker and employer organizations.

The ILO's tripartite constituents establish and supervise labor standards, many of which correspond to social determinants of health. They address freedom of association, forced labor,

child labor, equal opportunity and treatment, employment policy and promotion, employment security, wages, working time, occupational safety and health, social security, and maternity and social policy. Standards take the form of binding conventions and non-binding recommendations. Conventions adopted by the ILO are open to ratification by member states, which choose freely from among them which to ratify, and then are subject to supervision by ILO mechanisms.

Since 1919, the ILO has faced new social realities and challenges to its social justice vision, and consequently, has periodically updated its mission. At the end of the Second World War, the Declaration of Philadelphia deepened the ILO's social justice commitment within the new United Nations system, establishing that the central aim of global social policy is to improve conditions of work.[29] The ILO became the UN's first specialized agency in 1946.[30] Neoliberalism, ascendant from the 1970s, has profoundly challenged the ILO's social justice mission. Employer representatives and governments increasingly sought to marginalize ILO labor standards and replace them with market-based logics.[31] This led to a decline in convention ratifications in the 1990s and a decline in the power and influence of trade unions.[32]

In response, the ILO adopted two soft law initiatives to reinvigorate its relevance in global social policymaking. First, the ILO adopted the 1998 Declaration on Fundamental Principles and Rights at Work.[33] The Declaration established four core labor standards (CLS), separate from its regular convention and supervisory system. The CLS are: (1) freedom of association and the right to collective bargaining; (2) elimination of all forms of forced or compulsory labor; (3) abolition of child labor; and (4) elimination of discrimination in employment.[34] The Declaration was novel in that it bound ILO members to respect and promote the principles underlying the rights even if they had not ratified the conventions guaranteeing the rights. The CLS sparked sharp human rights critiques for being overly narrow, neoliberal friendly, and excluding important rights, such as work time limits, and health and safety standards.[35]

In 1999, expanding upon the CLS Declaration, the ILO launched its second soft law initiative, the Decent Work Agenda, which encompasses four strategic pillars to guide the ILO and member countries. The four pillars are:

1. *Employment promotion*: Policies, goals, and strategies to achieve full employment with appropriate pay.
2. *Social protection*: Prevention of oppressive working conditions; policies for the prevention of work-related injuries and illnesses; social security for sickness, disability, pregnancy, old age, unemployment, or other conditions that prevent a person from working.
3. *Social dialogue*: Support for tripartite consultation and negotiation between workers and employers from workplace to national levels.
4. *Rights at work*: Incorporation of the 1998 Declaration on Fundamental Principles and Rights at Work and its four CLS.[36]

The full institutionalization of the Decent Work Agenda into the ILO culminated in 2008 with the adoption of the Declaration on Social Justice for a Fair Globalization. This Declaration affirmed the ILO's mission to pursue social justice by placing "full and productive employment and decent work at the centre of economic and social policies" of the ILO and its members in the face of globalization.[37] In this way, the four pillars of the Decent Work Agenda became the basis for all ILO policy and programming.

An innovation of the Decent Work Agenda was that "work" was not narrowly conceived as only waged employment. Instead, it was broadly construed to encompass all the ways that people contribute to society and the economy.[38] This includes unpaid work, self-employment, and informal work.[39] The concept of "decent" in the Agenda aligns closely with the social determinants of health because it signifies that work must be of acceptable quality in terms of income, working conditions, job security, and rights and dignity.[40] As with the CLS, the Decent Work Agenda was not linked to

ILO conventions associated with each of the pillars. Decent work was not conceived as a "human right" but instead was framed as the ILO's primary goal and "the most widespread need, shared by people, families and communities in every society, and at all levels of development."[41]

Not surprisingly, in light of neoliberal orthodoxy, employers and governments did not intend—in the CLS or the Decent Work Agenda—to establish hard law or to impose specific legal obligations on ILO member countries. Within the ILO system, both are considered soft law and important policy objectives despite the fact that there are ILO conventions that align with virtually all aspects of CLS and the Decent Work Agenda.[42] Although the ILO is a specialized agency of the UN, neither CLS nor the Decent Work Agenda explicitly recognizes the human rights related to work, health, or the social determinants of health previously established in the UN system. Nonetheless, the ILO mainstreamed the CLS and the Decent Work Agenda extensively throughout international and national systems, receiving support from the UN General Assembly, the United Nations Development Programme (UNDP), the World Bank, and the IMF. Decent work was also incorporated (albeit late) in the MDG targets and then in SDG 8.[43] Arguably, the soft-law version of "decent work" that fails to challenge neoliberalism has dominated. This impairs the ability of the "right" to full employment and decent work to challenge the structural obstacles and power imbalances described by the CSDH as detrimental to health.

International human rights

International human rights also recognize full employment and decent work as central to human dignity. The UN Charter, adopted in 1945, established that the United Nations shall promote "higher standards of living, full employment, and conditions of economic and social progress and development" as well as "universal respect for, and observance of, human rights, and fundamental freedoms for all without distinction as to race, sex, language or religion."[44] Moreover, all members of the UN pledge to take joint and separate action in cooperation with the UN to achieve these purposes.[45] Thus, the ideas of full employment and human rights are both entrenched in the UN Charter, which prevails over any other obligations of UN members under international agreements.[46]

The Universal Declaration of Human Rights (UDHR), adopted in 1948, links human rights and employment, recognizing an array of work-related rights in Articles 22–24.[47] These include: (1) the rights to work, to free choice of employment, to just and favorable conditions of work, and to protection against unemployment; (2) the right to equal pay for equal work without any discrimination; (3) the right to just and favorable remuneration ensuring an existence worthy of human dignity; (4) the right to join trade unions; (5) the right to rest, leisure, limitation on work hours, and periodic holidays with pay; and (6) the right to social security and to realization of the economic, social, and cultural rights indispensable for human dignity and free development of the personality. All members of the UN commit to promoting and observing the rights in the UDHR and must report on their progress in this regard to the UN Human Rights Council every four years in a procedure known as the Universal Periodic Review.

Additionally, several international human rights treaties establish legally binding work-related obligations for states that have ratified them. The ICESCR, along with the UDHR and the International Covenant on Civil and Political Rights (ICCPR), forms the International Bill of Human Rights, and also contains the most widely applicable work-related rights.[48] Today, there are 169 State parties to the ICESCR, which provides detailed work-related rights. The main provisions are similar to those in the UDHR: Article 6 (the rights to decent work and freely chosen employment), Article 7 (the rights to fair remuneration and just and favorable conditions of work), Article 8 (union rights), and Article 9 (the right to social security). Other articles also include work-related rights, including, for example, Article 10 (the rights of working mothers to paid leave before and after childbirth, and the rights of children to be protected from economic exploitation),

Article 12 (the right to continuous improvement of workplace safety), Article 13 (the right to technical and vocational education), and Article 15 (the right of authors to protection of their interest in their scientific, literary, or artistic products).

In sum, there are a multitude of work rights in the ICESCR. Moreover, most of these rights have been further detailed by the Committee on Economic, Social and Cultural Rights (CESCR), which is charged with supervising states in implementing the Covenant, by way of General Comments, Concluding Observations on country reports, and Statements. As a result, there is a large body of international hard law and soft law on work rights, including the rights to full employment and decent work. In particular, the CESCR explains that the right to work in Article 6 is an individual and a collective right, and "encompasses all forms of work, whether independent work or wage-paid work."[49] Further, the CESCR maintains that the right to work must be the right to *decent* work.[50] It defines "decent work" as:

> *work that respects the fundamental rights of the human person as well as the rights of workers in terms of conditions of work safety and remuneration. It also provides an income allowing workers to support themselves and their families as highlighted in article 7 of the Covenant. These fundamental rights also include respect for the physical and mental integrity of the worker in the exercise of his/her employment.*[51]

In most respects, the CESCR's elaboration of the work rights in Articles 6, 7, 8, and 9 aligns with the ILO concepts of full employment and decent work because the committee draws extensively from the ILO conventions in interpreting these rights.[52]

The CESCR makes a significant contribution to the goals of full employment and decent work by also adopting the ILO's soft law initiative, the Decent Work Agenda, into its interpretations of the work rights in the ICESCR. In some cases, the ILO conventions linked to the four decent work pillars have not been widely ratified but the CESCR extends the obligations to all 169 State parties to the ICESCR.[53] For example, ILO Convention No. 158, which requires cause to terminate an employee, has been ratified by only 35 parties, however, the CESCR adopted it in General Comment No. 18 on the right to work, extending the "for cause" requirement to all 169 State parties to the ICESCR. Additionally, the ICESCR locates full employment and decent work in a holistic human rights framework that encompasses a full range of interconnected and interdependent economic, social, cultural, civil, and political rights that impact on health and health equity, aligning well with the CSDH's approach on the social determinants of health.[54] This human rights approach is also universal, applying to all people, and contrasts sharply with the ILO's piecemeal approach to labor standards, which are often adopted to protect only a specific group of workers, such as agricultural workers, dock workers, or domestic workers.[55]

On the other hand, there are limitations to the human rights approach, at least as it has been interpreted and implemented to date. In general, it has not successfully challenged neoliberal orthodoxies.[56] For example, the CESCR has greatly limited the right to full employment, declaring that "it should not be understood as an absolute and unconditional right to obtain employment."[57] Rather, it calls upon states to adopt measures aimed at achieving full employment—providing no examples of policies or best practices in this regard—and recognizes that international factors may create structural obstacles beyond the control of states, hindering realization of this right.[58] In contrast, many countries have adopted employment guarantee programs, which demonstrate that states may adopt policies that directly bestow the unconditional right to employment.[59] In other words, the CESCR has supervised rather timidly the human right to full employment and decent work, avoiding many controversial issues. Indeed, in the face of austerity measures in Europe, following the 2007–2008 economic crisis, which both had significant negative impacts on health and health equity, commentators have characterized the CESCR's application of the ICESCR as consistent with, or at least failing to challenge, the tenets of neoliberal ideology.[60]

Commission on the Social Determinants of Health

In 2005, WHO Director-General JW Lee established the CSDH to "collect, collate, and synthesize global evidence on the social determinants of health and their impact on health inequity, and to make recommendations for action to address that inequity."[61] The results of the CSDH's study were published in the 2008 report *Closing the gap in a generation*. In this report, the CSDH identifies three overarching recommendations: "(1) improve daily living conditions, (2) tackle the inequitable distribution of power, money and resources, and (3) measure and understand the problem and assess the impact of action."[62] In this respect, the CSDH "takes a holistic view of the social determinants of health."[63]

The report advances the discussion on the social determinants of health substantially by explicitly addressing social justice, power, and inequities in health between rich and poor people and between rich and poor countries.[64] It states:

> *Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair. It is this that we label health inequity. Putting right these inequities – the huge and remediable differences in health between and within countries – is a matter of social justice. . . . Social injustice is killing people on a grand scale.*[65]

As Audrey Chapman remarked, this type of language, unequivocally condemning such disparities in life opportunities, is rarely seen in a UN publication.[66]

The daily living conditions identified by the CSDH include focusing on: (1) early childhood development; (2) improved urban and rural living conditions; (3) fair employment and decent work; (4) social protection policy supportive of all; and (5) universal health care. Like the report in general, the section on full employment and decent work is holistic. It examines unemployment, precarious work, working conditions, the political economy of employment relationships, and vulnerable populations. In the report, the CSDH also makes five recommendations on fair employment and decent work: (1) prioritize full and fair employment and decent work in international and national institutions and policy agendas; (2) establish national policies on secure work and real living wages; (3) increase national capacity to promote and enforce fair employment and decent work standards; (4) reduce insecurity for people in precarious work; and (5) expand occupational health and safety standards to cover informal workers and include work-related stressors.[67]

The CSDH's agenda on fair employment and decent work was concrete and bold in challenging neoliberalism. The report identifies the structural obstacles to improving fair employment and decent work, including the politics and power that have maintained the gross inequities and social injustice. For example, the report challenges corporate structure and recommends that states consider changing corporate law to alter their objectives from maximization of shareholder value to improvement of social and environmental conditions, including employment.[68] It also recognizes the importance of labor unions to decent work, stating, "Unions are powerful vehicles through which protections for workers – nationally and internationally – can be collectively negotiated."[69] Additionally, the report links fair employment and decent work to many other conditions of daily living that impact on health and health inequities. This holistic approach mirrors that of the human rights approach and specifically incorporates most of the subjects of the rights spelled out in the ICESCR.

Nevertheless, the CSDH report fails to use a human rights framework. It acknowledges human rights sporadically. For example, it refers to the right to the highest attainable standard of health (or the right to health) several times but does not mention Article 12 of the ICESCR until page 158, and then very briefly, nor does it mention the Special Rapporteur on the right to health until page 173.[70] The report also mentions, as daily conditions of living, the human rights to housing, water, and sanitation. In addressing employment and work, however, the report fails to acknowledge that they are also human rights recognized in international law. So, while some aspects of human rights are identified as such, others, like full employment and

decent work, are downgraded from human rights to policy objectives of the CSDH. Moreover, the CSDH merely names the rights but does not use or acknowledge their substantive content. Additionally, under "labor standards," the CSDH mentions only the CLS, and merely refers to a broader range of labor standards without noting that they also align with the human rights to full employment and decent work.[71]

Perhaps most puzzling, the CSDH replaces the term "full employment"—which is in the ILO Decent Work Agenda and the MDGs—with the term "fair employment" as the complement to "decent work." Table 1 compares the definitions of these two terms. Importantly, "full employment" is a legal obligation under the UN Charter, the ICESCR, and ILO Convention 122, while "fair employment" appears to be a creation of the CSDH. According to its report, "Fair employment implies a just relationship between employers and employees."[72]

By invoking this new term, the CSDH indicates limited understanding of the concept of "decent work" as defined by the ILO and international human rights law, which both imply a just relationship between employers and employees, ensuring respect for the dignity of workers. As shown in Table 2, the components of the CSDH concept of "fair employment" corresponds precisely to elements of the human rights to full employment and decent work in the ICESCR. Moreover, the downgrading of "full employment" as the complement to "decent work" is not explained in the report.

After the ILO, the UDHR, the ICESCR, and the CESCR had defined and established global standards and human rights obligations for full employment and decent work, the CSDH created a new framework largely untethered to established law or other historical precedent. Moreover, as Audrey Chapman has explained in her comprehensive evaluation of *Closing the gap in a generation*, the CSDH chose a "weaker formulation" by framing the report in terms of ethical obligations and ignoring human rights laws and standards. This applies in particular to full employment and decent work, where the CSDH does not even acknowledge that these are human rights, much less the body of jurisprudence and scholarly work that had already been generated on these rights. For example, while seeking greater power for unions in order to increase protection for workers, the CSDH undermines

TABLE 1. Definitions of "Fair employment" and "Full employment"

Fair employment (CSDH)	"The term 'fair employment' complements the concept of decent work. It encompasses a public health perspective in which employment relations, as well as the behaviours, outcomes, practices and institutions that emanate or impinge upon the employment relationship, need to be understood as a key factor in the quality of workers' health. Fair employment implies a just relationship between employers and employees."
Full employment (ILO and human rights)	Full employment requires policy that aims to ensure that "there is work for all who are available for and seeking work."

TABLE 2. CSDH "Fair Employment"

Components of fair employment	Corresponding human rights provision
Freedom from coercion	ICESCR Article 6(1) (freely chosen work), Article 7(d) (rest, leisure, periodic holidays with pay, and limitations on work hours), 10(3) (protection of children from economic exploitation)
Job security	CESCR General Comment 18, para. 11 (valid grounds for dismissal and right to redress)
Fair income	ICESCR Article 7(a)(i) (fair wages), (ii) (decent living)
Job protection and social benefits	ICESCR Articles 7(b) (safe and healthy working conditions), 8 (union rights), 9 (social security), 10(2) (paid leave for working mothers before and after childbirth), 12(2)(c) (industrial hygiene)
Respect and dignity at work	CESCR General Comment 18, paras. 7-8 (decent work respects the human rights of the worker)
Workplace participation	ICESCR Article 8 (union rights)
Enrichment and lack of alienation	ICESCR Article 6(2) (policies and programs to achieve steady economic, social, and cultural development)

itself by failing to take advantage of international law in this area.

Additionally, by ignoring human rights law, the CSDH missed the opportunity to bolster its agenda and that of the international human rights mechanisms that share the concern for realizing full employment and decent work. By aligning the two frameworks—the ICESCR and the social determinants of health—the CSDH could have brought an entire range of international and regional mechanisms to bear in monitoring the implementation of its agenda.[73] Instead, we have merely another list of policy recommendations with no one responsible to take them forward. Further, the CSDH could have contributed to creating a coalition between public health activists, human rights nongovernmental organizations, and labor unions, which could have educated and mobilized people to support implementation of the CSDH's recommendations. Instead, the CSDH found that the ILO concept of decent work was inadequate to the task of requiring just relationships between employers and employees, marginalizing a potential key constituent—labor unions—which are responsible for ensuring such just relationships. It also potentially alienated human rights NGOs and activists by failing to acknowledge that they exist and might be relevant to implementation of the CSDH recommendations. Finally, the CSDH speaks to political empowerment, inclusion, and voice "that underpins social well-being and equitable health," and yet failed to recognize full employment and decent work as human rights, and thus failed to contribute to empowering people to demand these rights.[74]

Toward collaboration in achieving common goals

All three frameworks for full (and fair) employment and decent work have developed in the context of global neoliberalism, which has proven to be an extremely challenging paradigm for people who must work to support themselves – "workers." Neoliberalism emerged as a policy framework in the 1970s, first by Pinochet in Chile, followed by Thatcher in the UK, and then Reagan in the United States.[75] It was well entrenched globally by the time of the 1993 World Conference on Human Rights, which initiated a revival of attention to economic and social rights, and was also the context for the launch of the 1999 ILO Decent Work Agenda. Thus, in 2005-2008 when the CSDH was working on its report, the human rights to full employment and decent work and the ILO Decent Work Agenda were existing legal frameworks in the UN system.

In this light, the CSDH might have grounded *Closing the gap in a generation*—an important UN report—upon the solid foundation of the UN Charter and the UDHR, as well as the ICESCR, which aligns extraordinarily well with the social determinants of health. Indeed, Paul Hunt, then the UN Special Rapporteur on the right to health, pointed out in his 2005 UN report the synergies between these frameworks, and expressed his firm support for the CSDH's important mandate when it was established.[76] Yet the CSDH failed to acknowledge the "considerable congruity" Hunt highlighted between the CSDH's mandate and the framework on the rights to health, housing, food, and water.[77] Had these siloed efforts joined forces, they might have advanced a stronger case against neoliberalism and the obstacles it creates to advancing the right to health, the rights to full employment and decent work, and the social determinants of health.

What human rights and the ILO Decent Work Agenda could have provided to the CSDH report

Interestingly, the background report on Employment Conditions and Health Inequalities prepared by the Employment Knowledge Network (EMCONET) for the CSDH stated "today fair employment is not recognized as a human right," and thus called for "political and public health international institutions" to "recognize fair employment and decent working conditions as universal human rights."[78] The EMCONET failed to acknowledge that full employment and decent work are human rights enshrined in the UDHR and the ICESCR, among other international human rights instruments. Moreover, it created "fair employment" to cover a range of employment-related rights that are already

encompassed in the human rights concepts of full employment and decent work. Had the EMCONET, and thus the CSDH, recognized full employment and decent work as human rights, they might have delved into the jurisprudence (such as the CESCR General Comments) and scholarly literature in this area to obtain more detailed content of these rights, as well as connected to an ongoing system of authoritative interpretations and applications. Although the CSDH draws on ILO standards, it does so only to a limited extent, focusing primarily on the four core labor standards and leaving out fair wages, workplace safety, employment training, and other important components of full employment and decent work as though international law does not address them.[79] In short, the CSDH might have embedded its work more effectively in the existing UN institutional architecture, providing it greater visibility, legitimacy, coherence, and sustainability.

What the CSDH report could have provided to the ILO and human rights systems

By invoking the human rights to fair employment and decent work in *Closing the gap in a generation*, the CSDH would also have bolstered the human rights system, especially the right to health and the rights to full employment and decent work. Certainly, WHO and the ILO have much larger capacity to address these rights than the UN "mainland" human rights system, including the Office of the UN High Commissioner for Human Rights (OHCHR), the Human Rights Council, the Special Procedures, and the treaty bodies.[80] Had the CSDH fully integrated human rights into its report and its analysis, it would also have drawn attention to the impact of violations of the rights to full employment and decent work on health. Moreover, its bold pronouncements on reforming corporate law, supporting worker voice through labor unions and worker organizations, and effective regulation of the financial sector, might have encouraged the CESCR to do so as well. The CESCR has been relatively weak on these issues, as well as other issues that directly confront neoliberalism, and could have benefited from such support from the CSDH and WHO.[81] Moreover, by incorporating the Decent Work Agenda more fully, rather than focusing primarily on the CLS, the CSDH could have reinforced the ILO's holistic approach to full employment and decent work, strengthening the challenge to neoliberalism. In short, the CSDH was willing to confront neoliberal ideology and structures, and both the ILO and human rights systems would benefit from such inter-institutional support.

What the CSDH, the ILO, and human rights could have provided to SDG 8

The SDGs are the most recent global agenda seeking to address health disparities and other gross inequalities in life opportunities and outcomes. In many ways, the SDG framework is a plan of action on the social determinants of health and on the human rights in the ICESCR. Yet the human rights content in the SDGs is just as Paul Hunt described the human rights content in *Closing the gap in a generation*: "disappointingly muted" and "underdeveloped and understated."[82] No SDGs are framed in terms of human rights, and only a handful of the 169 targets integrate human rights language or standards.[83] SDG 8 states "Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all."[84] This SDG fails to align with human rights for several reasons. First, it appears to condition the human rights to full employment and decent work upon economic growth.[85] However, it is precisely when there is no or low economic growth that these rights are most important. Second, evidence has shown that economic growth does not necessarily result in realizing full employment and decent work.[86] Third, the merger of full employment and decent work with economic growth appears to be a retreat from the MDG 1 characterization of work as a target associated with poverty reduction.[87] Finally, improved education, health care, or water and sanitation could equally be conditioned upon economic growth, but they are not in the SDG framework. Why is full employment and decent work singled out to be linked to economic growth in SDG 8?

The CSDH takes a decidedly more human rights-friendly perspective on full employment and decent work, as well as the other social determinants

of health. It viewed full employment and decent work as essential components of health equity, like food, water, and housing. As it notes, "growth by itself, without appropriate social policies to ensure reasonable fairness in the way its benefits are distributed, brings little benefit to health equity."[88] A unified coalition—of human rights advocates, worker representatives, and WHO—on full employment and decent work might have influenced the formulation of SDG 8, resulting in a more human rights and health equity enhancing form. United, they might have been able to disengage full employment and decent work from the neoliberal economic growth-first paradigm. The resulting paradigm, however, is that full employment and decent work are not recognized as human rights or social determinants of health but merely as components of the neoliberal economy. In short, the CSDH could have helped to ensure that full employment and decent work were recognized as human rights or health equity goals in the SDG framework.

Conclusion

In a 2015 study, Di Ruggiero et al. found a "lack of consensus about what decent work means" in the policy texts of the ILO, WHO, and the World Bank, and considerable challenge across these institutions in promoting a single agenda.[89] This challenge was, at least in part, due to the neoliberal orientation of some governments, some specialized agencies of the UN system, and the international financial institutions, which conflicts with social justice paradigms, such as health equity and fair globalization, of others. The study found that ideological, institutional, and disciplinary barriers may have contributed to the contested notion of decent work.[90] Our analysis indicates that even where ideologies are closely aligned—the CSDH, ILO Decent Work Agenda, and human rights—the institutional and disciplinary silos may prevent natural allies from unifying around a common concept of full employment and decent work to challenge those with opposing ideologies. Here, the CSDH's presentation of fair employment and decent work in *Closing the gap in a generation* failed to take advantage of the opportunity to incorporate the ILO Decent Work Agenda and the related human rights in a manner that could have built a coalition of actors, as well as coherent and consistent law and policy across those institutions with established and sustainable systems for monitoring and accountability. As a result, the ILO and human rights also lost out, as the CSDH's bold and profound message on decent work as a social determinant of health was dislocated from existing international legal regimes. Willingness to collaborate across institutional and disciplinary boundaries with those who have common ideologies and goals—although different institutions and disciplines—may be the key to achieving the rights to decent work and health for all.

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PERSPECTIVE

Tax and the Right to Health

BERNADETTE ANN-MARIE O'HARE

Introduction

Human rights are enshrined in numerous international treaties, including the Universal Declaration of Human Rights; the International Covenant on Economic, Social and Cultural Rights; and the International Covenant on Civil and Political Rights. However, the right to health is limited by the principle of progressive realization, which has left loopholes allowing the deferment of fundamental human rights.[1] Many of these fundamental human rights—such as the rights to food, water, and sanitation—are critical determinants of health (see Box 1). Indeed, in its General Comment 14, the United Nations Committee on Economic, Social and Cultural Rights interprets the right to health as an inclusive right that encompasses the underlying determinants of health and health care.[2] The importance of these fundamental rights to health is demonstrated by the fact that access to them accounted for most of the reductions in child and maternal mortality between 1990 and 2015.[3] These rights are also among the Sustainable Development Goals (SDGs). However, many people throughout the world—particularly those in low-income countries—do not have access to them (see Figure 1). The United Nations Committee on Economic, Social and Cultural Rights, in its General Comment 3, has tried to compensate for the loopholes that facilitate governments' and their development partners' complacency in fulfilling these rights by defining non-derogable minimum core obligations that establish a minimum set of protections that are immediately applicable to all people in all nations and not subject to the flexibilities permitted by progressive realization.[4]

Technically speaking, it would be financially feasible to remedy these deprivations relative to the overall level of global resources. For example, the annual cost of providing improved water and sanitation for the unserved is US$28.4 billion, which is a mere 1.6% of annual global military expenditure.[5] However, in order to build a state-citizen relationship and to generate ongoing tax revenue, these rights should ideally be funded through a financial process that is transparent, accountable, and responsible and includes domestic revenue generation for public services.[6] The benefits of relying on domestic resources instead of overseas development aid are multiple: less volatility, more citizen participation, and a focus on local (as opposed to donor) priorities.[7] That said, government revenue in low-income countries is minimal—on average, it is less than US$100 per capita—and government expenditure on health is less than US$20 per capita.[8] Therefore, while the responsibility for fulfilling fundamental human rights lies within national borders, sometimes

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governments' ability to finance such fulfilment lies out of their reach.[9]

Tax abuses have a negative impact on fundamental human rights, yet human rights scholars have largely ignored the need for revenue, and tax scholars rarely analyze laws and policies through a human rights lens.[10] This essay discusses government revenue and public services as they relate to human rights and explores who the relevant duty-bearers are, as well as what actions they could take to increase the chances of everyone, everywhere, having access to their fundamental human rights.

Government revenue, public services, and fundamental human rights

The pathway between government revenue, government expenditure, public services, and fundamental human rights is known.[11] For example, a 10% increase in tax revenue leads to a 17% increase in public health spending in low-income countries, and increasing public health spending by 1% decreases under-five mortality by 0.86%.[12] However, the limiting factor in many countries is government revenue, and before identifying global mechanisms

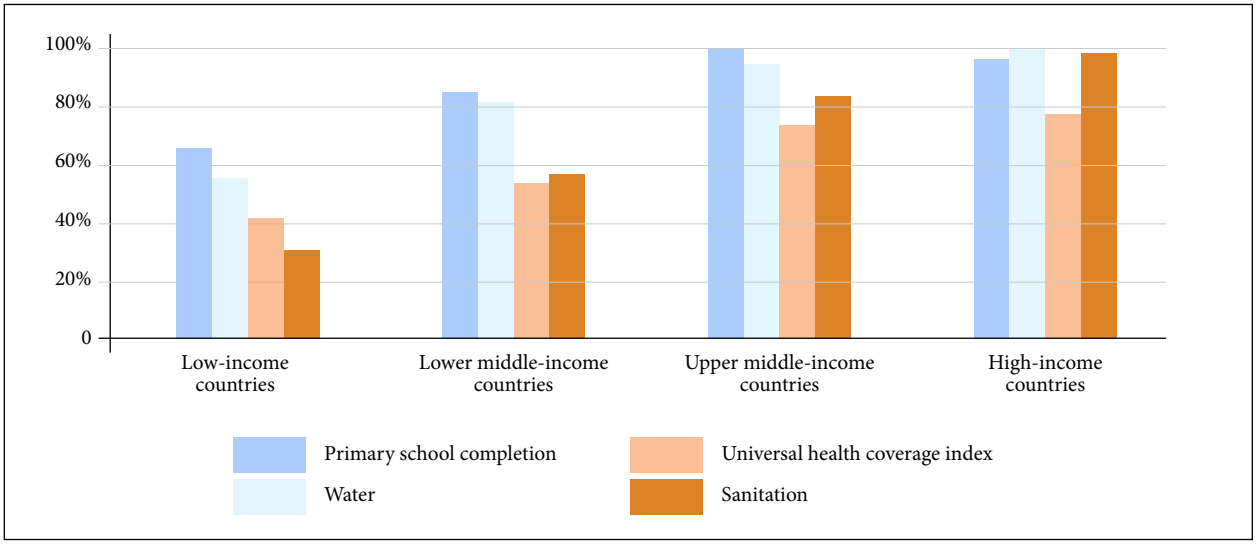
Box 1. Examples of minimum core obligations

Minimum core obligations—as highlighted by the Committee on Economic, Social and Cultural Rights in its general comments—require states to undertake the following actions:

- Ensure the right of access to employment, especially for disadvantaged and marginalized individuals and groups, enabling them to live a life of dignity.
- Ensure access to the minimum essential food that is nutritionally adequate and safe.
- Ensure access to basic shelter, housing, and sanitation, and an adequate supply of safe drinking water.
- Provide essential drugs as defined under the World Health Organization's Action Programme on Essential Drugs.
- Ensure free and compulsory primary education for all.
- Ensure access to a social security scheme that provides a minimum essential level of benefits that cover at least essential health care, basic shelter and housing, water and sanitation, food, and the most basic forms of education.

Source: Office of the United Nations High Commissioner for Human Rights, *Fact sheet no. 33: Frequently asked questions on economic, social and cultural rights* (2008). Available at https://www.ohchr.org/Documents/Publications/FactSheet33en.pdf.

FIGURE 1. Coverage of fundamental human rights, by country income level



Primary school completion = % eligible who complete primary school. Water = % of population using at least basic drinking water services. Universal health coverage index = coverage of essential health services. Sanitation = % of the population using at least basic sanitation services.

Source: World Bank, Databank (2018). Available at https://data.worldbank.org.

to plug these gaps, leakages from current revenue streams should be curtailed.[13] Lost government revenues as a result of international and national injustices and inefficiencies include tax waivers, the failure to tax wealthy citizens and the informal sector, corporate tax avoidance, corruption, and debt repayment by the state.[14] Taxes are the main contributor to government revenue in all countries. However, tax as a percentage of gross domestic product (GDP) is much lower (18%) in low-income countries than in high-income countries (40%).[15] Reasons for this tax gap include undertaxing the informal sector and wealthy citizens, granting tax waivers, and tax avoidance by international corporations.[16]

Domestic and international tax avoidance and waivers result in the burden falling on small domestic companies and individual taxpayers, which can often mean insufficient revenues that lead to reduced social spending and thus reduced access to fundamental human rights.[17] The resulting fiscal deficits may skew taxation toward indirect taxes, which tend to be regressive and place a burden on low-income groups, who often have the least voice on the political stage.[18]

The informal sector accounts for approximately 40% of GDP in many low- and middle-income countries.[19] Reasons for failing to tax this sector include logistical problems (especially in agricultural societies), weak financial systems (which inhibit the tracking of companies' and individuals' tax obligations), and a lack of capacity.[20] However, a further reason for undertaxed wealthy citizens and companies is their political influence on tax policy formulation and administration.[21]

Tax incentives are widely used to attract foreign investment, despite the lack of evidence that they promote economic growth.[22] Countries often compete with one another to attract foreign investment by offering incentives such as tax holidays, which sets off a race to the bottom in which public purses suffer and shareholders benefit. While tax avoidance in the informal sector and decisions about tax incentives fall under the remit of national governments, tackling international corporate tax avoidance is the responsibility of a broader group of actors, as explained in the next section.

International corporate tax avoidance and government revenue

In low- and middle-income countries, 20% of government revenue is derived from corporate income tax, compared to 10% in wealthy countries.[23] Therefore, multinational corporations (MNCs) have a substantial impact on government revenue in all countries but are critically important in low- and middle-income countries. Corporate income tax is payable only when MNCs realize profits. Taxing profit allows for avoidance opportunities, including overstating costs (including intangible services such as managerial support and interest payments in thinly capitalized projects) when selling to related entities (transfer pricing).[24] In theory, related entities use an "arm's length" price and charge subsidiaries the same price as they would an unrelated company, but this is often not done in practice.[25] Base erosion and profit shifting is a term used to describe the shifting of taxable profits out of the country where the income was generated into low-tax and secrecy jurisdictions (also called tax havens) where there may be little or no economic activity, using transfer pricing between related entities to reduce the amount of tax due.[26] In addition, tax treaties between countries are used to minimize tax by diverting profit via states with a favorable treaty in place.[27]

Who are the duty-bearers for tax avoidance and what can they do?

The United Nations Guiding Principles on Business and Human Rights direct MNCs to avoid adversely affecting human rights, and guidelines from the Organisation for Economic Co-operation and Development state that MNCs should contribute to environmental, economic, and social progress.[28] Despite these guidelines, international corporate tax avoidance is estimated to be US$500–650 billion each year, one-third of which is from low- and middle-income countries.[29] Leaders of MNCs that minimize tax payments in countries where large proportions of the population have unmet fundamental human rights are duty-bearers and should move this issue up on their agenda by ensuring

board-level scrutiny and by reporting profits and taxes paid publicly.

Among the strategies to tackle base erosion and profit shifting is one first proposed by the Tax Justice Network and now driven by the G20 and G8 and agreed to by 100 countries, which requires large MNCs to report profits and economic activity, by country, to the revenue authority of their parent company.[30] This information is confidential and shared only with authorities in countries where there is a related entity if there is a bilateral agreement in place.[31] However, an initiative by the Intergovernmental Working Group of Experts on International Standards of Accounting and Reporting (coordinated by the United Nations Conference on Trade and Development) proposes a public framework for country-by-country reporting, with indicators relevant to the achievement of the SDGs, including revenue, tax paid, green investment, and community investment.[32] The Global Reporting Initiative, which sets standards for stock exchanges and thousands of firms, is also developing a draft standard for public country-by-country reporting of tax and other payments to governments. The integration of these two methodologies may produce a robust, public country-by-country reporting framework for the SDGs.[33]

Governments are obliged to use their maximum available resources to realize fundamental human rights.[34] However, Nigeria, for example, has 5,000 tax inspectors for a population of 140 million, compared to the Netherlands, which has 30,000 inspectors for a population of 10 million.[35] Regarding international tax avoidance, only eight African countries have units within their revenue authorities that focus on transfer pricing, most of which were established recently. Kenya's unit uses techniques such as tip-offs from the public and screening processes that flag MNCs doing business in countries with a history of harboring tax abusers. These units face numerous challenges, including high-income countries not responding to requests for information even when a tax treaty is in place, a lack of data for price comparisons to allow estimations of arm's-length pricing, inadequate capacity, and corruption.[36] An approach taken by Vietnam has been to require domestic subsidiaries of large MNCs to provide a copy of the global country-by-country report to the Vietnamese tax authorities, which reduces the burden on these authorities.[37] Governments that grant tax incentives need to be confident that the economic and development gains as a result of the investments do not outweigh the costs regarding revenue available for public services and fundamental human rights. Recent evidence shows that tax treaties with low-tax and secrecy jurisdictions do not result in additional investment and lead to average revenue losses of 15% of corporate income tax.[38] Challenges to both domestic and international tax abuse in all countries include a lack of political will, as political leaders may have vested interests and wish to exempt specific industries.[39]

Other duty-bearers include the home countries (generally high-income countries) of MNCs, which are required to prevent infringements of rights outside their territory by business entities over which they can exercise control.[40] Stock exchanges could exclude MNCs with tax havens in their corporate structure; for example, one-quarter of the MNCs listed on the London Stock Exchange with mining operations in Africa use tax havens.[41] High-income countries should also review their tax treaties with low- and middle- income countries to ensure that there are no adverse spillover effects on fundamental human rights.[42]

Enablers of tax avoidance and their professional bodies, including tax professionals, accountants, lawyers, bankers, and the nominees of shell companies, need to appreciate that tax planning often adversely affects fundamental human rights.[43] The world's largest accounting firms have helped MNCs avoid billions of dollars in taxes.[44] The investment community, including pension fund managers, should stop regarding tax as a cost to be minimized; for example, 75% of pension beneficiaries in the UK feel it is vital that their pensions not be invested in MNCs that avoid taxes, and 78% believe that it is essential that MNCs pay their fair share of taxes in low-income countries.[45]

What role can individuals play? The links between individual choices and human rights

Elizabeth Ashford suggests that there is a web of complex interactions that results in structural injustices and, like Iris Young, believes that the collective that has produced it is responsible.[46] The concept of ownership, which motivates consideration of the links between one's decisions and others' lack of fundamental human rights, may drive different choices.[47] Thomas Pogge states that if more people understood their role in poverty, more might try to eradicate it.[48] For example, one link between individual choices and fundamental human rights is the taxes paid by MNCs, and an increased awareness of individual responsibility may drive consumers to choose brands and investments that do not avoid taxes, to vote for governments that act to change unjust global institutional arrangements, and to avoid banks that facilitate tax avoidance.[49] A familiar narrative used to challenge this approach is that action will be ineffective due to corruption by undemocratic governments. However, Pogge argues that some corrupt governments continue to be in power because of a global institutional order that enables the exchange of finance and weapons for natural resources.[50]

Conclusion

The critical determinants of health are water, sanitation, health care, and education. These are fundamental human rights and are included in the SDGs. They are most sustainably provided for by public services and financed with domestically generated revenue. Barriers to governments meeting their minimum core obligations for the right to health include insufficient revenue. International corporate tax avoidance is among the reasons for this.

Action is required at many different levels by a range of duty-bearers. These include MNCs, governments, professional enablers of tax avoidance, and individuals who are in a position to make voting, banking, consuming, and investment choices.

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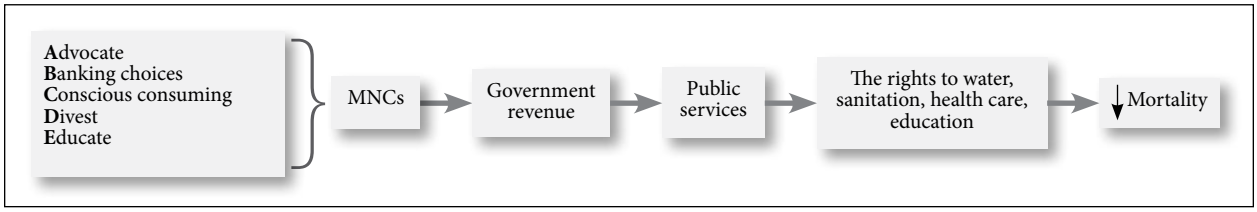
FIGURE 2. The pathway between individual choices and the core rights of others



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A Meta-Narrative Literature Synthesis and Framework to Guide Future Evaluation of Legal Empowerment Interventions

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Abstract

Legal empowerment is increasingly recognized as a key approach for addressing socio-structural determinants of health and promoting the well-being and human rights of vulnerable populations. Legal empowerment seeks to increase people's capacity to understand and use the law. However, limited consensus remains on the effectiveness of legal empowerment interventions in optimizing health outcomes. Leveraging

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a meta-narrative approach, we synthesized literature describing how legal empowerment interventions have been operationalized and empirically studied with respect to health determinants. The studies included here document diverse legal empowerment approaches and highlight how interventions changed the context surrounding the health of vulnerable populations. The absence of robust conceptualization, operationalization, and measurement of the risk contexts in which legal empowerment approaches operate limits the clarity with which interventions' impact on health can be ascertained. Despite this, legal empowerment is a promising approach to address the health of marginalized populations. To foster support between the fields of legal empowerment and health, we explore the limitations in study design and measurement of the existing evidence base; such scrutiny could strengthen the rigor of future research. This paper provides a guide to the socio-structural levels across which legal empowerment interventions impact health outcomes in order to inform future interventions.

Introduction

The World Health Organization (WHO) Commission on Social Determinants of Health (CSDH) identified improved living and working conditions and access to health care as fundamental to health equity.[1] The CSDH has highlighted the importance of tackling socio-structural drivers, including norms, policies, laws, and processes of governance, that tolerate or promote inequitable distributions of power and social resources.[2] Within this framework, legal empowerment is gaining recognition as a critical approach that provides a mechanism for individuals and communities to address structural barriers to health and human rights through improved access to justice—broadly defined to include access to public health and other services unjustly denied despite relevant rights and availability of adequate resources.[3]

Whether law is conceptualized as an enabling or limiting mechanism for rights holders or part of a more complex governance framework, it is deeply embedded within social, economic, and political processes. The health of vulnerable populations such as sex workers, people who inject drugs, men who have sex with men, ethnic minorities, and people living with HIV can be substantially impacted by their legal environment. These populations experience health inequities stemming from structural factors, including: stigma, discrimination, social and economic marginalization, criminal sanctions, and violence.[4]

Public health law studies have contributed to our understanding of how human rights and laws affect environments, behaviors, and health outcomes.[5] Studies have focused on how the legal environment can harm the health of vulnerable populations. For example, discriminatory laws affecting people living with HIV have been shown to reinforce social stigmas and be associated with increased violence and reduced health care access.[6] Discriminatory laws and systematic human rights abuses affecting ethnic minorities have also been linked to poorer health outcomes, including higher prevalence of maternal health risks and gender-based violence.[7] These examples emphasize the law as a determinant of health and demonstrate

that legal institutions often institutionalize inequities and contradict expectations of equality. This inverse relationship between the law's ability to recognize rights and its capacity to vindicate them is central to legal empowerment efforts. Recently, public health research has focused increasingly on law as a predominantly negative health determinant of vulnerable populations, focusing less on how law can be used to positively impact health.[8]

Legal empowerment has gained prominence as a framework for strengthening individuals' capacity to exercise their rights, with implications for their health and well-being.[9] The United Nations Development Programme and the World Bank Group have supported access to justice and rule of law programs around the world.[10] Legal empowerment is a concept that has emerged in support of access to justice, a broader initiative that has evolved over time and continues to lack a common definition. The United Nations Development Programme defines access to justice as the ability of disadvantaged groups to prevent and overcome poverty by seeking a remedy through the justice system for grievances, in accordance with human rights principles.[11] As articulated by the Commission on Legal Empowerment and the Poor, legal empowerment is rooted in an enabling human rights framework, whereby vulnerable people gain understanding and control of their legal entitlements.[12]

Legal empowerment is identified by the use of laws, legal systems/institutions, and services for socio-structural change. Interventions commonly encompass nontraditional forms of assistance and redress, such as access to community paralegals or customary law remedies.[13] They also include assisting the disadvantaged with nontraditional mechanisms such as monitoring health services constrained by corruption, entrenched bureaucracy, gender bias, and other forms of discrimination to bolster their responsiveness and efficacy.

With the increasing focus on legal empowerment, it is essential to understand the evidence base supporting these approaches. We conducted a meta-narrative review of the literature to identify legal empowerment interventions addressing health-related outcomes. Its objectives were to document the legal empowerment approaches used and the health domains and socio-structural levels addressed by these interventions, and to describe their impact.

Methods

Search strategy and selection criteria

To identify legal empowerment interventions targeting health-related outcomes, we adapted a meta-narrative review of the literature, following the RAMESES review standards.[14] The RAMESES approach involves an initial scoping of the literature, broader systematic searches of electronic databases, selection and appraisal of papers, and data extraction.[15] The method is particularly appropriate where a topic spans multiple disciplines, limiting the utility of a systematic review and meta-analysis.

Definition of terms

For this review, we adapted Golub's expansive definition of legal empowerment: "the use of law and rights to help increase disadvantaged populations' control over their lives."[16] We included interventions that sought to increase access and participation in legal processes, including initiatives that sought to change formalized laws and policies, as well as the systems and institutions that create, enforce, and implement those laws. In line with Goodwin and Maru (2014), our definition of legal empowerment required a process component, namely the expansion of people's ability to engage with law-making processes as a result of the intervention.[17] Finally, we adopted a definition of health-related outcomes that included health outcomes (such as infectious diseases and mental health outcomes), proximal individual or interpersonal level health behaviors (such as substance use and interpersonal violence), and socio-structural determinants (such as stigma, laws, and policies) that are risk factors for more proximal health outcomes.

Inclusion criteria

An article had to meet the following criteria for inclusion:

1. Published in a peer-reviewed journal or grey literature publication (including thesis publications) between 2002 and 2015.
2. Evaluation of an intervention for legal empowerment (as defined above) and its impact on a health-related outcome (as defined above).
3. Studies could be of any design from any country.
4. Studies could involve any population.
5. Studies had to be available in full in English.
6. As the objective of the meta-narrative was to identify the impact of legal empowerment interventions on health outcomes through the identification of broad health dimensions, sources were not excluded based on quality. However, studies were excluded if none of the intervention components addressed a health-related outcome.

Screening and data abstraction

This review followed the RAMESES review standard.[18] The first step, scoping, is the process of identifying key relevant background publications broader in scope than the inclusion criteria of the final review. We identified publications in public health law, health and human rights, and social epidemiology through the study team's internal expertise. The list was expanded through consultation with external experts in legal empowerment and public health law, and review of relevance-based searches of Westlaw, PubMed, Scopus, Embase, Sociofile, POPLINE, GlobalHealth (OVID), and PAIS International. Next, a list of publications was created by tracing the citations from the background publications forwards and backwards, using Scopus for peer-reviewed literature and Google Scholar for grey literature.[19] A full list of search terms and databases used is included in the supplementary files.

The first and second reviewer (MW and ID) did parallel screening of titles found in the completed search. If the article was deemed relevant by at least one reviewer, the abstract was retrieved. Next, the first and third reviewer (MW and IH) screened the abstract for relevant information. If one or both reviewers selected the abstract, the full article was reviewed. The first author served as a tie breaker and discussed discrepancies in order to reach consensus on whether to include an article. This review process allowed for inclusion of documents emergent in the full text review and abstraction process but not identified in the initial scoping and sampling. The first and second author read all articles and reached consensus on each paper. All papers selected were appraised alongside data abstraction using a standardized abstraction form (see supplementary files).

Data synthesis

We analyzed the final list of articles through a meta-narrative approach as it allows for different types of data and methods from diverse disciplines to be analyzed together.[20] This approach allowed for the inclusion of both quantitative and qualitative studies, which is not feasible in traditional systematic reviews. Initially, thematic analyses were conducted by the first author to identify broad themes within the interventions and outcome measures. Through the analytic process, the applicability of a socio-ecological model was examined to characterize how different types of legal empowerment processes address contextual risk factors for proximal health outcomes. Within the expansion of people's use and enjoyment of the law, the common themes of implementation at the grassroots level of legal empowerment interventions were "participatory legal empowerment strategies" and "institutional reform strategies" primarily occurring at the state level (see Table 3). We also identified whether the interventions were conducted as part of broader strategies (for example, community-based monitoring systems).

For all interventions, we present whether individual, interpersonal, or structural outcomes were considered in the study, using an adapted socio-ecological model to guide data abstraction. Socio-ecological models are particularly useful for understanding the contexts which influence disease acquisition across intersecting levels of influence, including individual (such as attitudes and behaviors), interpersonal (such as social support), community (such as social participation) and legal (such as local, state, and national laws).[21]

TABLE 1. Summary of legal empowerment intervention designs

Author(s)	Design of legal empowerment intervention(s)
Abdikeeva et al., 2013	Four NGOs carrying out a range of access-to-justice strategies with the collective goal of improving Roma health and human rights by (1) addressing systemic impediments to health care and (2) developing tools to bring about positive legislative changes.
Barendrecht et al., 2013	Paralegal program to help disadvantaged communities resolve disputes and legal problems in Nicaragua.
Beattie et al., 2010; Beattie et al., 2014; Gurnani et al., 2011	Multi-layered violence intervention targeting policy makers, secondary stakeholders including police, lawyers, and media, and primary stakeholders as part of a wider HIV prevention program in India.
Beletsky et al., 2011	Police-level intervention on police legal knowledge, syringe access attitudes, and ability to address needle stick injuries in the United States.
Beletsky et al., 2012	Introduction of national policy to prohibit police interference with public health outreach, targeting IDU and sex workers. Policy backed by public health and human rights groups' programmatic activities to support the policy in Kyrgyzstan.
Beletsky et al., 2013	Structural intervention to integrate HIV-prevention training into police officer training in Kyrgyzstan.
Biradavolu et al., 2009	Structural intervention to mobilize sex workers and address context-specific factors contributing to HIV vulnerability in India.
Bluthenthal et al., 2008	Legalization and provision for syringe exchange programs in the United States.
Dworkin et al., 2014; Lu et al., 2013	NGO community-led land and property rights intervention in rural Kenya to address women's disinheritance and its role in the spread of HIV among women.
Gruskin et al., 2013	Three NGOs offering legal integration programs, which look to integrate legal services into existing health care settings in Kenya.
Hughes et al., 2007	Law 30/2000, passed as a response to high prevalence of persons who inject drugs (PWID) in Portugal, accomplished several goals: (1) decriminalized use, possession, and acquisition of all types of illicit substance for personal use; (2) formally abandoned punitive exercise of police power as the state response to substance use, and moved that response to the public health sector; and (3) removed substantial barriers to the exercise of constitutionally protected rights by substance-using persons.
Kigodi et al., 2013	NGO program with trained paralegals offering legal knowledge, support, referrals, and advice to help women navigate legal cases and resolve conflict outside of the formal justice system in Tanzania.
Jardine et al., 2012	Passage of national HIV law including measures affecting police at ward level in Vietnam.
Kohrt et al., 2015	Educational intervention for police, targeting knowledge of mental health and law relevant to mental health users in Liberia.
Mac Dowell, 2003	Strategic litigation and advocacy on behalf of persons living with HIV/AIDS (PLWHA) in Venezuelan human rights courts, leading to (1) amendments to the 1999 Constitution to remove barriers for PLWHA enjoyment of right to protection of health under 1961 Constitution, and (2) expansion of access to treatment.
Midford et al., 2002	Intervention to implement a new model for illicit drug law enforcement that emphasizes harm reduction at a community level in Australia.

TABLE 2. Summary of studies evaluating health-related outcomes of legal empowerment interventions, 2002-15, by author, country, and population

Reference	Country	Target population	Method/data gathering	Sample size	Sampling	Aim/objective/purpose of study
Abdikeeva et al., 2013	Serbia, Romania, Macedonia	Roma	Review of Open Society Foundations (OSF) Legal Empowerment programs in Roma communities.	N/A	N/A	Proposal for a framework for the qualitative evaluation of legal empowerment, documentation and advocacy; media advocacy; and strategic litigation. Proposal suggests collecting data at four impact levels (NGO capacity, to individual accountability, to changes in law and policy, and to the effect on communities at large).
Barendrecht et al., 2013	Nicaragua	Disadvantaged persons, particularly those benefiting from informal conflict resolutions and reductions in domestic violence.	Mixed methods; prospective ecological study	480 pre-exposure; 1000 post-exposure; 36 qualitative	Random, augmented by quota sampling to match basic national demographics	Evaluation of the effect of access to justice programs on prevalence of legal needs, legal services use, and legal empowerment.
Beattie et al., 2014	India	Female sex workers	Quantitative; two cross-sectional integrated behavioral-biological assessment surveys	1975; 1934	Cluster sampling (FSW who sold sex at home, brothels, lodges, or dabhas); time-location sampling (street-based FSW)	Assessment of the impact of community mobilization on HIV and STI prevalence, HIV risk behaviors, and collective and individual power among FSWs.
Beattie et al., 2010	India	FSW	Quantitative; cross-sectional, combining anonymous polling booth surveys (PBS) and face-to-face integrated behavioral-biological assessments (IBBA) over a multi-year period	7,638 PBS; 3,852 IBBA	Random, cluster, and time-location cluster for both PBS and IBBA.	Evaluation of structural intervention on policy makers, secondary stakeholders (such as police), and FSWs, modifying the relationship between violence and FSW condom use, STI/HIV risk.
Beletsky et al., 2011	United States	PWID	Quantitative; cross-sectional pre- and post-interventions survey of police	94 pre-training; 78 post-training.	Not specified	Evaluation of the effect of police-level intervention on police legal knowledge, syringe access attitudes, and ability to address needle stick injuries.
Beletsky et al., 2012	Kyrgyzstan	PWID	Quantitative; cross-sectional post-intervention survey of police	319 law enforcement officers	Purposive	Assessment of links between Instruction 417 knowledge and legal and public health knowledge, attitudes towards harm reduction programs, and intended practices targeting vulnerable groups.
Beletsky et al., 2013	Kyrgyzstan	PWID	Quantitative; cross-sectional post-intervention survey of police	313 law enforcement officers	Purposive	Evaluation of the effect of police level trainings on legal and public health knowledge, positive attitudes toward public health programs and policies, occupational safety awareness, and intended practices.

TABLE 2. *continued*

Reference	Country	Target population	Method/data gathering	Sample size	Sampling	Aim/objective/purpose of study
Biradavolu et al., 2009	India	FSW	Qualitative; interviews and ethnographic observations with FSWs, NGO staff, and other actors (lawyers, police).	26 NGO staff meetings; 12 Crisis International team meetings; 60 CBO community meetings; 6 legal literacy sessions; 3 advocacy sessions in police stations; Interviews 75 FSW; 11 NGO staff; 36 other actors.	Not specified	Analysis of effect of interventions of community-based organization interventions on police practices affecting HIV risk.
Bluthenthal et al., 2008	United States	PWID	Quantitative; multivariate analysis of changes pre- and post-legal intervention	24 programs	Purposive	Assessment of effect of legalization of syringe exchange programs on syringe exchange, syringe exchange budgets, and police harassment of program staff and clients.
Dworkin et al., 2014	Kenya	Women	Qualitative; in-depth interviews with program leaders and implementers. Implementers randomly selected from inclusive list.	50	Random	Identification of the strategies that were used to prevent, mediate, and resolve property rights violations program was designed to reduce women's HIV risk at the community level by protecting and enhancing women's access to and ownership of land.
Gruskin et al., 2013	Kenya	Health service users, particularly PLWHA	Mixed-methods; program evaluation	Not provided	Purposive	Evaluation of three Open Society-funded legal integration programs providing LE interventions in health care settings, particularly PLWHA.
Gurnani et al., 2011	India	FSW	Quantitative; program evaluation	N/A; program consists of 83 project sites; 169 drop-in centers; and 619 STI clinics.	N/A; standardized, routine program monitoring indicators analyzed for entire intervention; daily tracking of news articles concerning HIV/AIDS and FSWs has been conducted manually by media monitors in selected districts.	Evaluation of effect of structural intervention on policy makers, secondary stakeholders (such as police), and FSWs on service provision, service uptake, and positive media reports on HIV and FSW.

TABLE 2. *continued*

Reference	Country	Target population	Method/data gathering	Sample size	Sampling	Aim/objective/purpose of study
Hughes et al., 2007	Portugal	PWID	Mixed-methods; including review of evaluative reports, and key informant interviews	11	Not given	Assessment of the impact of legislation ending use of penal sanctions for drug possession and introducing a system of referral to Commissions for the Dissuasion of Drug Addiction, through stakeholder perceptions of major impacts, successes, and challenges in adopting decriminalization, and patterns of drug use.
Kigodi et al., 2013	Tanzania	Women	Qualitative; including interviews, focus groups, observations, and secondary data sources.	31 interviews; 4 focus groups	Convenience	Exploration of the effects of legal services for women and children surviving GBV and other gendered injustices.
Jardine et al., 2012	Vietnam	PLWHA, PWID	Qualitative, post-intervention interviews	13 interviews with law enforcement personnel; 27 semi-structured questionnaires with street level police	Not given	Assessment of influence of regulation on ward level police regarding harm reduction in order to better target education and structural change.
Kohrt et al., 2015	Liberia	Mental health services users (MHSUs)	Qualitative and quantitative, pre- and post-intervention interviews.	14 law enforcement personnel	Not given	Assessment of education intervention on police knowledge of mental health, attitudes toward MHSUs, and law relevant to MHSUs.
Lu et al., 2013	Kenya	Women	Qualitative; post-intervention interviews	20	Not given	Identification of facilitators and inhibitors to implementation of intervention reducing HIV risk by promoting property rights of women.
MacDowell, 2003	Venezuela	PLWHA	Legal policy review	N/A	N/A	Review of the effect of changes to Venezuela's Constitution in 1961 and 1999, and legislation guaranteeing rights to ART and HIV treatment on numbers enrolled in treatment and compliance.
Midford et al., 2002	Australia	PWID	Mixed method; observations, police focus groups, interviews with key informants and participants; survey with police, review of media	9 focus groups with police officers; 301 police officer post-training survey	Purposive sampling	Investigation of the implementation and impact of structural intervention on drug harm.

TABLE 3. Research on legal empowerment and complimentary strategies for increasing access to justice and health outcome domain

Reference	Access to justice strategy															Outcome measure					
	Legal empowerment strategies								Complimentary strategies to legal empowerment (1)			Institutional reform strategies			Part of broader strategy			Structural			
	Educ.	Para legal	Legal Aid	Cust. Law	Health Law Int.	Conflict Res.	Partic. Human Rights	Citizen Partic.	Comm. Monitor.	Comm. Mobil.	Comm. Media	Litigat.	Police Train.	Law Change		Individual	Inter-Pers.	Comm. Outcome	Health Sys.	Legal Sys.	Macro Struct.
Abdikeeva et al., 2013	✓	✓					✓				✓	✓		✓		✓		✓	✓		✓
Barendrecht et al., 2013		✓				✓												✓			
Beattie et al., 2010	✓							✓	✓	✓	✓		✓		✓	✓(2)	✓				
Beattie et al., 2014	✓							✓	✓	✓	✓		✓		✓	✓(2)		✓			
Beletsky et al., 2012													✓							✓	
Beletsky et al., 2013													✓							✓	
Beletsky et al., 2011													✓							✓	
Biradavolu et al., 2009	✓							✓	✓	✓	✓		✓		✓					✓	
Bluthenthal et al., 2008														✓					✓	✓	
Dworkin et al., 2014	✓	✓		✓		✓				✓						✓					
Gruskin et al., 2013			✓		✓	✓										✓			✓		
Gurnani et al., 2011	✓							✓		✓	✓		✓		✓						
Hughes et al., 2007														✓		✓			✓		✓
Kigodi et al., 2013		✓														✓					
Jardine et al., 2012														✓	✓					✓	
Kohrt et al., 2015													✓						✓	✓	
Lu et al., 2013	✓	✓		✓	✓											✓		✓	✓		
MacDowell, 2003												✓							✓		✓
Midford et al., 2002													✓							✓	

Findings

The scoping process yielded 67 key background documents, including both grey and peer-reviewed literature (Figure 1). From the analysis of citations of this initial list, we identified 2,261 articles for review, of which 19 met our inclusion criteria (Figure 1). The articles described the results of 16 different legal empowerment interventions on health outcomes (Table 1). One intervention was considered by three articles, and another by two.

Study populations

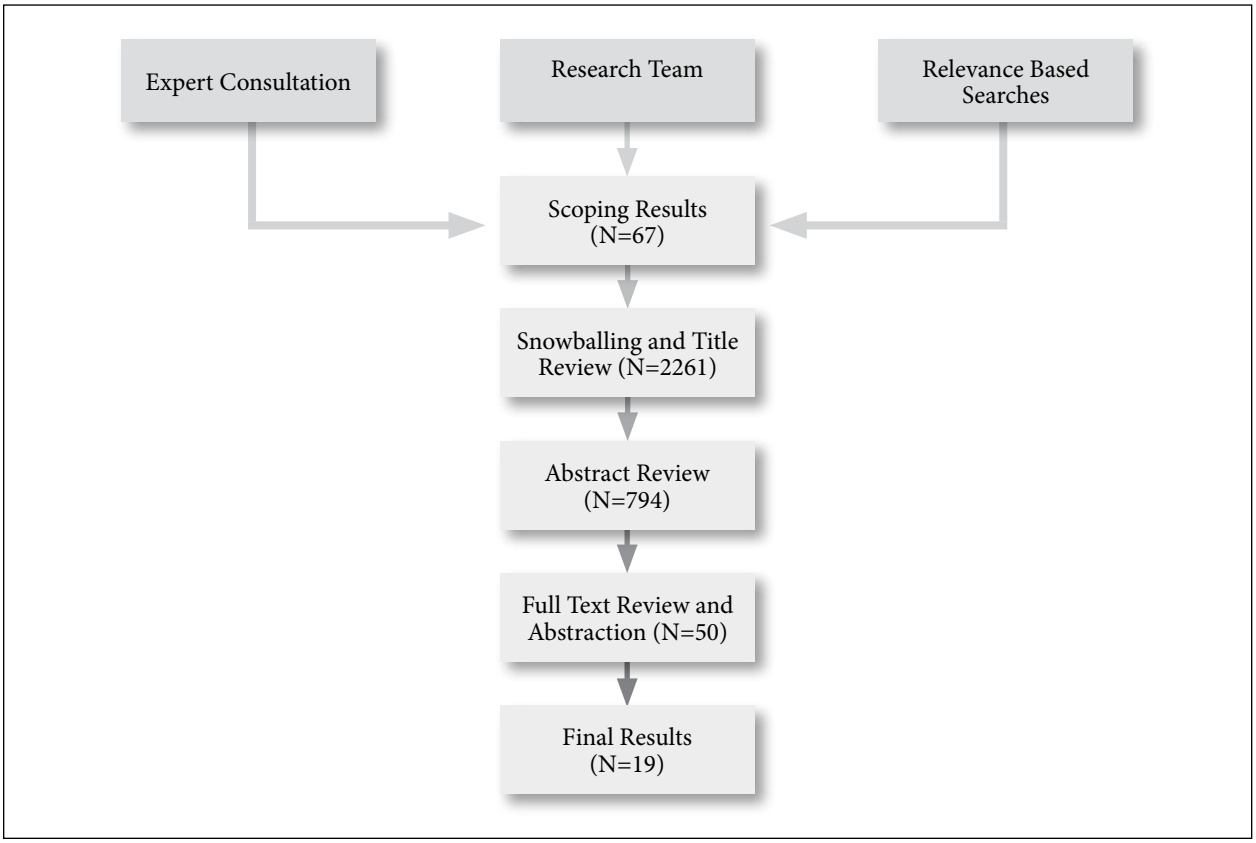
While there was at least one study from each continent, overall coverage was very limited, highlighting the small number of studies in general (Figure 2). The studies also included a wide range of different vulnerable populations (Table 2). The variety of populations reinforces the range of people that could benefit from legal empowerment interventions.

Legal empowerment interventions

Interventions in the review employed a range of access strategies appropriate to the socio-legal context in which communities live.[22] We categorized legal empowerment interventions as either "participatory" legal empowerment approaches or "institutional reform" approaches. Five (26%) studies used only participatory legal empowerment approaches and nine (47%) used only an institutional reform approach (Table 3).[23] The remaining five (26%) used both approaches.[24]

Crucial to participatory legal empowerment-focused interventions are people's participation and active engagement in the entire process (such as paralegal programs and community legal and rights education). Legal empowerment approaches that involve institutional reform processes were characterized as being more top down, while still linked to the expansion of people's involvement with lawmaking processes.[25] Building

FIGURE 1. Flow chart of search strategy



on this taxonomy of "participatory" and "institutional" legal empowerment approaches, we set out typologies of intervention under these two classifications, improving the conceptual understanding of the legal empowerment interventions.

Within the participatory legal empowerment strategies, we identified eight emergent themes (Table 3). These were interventions that included improved legal and human rights knowledge (n=7 studies); the training of community-based paralegals (n= 5 studies); citizen participation in governance (n=4 studies); informal conflict resolution (n=3 studies); the hiring of legal aid lawyers (n=2 studies); customary law strengthening (n=2 studies); integration of legal services into health care (n=2 studies); participatory documentation of human rights violations (n=1 study).[26] Of the studies using participatory legal empowerment strategies, six combined these efforts with complementary community-based approaches (either monitoring systems, mobilization, or media strategies), and four were integrated into larger interventions.[27]

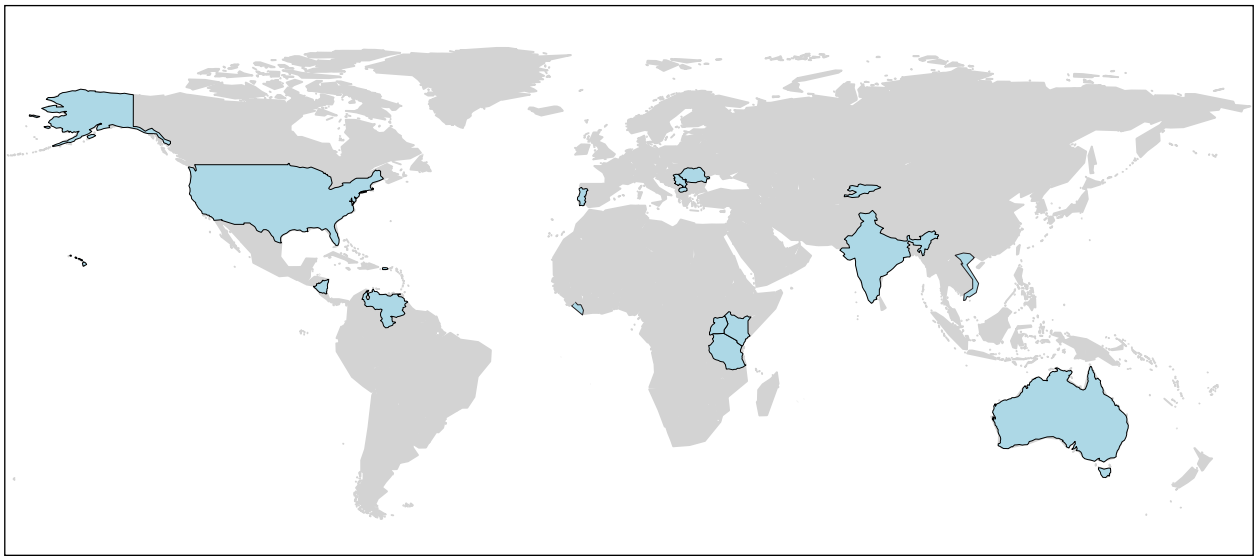
Within the institutional reform approaches, we identified three key themes. These were the training of police forces in their interactions with vulnerable populations (n=7); changes to law or policy to reduce discrimination or increase access to justice for at-risk populations (n= 4); and the use of strategic litigation (n=1 study).[28]

Most efforts to measure legal empowerment focused primarily on descriptions of interventions and measurement of intervention exposure. Many studies were excluded because they focused exclusively on measuring exposure to an intervention, without attempting to assess the relevance to health. Nine of the 15 studies measured exposure at a programmatic level or as part of the study design. This included reporting the number of legal cases in progress or completed; participation in group workshops or meetings; program records and routine data (for example, clients receiving paralegal services); general service provision and uptake of intervention by the community; police knowledge of law and completion of police training.[29]

Study design and measures

Studies representing varying types of methodological approaches were included: qualitative (n=6, 26%), quantitative (n=7, 37%) and mixed method (n=4, 27%), with two studies being a legal and programmatic policy review, respectively (13%).[30] The majority of quantitative studies were cross-sectional and only recorded exposure to the intervention and the outcome of interest at a single time point. Two studies included data before and after intervention exposure; however, none included a single

FIGURE 2. Distribution of legal empowerment interventions from the 19 studies



cohort followed through time.[31]

Studies differed substantially in the health-related measure of impact. These could be grouped into individual level health outcomes or health-related risk behavior, interpersonal outcomes that assess the impact of interventions on health-related interactions between individuals (in particular, interpersonal violence), and structural measures.

Forty-two percent of studies considered individual-level health related outcomes (n=8), with all but two considering behavior change. Of the five individual level studies that focused on behavior change, one looked at changes in HIV/STI related risk behaviors (condom use) and STI infection, and five examined changes in legal knowledge and rights awareness.[32] Two of the five studies that considered behavior change also reported on individual level empowerment, of which one measured "self-efficacy" around condom use within the context of HIV prevention.[33] In addition, one paper reported on changes in drug use and drug-related disease and death.[34] Three studies considered interpersonal violence. One looked at violence as a proxy for HIV-related health outcomes, while the others looked at reductions in violence as an outcome in and of itself.[35]

Four studies considered community-level change.[36] Only one study, a complex community intervention (of which legal empowerment was one component), included a validated measure based on recognized constructs, in this case "collective power."[37] Another two studies measured prevalence of "community conflicts" post intervention and changes in community attitudes around women's legal property rights.[38] Changes at the health system level were reported in seven studies (36%), most of which looked at health care access and reported different indicators including access to health insurance, provision of drug treatment, access to HIV treatment, and access to needle exchange programming.[39] Three studies measured rights awareness and changes in the health care setting. One study looked at partnering between health providers and police.[40]

Structural changes to institutional/legal systems were considered the outcome in eight (42%) of the papers; these were conceptualized as changes to the operation of legal institutions (that is, police practices and judicial decision making). All the studies measured changes in police practices or knowledge, which included measuring the impact of harm reduction trainings and changes to the law on policing of people who inject drugs and sex workers; the enforcement of previously ignored due process laws; knowledge around mental health; and the level and quality of cooperation between police and health agencies.[41]

Finally, changes in macro-structural factors tied to health were considered in three of the studies through changes to the law, national educational curricula, and state fulfillment of legal obligations.[42]

Intervention impact

All eight of the studies that considered an individual-level determinant found evidence that a legal empowerment intervention had a positive impact on health or on a socio-structural determinant relevant to a more proximal health outcome. Five of these studies reported evidence of a legal empowerment intervention's impact on increased legal knowledge and rights awareness (hypothesized as being relevant to HIV prevention) and reduction in stigma and discrimination.[43] Two reported increased individual empowerment; one of these measured this increase quantitatively, finding that female sex workers who were highly exposed to a broad intervention—which included a legal empowerment component—were significantly more likely than women with low exposure to the intervention to be tested for HIV, use condoms regularly, and test positive for chlamydia or gonorrhea.[44] Notably, this study measured exposure to a range of HIV interventions including peer navigation, which was supported by legal empowerment strategies implemented previously, illustrating the complex nature of assessing the impact of any single measure. One paper reported a national decline in substance use and drug-related deaths in Portugal following a change in the law intended to expand access to harm reduction services for people who inject drugs.[45]

Of the three studies looking at interpersonal

violence, two found positive changes associated with a legal empowerment intervention. These studies evaluated a multi-layered violence intervention in India, which included institutional legal empowerment components targeting the sensitization of police and lawyers. The studies found reductions in the proportion of female sex workers reporting violence post-intervention, as well as female sex workers supported in seeking redress in more than 90% of 4,600 incidents of reported violence.[46] Finally, a study evaluating a paralegal community program in Nicaragua found a drop in the perceived prevalence of violence in both the intervention area and the control area.[47] Interestingly, the study hypothesized that this drop in both areas may have been the result of an introduction in Nicaragua of a comprehensive law against violence to women.[48]

All four of the studies that measured community-level changes reported increased community mobilization relevant to more proximal health outcomes.[49] In one paper, this community mobilization was associated with increased uptake in HIV/STI-related services (although legal empowerment was not a key exposure in the intervention).[50] One study looking at a community paralegal intervention found a reduction in the prevalence of "community conflicts" post intervention, relevant to community level "well-being."[51] Another study, evaluating a community-led property rights intervention in Kenya, found improvement in community attitudes around women's legal property rights and entitlements relevant to HIV prevention strategies.[52]

Of seven studies considering changes at the health care system level, four reported increased access to health-related services as a result of the intervention.[53] Two reported increased rights awareness in the health care setting which was hypothesized, based on the literature, to have an impact on mitigating discrimination.[54] One found an intervention increased collaboration between health professionals and the police, important to improved health outcomes for people with mental health problems in Liberia.[55]

Of the papers measuring structural changes, a positive increase in police knowledge (particularly around harm reduction) and practices towards people who inject drugs was observed in seven of the eight studies. This included an increase in referrals of people who inject drugs to health agencies (adjusted odds ratio (aOR) 2.21, 95% CI: 1.33-3.9), a decline in police harassment, and reduced police intent to confiscate syringes following training.[56] Two interventions designed to improve collaboration between health services and law enforcement found increased cooperation, relevant to the health and well-being of PWID and those with mental illness.[57] Legal changes prohibiting police interference with harm reduction programming in Kyrgyzstan was significantly associated with better knowledge of and attitudes to harm reduction programming (aOR=1.84, 95% CI:1.12-3.00).[58] Conversely, in Vietnam, similar changes to the law did not result in positive changes to police behavior, suggesting the importance of incorporating police training as part of any law reform.[59]

In the three studies that documented changes at the macro structural level, one reported that participatory human rights activities by the Serbian Roma population brought about laws that expanded health care access to include them, exemplifying how community-led advocacy can bring about structural changes relevant to health.[60] The other two involved a change to the law: the decriminalization of certain drugs in Portugal was followed by the inclusion of drug education in the national educational curricula; the law guaranteeing rights to antiretroviral therapy in Venezuela was associated with access to adequate treatment for people living with HIV.[61]

Methodological limitations to study designs

Notably, none of the studies followed a single cohort through time, which would have provided an opportunity to measure changes over time. Studies relied on serial cross-sectional assessments or the comparison of different populations (for example, pre- and post-intervention).

Studies evaluating broader, more complex interventions were limited in that they could not explore the impact attributable to legal empowerment specifically.[62] To properly understand the role of legal empowerment, we need studies that are appropriately

powered to assess the contribution of legal empowerment in the context of broader interventions. One study used a prospective ecological design to evaluate the impact of a paralegal/mediator program.[63] However, care should be taken when interpreting the results of ecological studies, as they can be subject to ecological fallacy. Overall, the sampling strategies used to recruit study participants were poorly described or not described at all. Where they were available, studies typically relied on convenience approaches that may induce selection bias and limit generalizability. Finally, the studies included in this review predominantly considered the impact of legal empowerment interventions on social and structural influences relevant to health. There was often limited clarity around defining these higher order determinants of risk, mitigating the value of the findings as actionable data for interpreting the impact of legal empowerment to improve proximal health determinants.

Current gaps and opportunities

Health inequities are hypothesized as arising from intersecting social-structural determinants, particularly for vulnerable populations. Law is recognized as a structural factor that can negatively impact vulnerable populations. Consistent data in multiple fields including social epidemiology, health and human rights, and public health law research have increased the focus on law as an important socio-structural determinant of health.[64] Legal empowerment interventions offer an important means of expanding people's individual and collective enjoyment of their legal rights, which we suggest has positive implications across socio-structural levels and a potential effect on health and health equity. These findings suggest that there is an opportunity for implementing and disseminating studies formally evaluating the impact of legal empowerment interventions on health-related outcomes. Moreover, there is utility in studying optimal strategies to implement legal empowerment interventions. Gruskin et al. provide a useful example of a program monitoring study that included a human rights logic model to aid evaluation and reporting on health-related outcomes. The study highlights how implementation evaluations of legal empowerment interventions can be grounded in a clearly articulated human rights-based approach.[65]

Randomized control trials are the gold standard in intervention studies but are increasingly difficult to implement given the movement toward multiple combined intervention packages. Moreover, RCTs can be difficult to design, necessitating community-level randomization which limits feasibility and appropriateness. In addition, where the intervention applies to the entire population (that is, change in the law), randomization is not possible.[66] The studies included in this review rely heavily on qualitative data, which is important in understanding an intervention's impact in context and helping inform quantitative indicator development. However, while we adopt WHO's pragmatic approach of evidence being judged on "fitness to purpose" as opposed to "strict traditional hierarchies of evidence," the lack of more diverse evidence hampers the recognition of legal empowerment as a key access to justice strategy for improving health and health equity.[67] Possible approaches include the use of regression-discontinuity study designs that offer comparable internal validity to randomized trials, but are unique in the method of participant assignment, using a pre- and post-test program comparison strategy.[68]

This review also raises the importance of articulating implementation and outcome measures. Similar to other types of structural intervention, individual-focused behavior change is a popular pathway to measure. However, individual level constructs such as self-efficacy and stigma are important under-utilized measurement domains relevant to legal empowerment interventions, with validated indicators that could demonstrate more nuanced and rigorous pathways that mediate health outcomes.[69] One study in this review sought to measure legal empowerment as an individual-level process outcome, using a subjective measure of a person's perceived confidence to solve potential future legal problems.[70] More rigorously operationalizing legal empowerment as an individual and community level construct is essential to

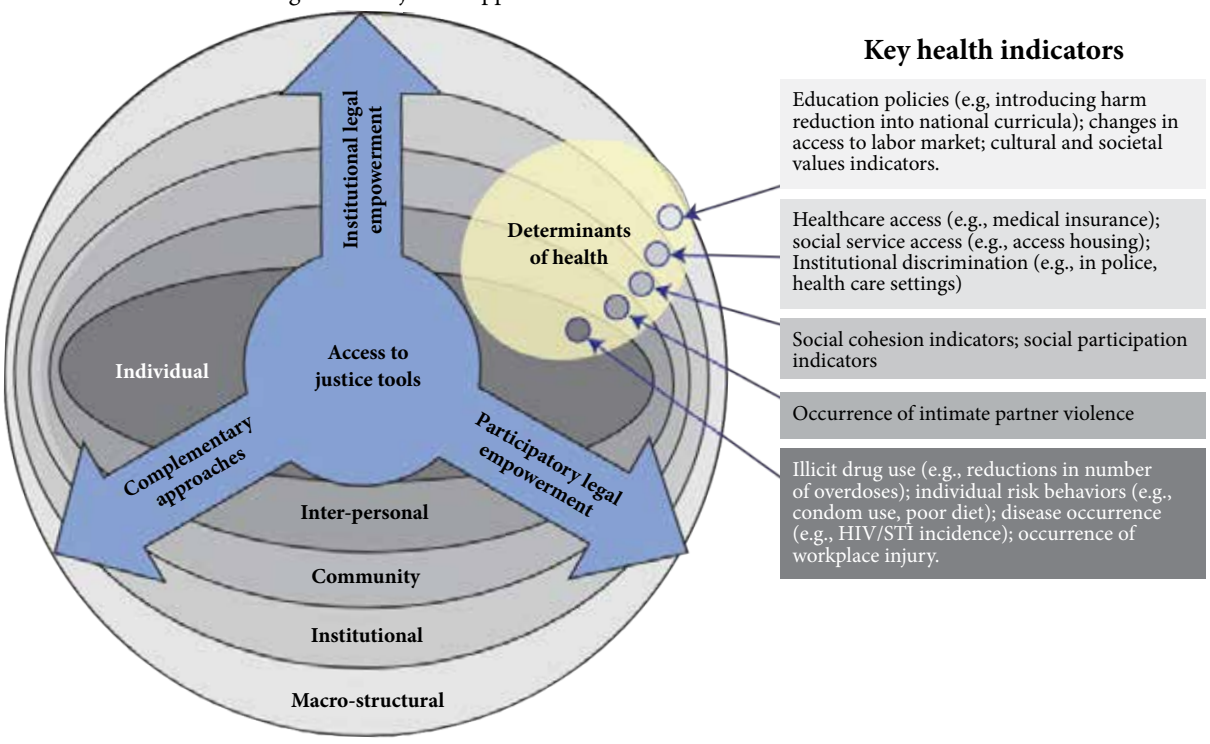
document the complex pathways by which it may bring about change. The studies reviewed often hint at interpersonal and structural processes, but not in a way that links them to recognized conceptual constructs and measurable indicators.

Furthermore, to better capture change at the institutional and macro-level, it is necessary to better integrate large health and legal data sets into study design. The methodologies required for this remain under-developed and constitute an area ripe for rigorous innovation. Our studies highlight the absence of a number of vulnerable populations, including transgender persons and men who have sex with men. There undoubtedly exist more legal empowerment interventions at a grassroots level with a range of vulnerable populations—though with limited formal documentation—highlighting the need for continuing investment in more rigorous evaluation.

A conceptual framework to guide evaluations of health outcomes of access to justice interventions

This review used a definition of legal empowerment put forward by Golub, 2013, with the intention of providing the broadest conceptualization from which to commence our meta-narrative. Our analysis and synthesis allowed for the distillation of a more refined typology of legal empowerment processes and approaches. Using a socio-ecological model to guide data abstraction helped contextualize the health impact of legal empowerment interventions, mapping them across the socio-ecological dimensions of individual, interpersonal, community, institutional, and macrostructural. After critical reflection on the definitional, practical, and measurement aspects of legal empowerment, we present a framework that: a) provides a refined typology of legal empowerment approaches that promote access to justice and b) links these approaches to

FIGURE 3. A framework linking access to justice approaches to health outcomes



five layers of socio-ecological health risk (Figure 3). The framework presented is not a prescriptive list of mediators and health outcomes. Rather, it is intended to help researchers and practitioners of legal empowerment to begin to contextualize how legal empowerment as an access to justice approach can impact health and begin to generate discussion on the most important and attainable outcomes to measure (Figure 3). The legal empowerment approaches set out by the framework have also been defined in this paper, along with complementary approaches often found to accompany legal empowerment strategies (Box 1).

Limitations of the meta-narrative review

Including four fields (social epidemiology, health and human rights, public health law research and international development literature) in the initial scoping and chain-referral process was intended to ensure that our findings represented the work of a diverse range of disciplines. However, the re-

Box 1. Access to justice tools

Participatory legal empowerment strategies
Legal and human rights education: Education of vulnerable populations on their legal and human rights options.
Community-based paralegal: A community-based person with some legal knowledge and skills that they use for the benefit of their community. Particularly important in deformalizing the justice system for communities.
Customary law strengthening: Working with local populations on strengthening customary law approaches, including ensuring that customary structures do not discriminate against women or socially exclude a population.
Legal aid: Free or inexpensive advice, assistance, or representation concerning the law from a person with formal legal training and qualifications.
Integration of legal services into health care: this can involve the integration of relevant legal services into health care settings (such as HIV clinics and hospices) and enables health care providers to connect their patients to legal assistance.
Informal conflict resolution: A process that can take on a variety of forms, but is used to solve problems without having to resort to more formal grievance and complaint processes.
Participatory human rights documentation and advocacy: Involves the documentation of human rights violations and advocacy that is undertaken by, or includes those affected.
Citizen participation in governance: Ordinary citizens being actively involved in assessing their own needs and participating in projects that alter governance structures (such as improving transparency in local government or bringing about a policy change).
Legal empowerment institutional reform strategies
Strategic litigation: The selection of cases intended to achieve broad change at the level of law, policy, practice, or social discourse for the benefit of a vulnerable group.
Police training: Training for law-enforcement institutions that improves people's access to correct legal process.
Changes to law or policy: Work with lawmakers to change law or policy to reduce discrimination against vulnerable populations or increase access to justice.
Complementary legal empowerment strategies
Community-based monitoring system: Provides a form of community oversight around changes to or introduction of a social or health program. Members of an affected community are involved in tracking change and local impacts, from which they can generate demands, suggestions, critiques, and data that can be acted upon.
Community mobilization: A process through which action is stimulated by a community itself, or by others, that is planned, carried out, and evaluated by a community's individuals, groups, and organizations on a participatory and sustained basis to improve health, hygiene, and education levels, so as to enhance the overall standard of living in the community.
Media-based strategies: Print and news media, social media, video documentaries, radio talk shows, and live events in the community can help disseminate legal information to socially excluded groups, promote the accountability of state actors, and contribute to sensitizing the broader public. Communications and media techniques can both strengthen a program's other advocacy efforts and enhance its overall impact.

view focused particularly on legal empowerment's relevance to health, and as such, the limited pool of papers reflects the scope of the review's objective and is not intended to reflect the broader legal empowerment intervention literature that exists. A meta-narrative review was used to ensure that a range of approaches were included. For instance, this led the study team to revisit the inclusion of police trainings as a legal intervention that fit within an overarching legal empowerment narrative. The process of teasing out approaches was not intended to result in an exhaustive inventory of publications.

Given the diversity of interventions and outcomes, a meta-analysis was not possible. We could therefore not conduct pooled analyses to quantify the association we observed. Even at the level of individual studies, the quality of the evidence was severely hampered by the choice of methods, as discussed earlier. Finally, a noteworthy limitation to the synthesis of some studies concerned the decision to include a number of complex interventions, of which legal empowerment was only one component.

Conclusion

Legal empowerment is a diverse and rich tool for increasing access to justice. However, the health benefits of this intervention approach remain understudied, especially where interventions are focused on "participatory" legal empowerment strategies at a grassroots level. There is a lack of clarity about the relationship between the socio-structural factors that are the target of most legal empowerment interventions and more proximal health risks and outcomes. Legal empowerment interventions are by nature difficult to evaluate where change is sought at a community or structural level. Even when assessing individual-level change, determining how increased legal knowledge and rights awareness influences health requires explicit attention to legal empowerment as a key measurable variable on an equal footing to the inclusion of other socio- and attitudinal factors (such as stigma and self-efficacy), variables which themselves lack explicit consideration. We have proposed a framework that seeks to clarify the types of legal empowerment approach, the levels across which interventions may take effect, and potential measurable variables.

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PERSPECTIVE

Human Rights in Public Health: Deepening Engagement at a Critical Time

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ON BEHALF OF THE AMERICAN PUBLIC HEALTH ASSOCIATION'S HUMAN RIGHTS FORUM

This year marks the 70th anniversary of both the birth of human rights law through the Universal Declaration of Human Rights (UDHR) and the birth of global health governance through the World Health Organization (WHO). Over the past 70 years, human rights have developed under international law as a basis for public health, providing a foundation for human rights realization through public health practice. Yet this "health and human rights" movement now faces unprecedented threats amidst a shift toward populism—with the populist radical right in ascendance in the United States and in countries throughout the world.

Commemorating these twin anniversaries for human rights and global health, it is imperative—now more than ever—that scholars, practitioners, and advocates engage with human rights in public health policies, programs, and practices. Within the American Public Health Association (APHA), the newly established Human Rights Forum seeks to build the capacity of public health professionals to mainstream human rights in public health. Reflecting on the evolving engagement of health professionals to advance health and human rights, this essay examines the changing role of human rights in public health policy over the past 70 years and analyzes the continuing promise of human rights in framing public health practice into the future.

In this perpsective, we seek first to explore the development of human rights under international law and the implementation of health-related human rights through public health policies. We then examine the contemporary operationalization of human rights in public health efforts, through which human

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rights standards seek to provide normative clarity in health policy and legal accountability for public health outcomes. Addressing APHA's unfolding efforts to mainstream human rights in public health practice, we recognize the importance of professional organizations in building capacity for a rights-based public health workforce. It will be crucial to extend this model across health-related disciplines in responding to contemporary health and human rights threats. This perspective ends by examining the threat that the populist radical right poses to the advances of the past 70 years, concluding that the public health workforce must deepen engagement with human rights-based approaches to health in responding to these existential threats to health and human rights.

Developing health-related human rights

Human rights offer a universal framework to advance justice in public health, elaborating the freedoms and entitlements necessary to realize dignity for all. With international law evolving to address threats to health, a rights-based approach transforms the power dynamic that underlies public health. Rather than passive recipients of governmental benevolence, individuals are recognized as rights-holders, with human rights imposing corresponding obligations on governmental duty-bearers.[1] Human rights law is now understood to be central to public health policies, programs, and practices. International human rights standards have been shown repeatedly to play a key role in public health over the past 70 years, framing health concerns within a legal context, integrating core principles into policy debates, and facilitating accountability for realizing the highest attainable standard of health.[2]

In developing human rights law for public health promotion through the United Nations (UN), the WHO Constitution conceptualized for the first time that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being," defining health positively to include "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."[3] With human rights framing a healthier world out of the ashes of the Second World War, nations adopted the UDHR on December 10, 1948, embracing within it a set of interrelated economic and social rights by which:

> *[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widow-hood, old age or other lack of livelihood in circumstances beyond his control.*[4]

Seventy years ago, the UN proclaimed the UDHR as "a common standard of achievement for all peoples and all nations," holding that the human right to health includes both the fulfillment of necessary medical care and the realization of underlying determinants of health—including food, clothing, housing, and social services.[5]

However, the rapidly escalating Cold War would limit international opportunities to advance human rights for health in the UN system, with the 1966 International Covenant on Economic, Social and Cultural Rights providing only for "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[6] From the human rights system to global health governance, WHO would work with advocates in the 1970s to revitalize health-related rights in its "Health for All" campaign, which culminated in a rights-based approach to "primary health care" in the 1978 Declaration of Alma-Ata.[7] Extending these human rights advancements in the years after the Cold War, the UN Committee on Economic, Social and Cultural Rights formally clarified state obligations regarding the right to health in 2000, finding that the right to health depends on a wide variety of interdependent and interrelated human rights through public health systems—including both preventive and curative health care and encompassing underlying social, political, and economic determinants of health.[8]

Given the dramatic development of these

health-related human rights, the human rights system has now shifted from the development of human rights under international law to the implementation of those rights through national governance. Policy makers have been pressed to implement rights through national policies, assuring that determinants of health are available, accessible, acceptable, and of sufficient quality.[9] Each country has codified a unique set of constitutional obligations, laws, and regulations that implement international law through national policy, with contextually specific social movements rallying to assure that "health is a human right." Even in the United States, which has long resisted international human rights obligations—especially for economic, social, and cultural rights—there are expanding areas where health policies reflect human rights norms and increasing calls to realize the right to health.[10]

Operationalizing human rights in public health

The operationalization of these human rights standards has provided normative clarity in public health policy and legal accountability for public health outcomes.

Reversing a political neglect for human rights during the Cold War and a policy focus on medical care within WHO, the global response to AIDS in the 1980s clarified the inextricable linkages between human rights and public health, as scholars and advocates looked explicitly to human rights in framing HIV prevention, care, and support.[11] Where governments responded to an emerging AIDS crisis through traditional public health policies—including compulsory testing, named reporting, travel restrictions, and isolation or quarantine—human rights activism both questioned intrusive infringements on individual liberties and revealed the inadequacy of government responses.[12] Focusing on the individual and structural factors underlying HIV transmission, activists demanded a public health response that recognized the inherent dignity of people living with HIV, recognizing the importance of human rights protection to public health promotion and giving birth to a "health and human rights" movement.[13] With the advent of antiretroviral treatment in the 1990s, human rights thereafter framed demands for access to medicines—in the streets and in the courts—establishing the normative, and in many settings judicially enforceable, socioeconomic right to health.[14] A global movement mobilized human rights to challenge the patent system and secure access to generic medicines in the Global South, driving down the cost of HIV treatments by up to 99%.[15] This human rights framework—which demanded agency, dignity, and access—has since been expanded far beyond the HIV/AIDS response.

Into the 21st Century, this movement has brought human rights to bear in the context of disease prevention and health promotion efforts throughout the world. Litigation to enforce health-related rights has extended across tuberculosis in prisons in South Africa, maternal mortality in Uganda, the health insurance system in Colombia, and the regulation of medicines in India.[16] In the United States, activists have utilized the right to health to frame health policy reforms in Vermont.[17] While some have questioned whether a rights-based framework is too individualistic to address public health, the right to health has been seen to bring about lasting societal improvements, with empirical evidence beginning to show how countries that implement human rights see a benefit to population health.[18]

This national implementation of human rights in public health provides a basis to facilitate accountability for the progressive realization of health-related human rights. As governments have implemented human rights in health policy, scholars, practitioners, and advocates have sought to create accountability mechanisms to assess the progressive realization of rights, with these mechanisms committing governments to health-related rights, maximizing available resources through health policy, and improving programmatic results in health outcomes through:

- Political advocacy: *Social movements engage in political advocacy to analyze and assess public policy; to shape public awareness on*

national policies; and to press governments to comply with their health-related human rights obligations (whether by advocating human rights principles or by "naming and shaming" recalcitrant governments).[19]

- Litigation: *With individuals enforcing human rights obligations through the courts, litigation empowers the judiciary to remedy rights violations—setting legal precedents to define government health obligations—and provide rights-based accountability in national, regional, and international courts and quasi-judicial bodies*.[20]
- Treaty monitoring: *UN human rights treaty bodies monitor national implementation of treaty obligations—reviewing periodic reports, engaging in "constructive dialogue," and issuing concluding observations—with these treaty bodies complemented in the past decade by the Universal Periodic Review, through which the UN Human Rights Council assesses the human rights performance of all UN member states*.[21]

Mainstreaming human rights across public health practice

The links between public health and human rights have been established in international law, national policy, and now public health practice. Over the past few decades, the academic literature has reflected a steady increase in work linking international human rights law, the right to health, and rights-based approaches to the field of public health—and the *Health and Human Rights Journal* is a testament to the growing strength of the field. Whereas only three schools of public health offered a course in health and human rights at the turn of the century, scores of courses now exist throughout the world, and human rights analysis is now considered a core competency of the master of public health (MPH) curriculum.[22] Where both the fields of public health and human rights share a focus on marginalized populations, health professional organizations have increasingly addressed rights-based approaches to public health, emphasizing individual empowerment, community participation, and government accountability.[23]

At the forefront of health professional organizations, APHA has sought to facilitate this mainstreaming of human rights in public health practice over the past 70 years. Laying a foundation for the birth of WHO, it was at the 1944 APHA Annual Meeting where practitioners first advocated for the development of a post-war public health mandate under the mantle of human rights.[24] Since 1973, APHA's Governing Council has voted to adopt 84 policies that directly address human rights violations or explicitly reference human rights principles.[25] As a central actor in the budding health and human rights movement, the APHA Executive Board in 1983 established the International Human Rights Committee (IHRC) to provide an impartial platform to examine, discuss, and take action on human rights issues that have an impact on public health. The IHRC worked over three decades to introduce human rights into public health discourse and apply human rights through public health practices.[26] Recognizing the importance of human rights in public health education, APHA convened a 2002 working group on teaching human rights, culminating in the report "Health and Human Rights: The Educational Challenge."[27] In supporting these educational initiatives, IHRC members developed a 2010 public health textbook, *Rights-Based Approaches to Public Health*, advancing human rights analysis across a range of public health issues.[28] APHA has facilitated these rights-based discourses for public health professionals, organizing its 2006 Annual Meeting under the theme "Public Health and Human Rights" and its 2016 Annual Meeting under the theme "Creating the Healthiest Generation: The Right to Health."

Yet none of these efforts proved sufficient to mainstream human rights throughout public health practice.

The development of APHA's Human Rights Forum, launched in 2015, has sought to support human rights capacity-building across the public health workforce, providing a model for other health-related professional associations to mainstream human rights in health practice. While many public health practitioners work under the mantle of human rights, they lack the capacity to engage with the formal legal frameworks necessary to realize human rights in public health practice.

To build human rights capacity across APHA's membership, the Human Rights Forum welcomes members from all 31 APHA sections, and its membership has grown across all professional categories (students, early career professionals, regular members, and retirees). The Forum now represents more than 1000 APHA members, and this increased engagement—alongside capacity-building publications, trainings, and conferences—has given practitioners the tools necessary to realize human rights in public health at this critical time.

A critical time for human rights in public health

With human rights developed, operationalized, and mainstreamed over 70 years, the realization of these rights is now imperiled by the populist radical right, threatening the protection of human rights and the advancement of public health. This right-wing populism seeks to undo the progress of past struggles, and it remains unclear how this opposition will affect the continuing evolution of human rights in public health.

In challenging the shared goals of human rights in public health, right-wing populism—abetted by the resurgent horrors of racism, xenophobia, anti-Semitism, and Islamophobia—seeks a nativist definition of the rights of citizenship. Populist politicians have thus sought to define ethnic nationalism to the exclusion of the common humanity first proclaimed in the UDHR.[29] Politicians have advanced radicalized responses to the harms of a globalizing world, stirring mass fear about global "elites" and collateral anger toward international migration. This ethnic nationalism, viewing human rights as anathema to national identity, has subverted the universality of rights, undercutting the very foundation of the health and human rights movement.[30] With liberal democratic values in retreat, populist governments have violated human rights principles, restricted civil society advocacy, repressed minority populations, attacked gender equality, ignored scientific evidence, and neglected public health.[31] Where these human rights challenges have largely been met with silence by the global community, with national governments avoiding international sanctions for human rights violations, there are concerns that this unchecked repression of human rights will lead to a "post-human rights world."[32]

This right-wing populism also seeks to retrench nations inward, with rising nationalist movements directly threatening the cosmopolitan vision underlying global health and spurring isolationism in international affairs. As a direct response to the increasing interconnectedness of a globalizing world, populist nationalism has come to challenge the globalized world order and collective international decision-making.[33] This backlash against "globalism" has led to nationalist attacks on the legitimacy of global institutions. Populist nationalism has thus sought to erect walls to re-divide an integrated world, with states abandoning the multilateral institutions that govern public health and human rights. This poses an existential threat to the global health governance system first established under WHO.[34] The resurgence of national sovereignty is isolating national governments in addressing common health challenges. Undercutting the efforts of international organization to implement human rights in global health, such national retrenchment could lead to a rejection of both global governance and human rights as a basis for public health advancement.[35]

Conclusion

Human rights have increasingly brought the world together in unprecedented public health cooperation over the past 70 years; however, the current populist age casts doubt on many of these governance successes and raises obstacles to future progress. Threats from the populist radical right have subverted the universality of human rights, rejected the science of public health, and threatened health cooperation within global governance. Where the development of WHO and the UDHR gave birth to a revolution in global governance for public health—binding the world together around shared rights-based values—the populist counter-revolution threatens to undo decades of progress

and return us to a far less healthy world. Public health practitioners have a crucial role in responding to the populist radical right, pursuing political advocacy to assure the future of human rights in public health. Reflecting on the progress of human rights at this critical time, there is a need for health professionals associations to support the rights-based public health workforce necessary to realize the highest attainable standard of health.

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Engaging Human Rights Norms to Realize Universal Health Care in Massachusetts, USA

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Abstract

Massachusetts is a national leader in health care, consistently ranking in the top five states in the United States. In 2006, however, only 86% of adults aged 19–64 had health insurance. That year, Governor Romney signed into law An Act Providing Access to Affordable, Quality, Accountable Health Care. By 2017, more than 96% of these adults were insured. The 2006 Massachusetts health insurance reform later became the model for the 2010 federal Patient Protection and Affordable Care Act, also known as Obamacare. This article examines, through a human rights lens, the 2006 Massachusetts health insurance reform 10 years after its implementation (2007–2017) to shed light on the effectiveness of this approach in achieving universal health coverage. Drawing on documentary and interview data, and applying international human rights norms, we found that (1) the 2006 Massachusetts health reform replaced a crisis of uninsurance with a crisis of underinsurance; (2) state leaders in health reform propose widely diverging solutions to the increasing health care costs, the inability of many residents to afford needed health care, and the persistence of medical bankruptcies; and (3) health care is recognized as a human right in Massachusetts, but understanding of the substance or potential of the right is limited.

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Introduction

In September 2015, the United Nations General Assembly adopted the 2030 Agenda for Sustainable Development, which set forth 17 Sustainable Development Goals (SDGs) and 169 targets.[1] These include target 3.8, which aims to achieve universal health coverage, including financial risk protection and access to quality essential health care services, by 2030.[2] Every member of the United Nations, including the United States, has thus committed to achieving universal health coverage. Further, the 2030 Agenda is guided by the principles of the United Nations Charter and is grounded in international human rights law.[3] On this basis, this study uses a human rights lens to consider efforts to universalize health care in one US state, Massachusetts. The 2006 health care reform in Massachusetts is particularly important to understanding efforts to universalize health care in the United States because it was the model for the subsequent 2010 federal health care reform, known as the Patient Protection and Affordable Care Act (PPACA) or Obamacare.

Massachusetts is a national leader in health care, consistently ranking in the top five states on the Commonwealth Fund Scorecard on State Health System Performance.[4] In 2006, however, only 86% of adults aged 19–64 had health insurance.[5] That year, Governor Romney signed into law An Act Providing Access to Affordable, Quality, Accountable Health Care, also known as Chapter 58.[6] The law sought to increase health care insurance coverage for residents of Massachusetts by (1) mandating that all adults in the state have health care insurance unless an affordable option was not available; (2) expanding Medicaid, the publicly funded health care program for very low-income residents; (3) creating a new program of subsidized private insurance for low- and moderate-income residents; and (4) establishing a transparent health care insurance market exchange, the Health Connector.[7]

By 2017, Massachusetts had the highest rate of health insurance coverage of all US states, with less than 4% of the population uninsured.[8] Yet, with a population of 6.745 million people, more than 200,000 people still lacked health insurance. Moreover, many people with health insurance could not afford health care due to high deductibles and co-payments. A 2016 study found that the 2006 law had not made health care more affordable for residents; indeed, 10 years after the reform, 43.1% of insured adults reported that the cost of health care was causing them financial problems.[9] Studies examining the impacts of Chapter 58 have found that (1) the reform has achieved greater health insurance coverage; (2) some health outcomes have improved for certain populations; (3) increased access to insurance has increased the utilization of health services for some low-income residents; (4) many residents—especially low-income residents, documented and undocumented immigrants, the working poor, and Latino, black, and middle-income individuals in poor health—still do not have health insurance; and (5) medical bankruptcies and high medical debt have persisted.[10]

Despite mixed results, the 2006 Massachusetts health insurance law had tremendous impact beyond state borders. In 2010, President Obama signed into law the PPACA, which was modeled on the Massachusetts law.[11] The PPACA mandated that all individuals maintain health insurance unless there was no affordable option; provided support for states to expand Medicaid; created new subsidized programs for low- and middle-income people; and required each state to maintain a health insurance exchange.[12] Not surprisingly, the PPACA has also had mixed results. Although the law has expanded insurance coverage to many people, recent research shows that a quarter of all adults with private insurance still cannot afford health care when premiums, deductibles, and out-of-pocket costs are taken into account.[13] Additionally, more than 27 million people remain uninsured.[14]

Most of the PPACA-mandated reforms have taken place at the state level, and each state has taken its own approach to implementation within the boundaries set by the federal law. As a result, there remain wide discrepancies in health insurance coverage and access to health care across states.[15] For this reason, research on state-level health insurance

coverage and access to health care is useful even after the PPACA. The Massachusetts case is particularly relevant, as Massachusetts has had a decade of experience with a system similar to those more recently implemented under the PPACA, which, although adopted in 2010, did not come fully into effect until 2014. This state-level research, particularly on Massachusetts, may provide insight into how best to move toward universal health insurance—and not slip backward—in the future.

Our study differs from previous studies on health law reform in Massachusetts in that it uses a human rights lens to assess the success of the 2006 law. In this way, it analyzes Massachusetts's progress in comparison to international legal and ethical norms rather than in comparison to the state's pre-2006 situation. In addition, this study examines the extent to which leaders in health law reform in Massachusetts believe that human rights frameworks generally, or the human right to health care in particular, could be useful in securing universal health care in the state. The right to health is widely recognized in international human rights law and in the majority of national constitutions around the world.[16] It therefore provides a legitimate legal and ethical framework for evaluating the success of health law reforms and may also be a useful foundation for moving toward universal health insurance and universal health care.

Following this introduction, the second part provides background on the 2006 Massachusetts health law. The third part presents our research questions, design, and methodology. Part four explains our findings, which are based on 19 interviews with leaders in health law reform in Massachusetts. Part five uses a human rights lens to analyze the findings from our document review and interviews. Finally, the conclusion offers our thoughts on the future of universal health insurance and universal health care in Massachusetts and the United States. Throughout the article, we distinguish between universal health insurance (the focus of the 2006 Massachusetts health law) and universal health care (the focus of international human rights law).

Background on the Massachusetts health law reform of 2006

Massachusetts has been engaged in state-level health law reform efforts for decades. In 1988, for example, Governor Dukakis enacted legislation that would have provided almost universal health insurance by 1992.[17] Following the election of Governor Weld in 1990, most aspects of the legislation were repealed before they were implemented; however, provisions expanding Medicaid coverage to working adults and children with disabilities were left intact.[18] In 1997, Massachusetts used a Medicaid waiver to further expand health insurance coverage to hundreds of thousands of residents.[19] Medicaid is a federal program that works in partnership with states to provide health insurance to low-income American citizens and some legal residents.[20] States have broad discretion to design and administer their Medicaid programs, provided they meet federal standards.[21] Moreover, states can seek federal waivers allowing them to use federal Medicaid funding in ways that would typically not be allowed under federal rules.[22] The 1997 Medicaid waiver provided Massachusetts with additional federal dollars and allowed the state to expand insurance coverage beyond that required by the federal rules.[23]

As a result of these earlier efforts, by 2006, uninsured rates in Massachusetts were significantly lower than the national average.[24] Massachusetts also had a highly regulated health insurance market with extensive mandatory coverage requirements, prohibitions on exclusions for preexisting conditions and insurance premium variations based on gender, and a limit on premium variations based on age and geography.[25] Despite this progress, hundreds of thousands of residents still lacked coverage, and health insurance premiums and health costs continued to rise.[26] Moreover, the Medicaid waiver that Massachusetts had received in 1997—which provided US$385 million in federal funding—was set to expire on July 1, 2007.[27] These issues created a political opening for health law reform in the early 2000s. In this light, in 2003, activists began organizing and advocating for the adoption of a constitutional amendment rec-

ognizing a right to health insurance.[28] The proposed amendment stated:

> *Section 1: The People of the Commonwealth of Massachusetts hereby declare it necessary and expedient to alter the Constitution by the adoption of the following Article of Amendment:*
>
> *Upon ratification of this amendment and thereafter, it shall be the obligation and duty of the Legislature and executive officials, on behalf of the Commonwealth, to enact and implement such laws, subject to approval by the voters at a statewide election, as will ensure that no Massachusetts resident lacks comprehensive, affordable and equitably financed health insurance coverage for all medically necessary preventive, acute and chronic health care and mental health care services, prescription drugs and devices.*[29]

The proposed amendment would have created a legal duty on the part of the Massachusetts legislature and executive branch to ensure that every Massachusetts resident have comprehensive, affordable health insurance, but it did not mandate a specific form of health care system.[30] Massachusetts law provides that the Massachusetts Constitution may be amended through a ballot initiative process.[31] The process requires that petitioners collect certified signatures representing at least 3% of the total vote cast in the last gubernatorial election; that at least 25% of the legislature then vote in favor of the initiative in two consecutive constitutional conventions; and finally, that the initiative receive approval by a majority of voters.[32]

The concept of health care as a right was widely popular with Massachusetts residents, and a grassroots campaign was successful in collecting the required number of signatures for the petition initiative.[33] At the first constitutional convention in 2004, the Massachusetts legislature voted 153-41 in favor of the amendment.[34] At the same time, the Romney administration and legislators were drafting Chapter 58, which was enacted in April 2006.[35] At the second constitutional convention, held in July 2006, legislators voted 118-76 to send the amendment to a special committee for further study.[36] Two senators spoke against voting on the constitutional amendment, arguing that Chapter 58 should be implemented and evaluated before a vote was taken to amend the constitution.[37] In 2007, the legislature voted against discharging the amendment from that committee, effectively killing it.[38]

Supporters of the initiative then filed suit with the Supreme Judicial Court of Massachusetts in 2007 seeking a judicial remedy for the legislature's failure to vote on the amendment.[39] The court acknowledged that the legislature had a constitutional duty to vote on every initiative pending before it but ruled that there was no judicially enforceable remedy for such a violation.[40] As a result, the amendment was not placed on the statewide ballot in 2008. Although it failed, the constitutional amendment movement is widely credited with creating sufficient pressure on legislators and special interest groups to ensure the passage of Chapter 58 in 2006.[41] Although hospitals, health insurers, and other stakeholders might have opposed the proposed legislative reforms, the threat of the constitutional amendment appears to have made them more willing to support the legislation. In fact, many stakeholders conditioned their support for the legislation on the legislature blocking the constitutional amendment on universal health insurance.[42]

The 2006 Massachusetts health law reform is based on the concept of shared responsibility, meaning that individuals, employers, and the government each share part of the burden of health insurance coverage.[43] The reform featured individual and employer mandates and public subsidies to enable low- and moderate-income people to purchase private health insurance online in a marketplace known as the Health Connector.[44] Ten years after the passage of Chapter 58, Massachusetts has the highest rate of health insurance coverage in the United States, and the insurance gap among racial and ethnic groups has narrowed significantly.[45] The reform has also resulted in increased access to health care, general improvement in health outcomes, and an overall decline in mortality.[46] However, improvements have not been even across all groups in Massachusetts. One study showed no progress in reducing the unmet health needs of Latino, African American,

and middle-income individuals, and another report showed almost half of non-elderly adults reporting difficulty finding providers or getting appointments when needed.[47]

Despite the title of the act—An Act Providing Access to Affordable, Quality, Accountable Health—the legislation did not address cost containment or affordability.[48] In 2017, 25% of Massachusetts residents surveyed reported forgoing needed health care due to cost.[49] Further, 15% reported difficulty paying medical bills in the last 12 months, and of the people who had incurred medical debt, 78% had insurance at the time the debt was incurred.[50] These affordability challenges were often most acute for lower-income residents.[51] With this background, it is clear that there is a need for further health insurance reform to fully achieve universal health insurance and universal health care, to equalize health care benefits, and to address cost containment.

Research questions, design, and methods

Focusing on the 10 years after the 2006 Massachusetts health insurance reform (2007–2017), our study uses a human rights lens—drawing specifically on the international human right to health care—to examine the reform's successes, as well as remaining challenges, and the potential avenues for achieving universal health insurance and universal health care in the state. We employed multiple qualitative methods in our research. Step one involved a document review, including examination of the legislative history of the 2006 reform, and quantitative and qualitative studies of the impacts of the reform on universalizing health insurance and health care in Massachusetts. Additionally, a search of nongovernmental organizations' websites provided information concerning past and current efforts to promote universal health care in Massachusetts. This document review provided the background explained above, prepared us for interviews with experts in the field, and established the context for the discussion in section five below.

In the second step, we conducted semi-structured interviews with 19 leaders in Massachusetts's health care reform efforts (past and present) between August 2016 and May 2017. These interviews sought answers to the following three research questions: (1) To what extent do leaders believe that the 2006 health law has been successful in achieving universal health care in Massachusetts? (2) What do leaders believe can be done to achieve universal health care in Massachusetts? and (3) Do leaders believe that human rights can be useful in achieving universal health care in Massachusetts? In addition to questions about the impact of Chapter 58, we asked interviewees about the impact of the constitutional ballot initiative, the potential impact of a constitutional right to health insurance in Massachusetts, and the role of the international right to health in advancing universal health care.

We recruited interviewees who have played a major role in health law reform, such as legislators, executive branch officials, leaders of nonprofit organizations, and policy analysts whose work has informed past or current debates on universalizing health insurance or health care in Massachusetts. We recorded, transcribed, and then coded the interviews, using data analysis software (NVivo 11) to draw out emerging themes. The data was then analyzed using a human rights framework, based on the right to health care (affordability and nondiscrimination) and the human rights principles of universality, equality/equity, transparency, participation, and accountability. The study received ethics approval from the University of Massachusetts Boston Institutional Review Board (#2016123).

Findings

The goals and process of the 2006 Massachusetts health reform

All 19 leaders indicated that the focus of the 2006 health law reform was on expanding health insurance to achieve universal or "near universal" insurance coverage as a means to increase access to health care. Some interviewees used these terms—health insurance and health care— interchangeably. Julie Pinkham, executive director of the Massachusetts Nurses Association, pointed out this problem in Chapter 58:

> *The way it's written would suggest that you actually get health care. But really the way the reform was written is you get insurance, and those are two different things.*[52]

Although most interviewees indicated that grassroots pressure—for health care as a human right, universal health care, a single-payer system, and health care access—played a significant role in generating political pressure on the legislature to address health care and pass the 2006 law, they noted that grassroots groups were not well represented during the discussions designing the reform and that their desires were not reflected in the final bill.

In contrast, a few interviewees described the legislative process that ultimately resulted in the reform law as collaborative, involving all stakeholders, and one where a diverse group of participants all sacrificed something to achieve their shared goal of expanding access to health insurance coverage. Jack Evjy, former chair of the Massachusetts Medical Society Task Force on Universal Access (2004–2006), thought the exercise of bringing a diverse group together to craft the reform allowed the group to pick the best aspects of each model, thus strengthening the end result.[53] While this process ensured political buy-in from powerful interests, other interviewees indicated that this buy-in came at great cost. State Senator Dan Wolf, for example, opined that health care reform has failed because insurance companies and other powerful actors have been able to co-opt the processes, preventing broad reforms.[54] In his view, these powerful interests narrowed what was politically possible:

> *It is an insane system right now. It makes absolutely no sense. And the only reason we're not changing it is because there are wealthy interests in the State House that are preventing that from happening, in the insurance industry, in the pharmaceutical industry, and in the providers industry.*[55]

Ben Day, executive director of Healthcare-NOW!, suggested that the failure to include cost containment measures in the health law reform might have been a deliberate decision so as not to affect the revenue streams of some stakeholders.[56] In short, the narrow universe of policy options under discussion in 2006 ensured that corporate and other private stakeholders did not have to give up much, if any, of their essential interests.

Success of the 2006 health reform in achieving universal health insurance

Among the leaders interviewed, there was consensus that the resulting law was successful in achieving near universal insurance coverage. Jonathan Gruber, a professor of economics at the Massachusetts Institute of Technology and one of the chief architects of the reform, explained:

> *[T]he bottom line is it was a law about making health insurance affordable for people and moving towards a market where everyone was guaranteed to have affordable and fairly priced health insurance. That's what the law is about, and it accomplished that goal.*[57]

However, other interviewees noted that the legislation did not address the rising costs of health insurance and health care. Gerald Friedman, a professor of economics at the University of Massachusetts Amherst, attributed this limitation to the fact that the reform never intended to address cost concerns:

> *It failed utterly at things that it was never intended to do, which included improving coverage for people with insurance [by] controlling.*[58]

Because the law has not contained costs, people—even those with insurance—are not necessarily able to afford health care. Ben Day of Healthcare-NOW! argued that the "crisis of uninsurance" has been replaced by a much larger "crisis of underinsurance." He explained:

> *[T]he expansion of insurance was accompanied by … a dramatic rise in high deductible plans, dramatic rise in out-of-pocket expenses, and … insurance started covering less and less for a much larger share of the state. So it was like a halfway measure. I think it was relatively successful at addressing the crisis of uninsurance, [but] it created a new sort of larger crisis of underinsurance.*[59]

Similarly, Professor Friedman from the Univer-

sity of Massachusetts Amherst maintained that working people who earn too much to qualify for Medicaid might be worse off now because of rising prices, including more expensive premiums and co-payments.[60] Affordability is still seen as a barrier to access that keeps people from seeking health care when they need it, a reflection of the limited outcomes that resulted from the reform.

The next step(s) to achieving universal health insurance

Interviewees viewed the continuing rise in health care costs as a problem that was not addressed by Chapter 58. However, they did not agree on the main cost drivers or on how the cost challenge might be addressed moving forward. They attributed the rising costs to a variety of sources: the overall complexity of the health care system; consumers wanting to go to expensive hospitals; providers billing by procedure and not taking cost into account when they treat patients; and the cost shift from public to private payers due to low Medicaid reimbursement rates. Others attribute it to the failure to adopt a single-payer health care system, which would reduce administrative costs and provide greater purchasing power due to the larger pool it would create. In this vein, interviewees disagreed on whether the expansion of public health insurance coverage—particularly Medicaid—is a positive outcome. Some viewed it as a failure of the 2006 health reform that now more than one-third of the Massachusetts population has public health insurance in the form of Medicaid or Medicare. Others viewed the expanded Massachusetts Medicaid program—though underfunded—as a great success worth fighting to keep in place.

Among myriad solutions offered as a next step in controlling costs, Amy Lischko, former assistant commissioner of health care finance and policy under Governor Romney, indicated that the focus must be on consumer education to change the perception that the most expensive health facilities offer the best quality.[61] Others proposed that effective solutions might stem from better measures, data, and analysis; reprioritized state revenues; and rate regulation. Some interviewees also acknowledged the need to address the social determinants of health, as this would reduce the need for health care, thus reducing the overall costs of the system.

Jack Evjy, former chair of the Massachusetts Medical Society Taskforce on Universal Access, indicated that controlling health care costs could be done only incrementally:

> *[N]o one plans to throw out everything having to do with Obamacare. It's not what's going to happen. On the other hand, folks are not going to put up with the problems that exist today … But I suspect they'll go to the Senate, and then there'll be this change and then that change … Compared to where things were … a decade and a half ago, we've evolved to a much better place. In fact, we're scared to death we're going to lose all the good gains that we have made. That's increasing the anxiety that there is today. So I have great faith that what's going to happen is going to be the next step. And then a couple years from now, there'll be another step. And a few years after that, there'll be another step as we evolve to make things even better than they are today.*[62]

One incremental step, proposed by State Senator Dan Wolf, was to create a public plan for private employers to purchase health insurance for their employees.[63] However, he thought it would take a ballot initiative to get this done.[64]

Some interviewees, however, were skeptical about an incremental approach, noting that rising health care costs cannot effectively be addressed without moving to a single-payer system. For example, Ben Day of Healthcare-NOW! explained that tinkering around the edges simply would not work:

> *[I]f you're not willing to do something like a single-payer plan, if you are not willing to . . . cut out all these for-profit middlemen, and cut out the complexity of this system that drives up administrative wastes, and if you're not willing to negotiate as sort of a whole society, with drug manufacturers, and medical device manufacturers, if you're not willing to do any of those things, I think your options are really limited … I think you really only have two options. You have the structural-change option, which changes the total cost structure dramatically, or you have the sort of moving-money-around-onto-different-shoulders approach.*[65]

However, not everyone agreed that a single-payer system would solve cost concerns. And there was a split among interviewees on whether states can move to such a system independently of the federal government.[66] Professor Friedman of the University of Massachusetts Amherst had some specific ideas for moving toward a single-payer system. One was to begin with greater regulation of hospital and provider pricing, thus reducing profits and the incentive to oppose a single-payer system. He also believed that if such a system were to come about through a referendum process, there would be significant challenges in getting an unwilling government to actually implement it. He likened it to the marijuana decriminalization referendums where state and local governments dragged their feet as long as possible after the measures passed. Thus, he thought there were limitations to people-driven referendums, as people still need government to implement them.[67]

The value of human rights in the struggle for universal health care

According to interviewees, health care is or should be a right. They also believe that most Massachusetts residents consider health care to be a right. It was less clear to interviewees, however, how this right could be translated into concrete policy. Ture Turnbull, executive director of MassCare, noted that the concept of health care as a right "connects" with more people than confusing technical terms such as "single-payer."[68] Ben Day of Healthcare-NOW! explained that rights-based language is "necessary but not sufficient" and therefore made the case for simultaneously addressing financing concerns.[69]

While most interviewees viewed the right to health care as inspirational and therefore useful in organizing grassroots campaigns, they did not see a practical role for human rights in addressing cost control or achieving universal health care. For example, Professor Wendy Parmet of Northeastern University Law School questioned whether human rights speak to specific aspects of health policy:

> *"Health care as a human right." Well, what does that actually mean? . . . What does that mean when we're paying for insurance? I mean, details matter, and how do we get this done?*[70]

Despite the role played by the right to health care in building a grassroots movement that created pressure for the passage of Chapter 58, many interviewees did not see any benefit to enshrining the right in the state constitution. They noted that a constitutional right is unnecessary given that health care is already viewed as a right by Massachusetts residents. Former Romney administration official Amy Lischko stated:

> *I also think everybody in their heart thinks that people who are sick should have access to care. I think where we maybe have some differences is around behavior and how to motivate good behavior … And who should, how much is your responsibility versus others' responsibility. And as the cost gets more and more, those questions are really hard … But I don't think anybody disagrees with it being kind of a right, and that people should have access to it.*[71]

On the other hand, John Goodson, former co-chair of the Health Care for Massachusetts Campaign, explained that the whole system is precarious because Chapter 58 is a mere law that could be repealed or defunded at any time.[72] For this reason, he argued that a constitutional amendment would be a better approach, as it could not be so easily undone by the legislature. Goodson stated:

> *[W]e believe strongly that health care access should be part of the social contract. We concocted a strategy that would ensure a protected commitment for the indefinite future. What we have now in the Commonwealth really depends on the ongoing support of the Commonwealth to universal health care access. But the whole thing could come apart, could be taken apart, could be dismembered, it could be dismantled. So, we believe strongly, I believe strongly … that in order to really make this happen, we should go back to the Commonwealth, and we should get this amendment put in the constitution.*[73]

Although most interviewees believed that health care is a human right, Goodson was the only one who recognized a practical value to enshrining the right in the Massachusetts Constitution.

Discussion

Drawing on our document review and interview data, and applying international human rights norms, we respond to our research questions as follows. First, to what extent do leaders believe that the 2006 health law reform has been successful in achieving universal health care in Massachusetts? Interviewees considered Chapter 58 successful in achieving its goal of lowering uninsured rates; however, the law was not intended to achieve and has not achieved universal health insurance coverage (much less universal health care) in Massachusetts. A little less than 4% of Massachusetts residents, approximately 240,000 people, remain uninsured.[74] In addition, Chapter 58 failed to address—and some interviewees believe exacerbated—the problem of underinsurance. According to a 2017 survey, one-quarter of Massachusetts residents report difficulty accessing needed medical care due to cost.[75] In short, although Chapter 58 reduced the uninsurance rate in Massachusetts, continuing problems of uninsurance and underinsurance demonstrate that the reform has not achieved universal health insurance or universal health care.

Second, what do leaders believe can be done to achieve universal health care in Massachusetts? All interviewees indicated that further reform is needed to address cost control and financial stability. There was no consensus, however, on the main cost drivers, and interviewees offered widely different ideas on how to address cost control, including educating patients and providers to use less expensive health care, reforming the way providers are reimbursed, and changing antitrust laws to address monopolies within the health care system. While all these approaches might control health care costs and thus ameliorate the problem of underinsurance, they would not ensure universal health insurance or universal health care. To achieve universal health care, some interviewees favored the creation of a single-payer health care system. Even among those who favored this approach, however, there was no agreement on whether it is possible, under federal law, to have a single-payer system at the state level.

Third, do leaders believe that human rights can be useful in achieving universal health care in Massachusetts? Most interviewees viewed health care as a human right and believed that most Massachusetts residents held the same view. However, there seemed to be little understanding of the substance of the right to health care or how to implement it in practice. Interviewees viewed human rights rhetoric as useful for organizing grassroots movements but did not see how the right to health care could inform health care policy. Further, most saw no practical value to a constitutional right to health care. Some interviewees asserted that such a right is unnecessary because Massachusetts residents already view health care as right, and others were concerned that such a right would lead to costly litigation with very little benefit to the system or to residents. Only one interviewee saw practical value in constitutionalizing the right to health care; he maintained that it would make the right more permanent and less vulnerable to the whims of changing governments.

To our original three research questions, we add a fourth question. Do leaders in health law reform in Massachusetts understand the international human right to health and core human rights principles, such as universality, equality/equity, transparency, participation, and accountability? In short, the answer is—with few exceptions—no. There is now, however, a substantial literature on the content of the right to health, as well as methods of implementing the right. Moreover, 178 countries have ratified the International Covenant on Economic, Social and Cultural Rights, which enshrines the right to health, and the majority of countries include the right to health in their constitutions. Nonetheless, leaders in health reform in Massachusetts do not view the right to health as a practical guide to implementing and measuring progress in achieving universal health care. The lack of support for a constitutional right to health care among leaders—as opposed to a constitutional right to education, which is already recognized in Massachusetts—deserves further attention from researchers.

Additionally, while Massachusetts leaders have some understanding of the concepts of universality and equality/equity, many do not seem aware

that participation, transparency, and accountability are also components of the international human right to health. For example, some interviewees expressed the view that it was impossible to create a health care system that was truly universal and were content to achieve a system that covered most, but not all, residents. When asked to define accountability in the health care context, interviewees focused on providers' accountability to patients rather than the government's accountability to abide by and enforce human rights standards and to answer to the people for its decisions and actions. Similarly, when interviewees discussed transparency, they described efforts to make providers and insurers more transparent regarding costs rather than—or in addition to—the government's transparency regarding health policy decision making. Lawmakers' decision to jettison the constitutional amendment and adopt Chapter 58 instead is also an example of a failure to ensure transparency and participation in decision making—and neither the process nor the outcomes are understood as human rights issues.

Even interviewees who believed that human rights rhetoric was useful for movement building were unaware of the robustness of the international right to health or how it could be translated into concrete policy. With few exceptions, interviewees expressed little to no understanding of the importance of entrenching the right to health in law and policy, although this is well understood and accepted in much of the rest of the world. This lack of knowledge about the right to health reflects US attitudes toward economic and social rights more generally—that these are issues that arise in other countries and not in the United States—and suggests the need for education on international human rights norms and on the right to health specifically.

Conclusion

Although Massachusetts has been a national leader on health insurance coverage, it has not achieved universal health insurance or universal health care. Further, while the consensus is that cost containment must be the next step, opinions of the experts on how to contain costs diverge widely, making imminent progress at the state level difficult. The situation is not without hope, however. Notably, in September 2017, Senator Bernie Sanders of Vermont and 17 co-sponsors, including Massachusetts Senator Elizabeth Warren, introduced a bill in the US Congress to establish "Medicare for All." Medicare is a public health care program that currently serves US residents who are at least 65 years old. This bill would automatically enroll all children under age 19 in the first year after the act's adoption and would lower the age of eligibility for Medicare (from 65 years) by 10 years each year until everyone had health insurance.[76] Importantly, Senator Sanders introduced a similar bill in 2013, but it had no co-sponsors.[77] Now that "Medicare for All" has 17 co-sponsors in the US Senate, it appears that universal health care may be gaining traction at the national level. In this light, the question arises whether Massachusetts will continue to be a leader among US states in achieving universal health insurance and health care. Adopting a constitutional right to health care is one step Massachusetts could take to ensure that it continues to be a pathbreaker in the field.

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The Rohingya in Cox's Bazar: When the Stateless Seek Refuge

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Abstract

The Rohingya people of Myanmar have been subject to human rights violations through government-sponsored discrimination and violence. Since August 2017, an intensified assault by Myanmar authorities has resulted in a rapid increase of Rohingya pouring into Bangladesh, and the expansion of refugee settlements in the district of Cox's Bazar has strained humanitarian and government relief efforts. Assessing Rohingya and host community needs is critical for prioritizing resource allocations and for documenting the rights violations suffered by Rohingya refugees. From March 15 to 18, 2018, we

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conducted a rapid needs assessment of recently arrived Rohingya and host community households. We collected data on demographics, mortality, education, livelihoods, access to food and water, vaccination, and health care. Among other things, our survey found high levels of mortality among young Rohingya men, alarmingly low levels of vaccination among children, poor literacy, and rising poverty. Denied formal refugee status, the Rohingya cannot access due protections and find themselves in a state of insecurity in which they are unsure of their future and unable to formally seek work or send their children to school. While the government of Bangladesh explores the options of repatriation, relocation, and third-country resettlement for these refugees, it is important to ensure that they are not denied a life of dignity.

Introduction

The Rohingya people of Myanmar are one of the most persecuted minorities of our time. Denied citizenship since 1982, they have been subject to government-sponsored discrimination, detention, violence, and torture, causing several waves of mass exodus to Bangladesh, the most recent in 2017.[1] Since August 25, 2017, close to 700,000 Rohingya have entered Bangladesh, almost half of whom are now settled in holding camps on the narrow strip of land in Cox's Bazar District.[2]

There is now irrefutable evidence of ethnic cleansing in Myanmar's systematic expulsion of Rohingya across international borders and in the periodic fierce and indiscriminate killings, rapes, and burning of Rohingya homes and farms.[3] In Myanmar, the Rohingya are denied legal identities, birth certificates, and even access to essential childhood vaccinations. Restrictions on movement have forcibly confined the Rohingya in Rakhine State, requiring that those seeking work outside their village receive prior authorization from the government.[4] Poverty rates in Rakhine, where the Rohingya constituted one-third of the population before the latest mass flight, is nearly twice that of the national average (43.5% of Rakhine's population live below the poverty line, compared to the 25.6% national average).[4] For the Rohingya, this sweeping and selective denial of rights has resulted in abysmal health outcomes. While data from Rakhine State are scarce, key indicators of acute malnutrition, child mortality, and maternal mortality provide a glimpse of the suffering that is occurring due to negligent and hostile government policies.[5] Since August 2017, there has been an escalation of campaigns to drive the Rohingya out of Myanmar, transforming a slow but steady stream of Rohingya crossing the border into a massive exodus of hundreds of thousands of people.

Though not a signatory to the 1951 Refugee Convention, Bangladesh has allowed the Rohingya to seek shelter within its borders. Since the first waves of forced migration to Bangladesh in 1977, the Rohingya have been settled in two refugee camps run by the United Nations High Commissioner for Refugees (UNHCR) in Nayapara and Kutupalong. In 1992, the government of Bangladesh stopped recognizing these Rohingya as refugees. After that point, the Rohingya first settled in "unregistered" camps adjacent to the UNHCR camps and finally self-settled in nearby host communities. There are ongoing bilateral attempts to "repatriate" large numbers of Rohingya refugees to Myanmar, but many Rohingya who were sent back have since returned.[6] Since August 2017, Bangladesh, the fifth most densely populated country in the world, has accommodated over a million Rohingya refugees and is mobilizing to find resources to take care of these people who literally have nowhere else to go.

However, the refusal of Bangladeshi authorities to grant formal refugee status to this population fleeing from massacre and pillage has placed the Rohingya in a legal and humanitarian limbo. They cannot obtain the protections guaranteed by legal recognition. They can work only in the informal sector, face barriers to accessing education and health services, do not have recourse to the law, and are often arbitrarily detained.[7] In response to the latest influx, the government of Bangladesh has provided Rohingya with access to UNHCR services but continues to categorize the Rohingya as illegal migrants. The government does not view their settlement in Cox's Bazar as a tenable solution and continues to explore all options, including resettlement elsewhere in Bangladesh and onward migration to a third country.[8] Competing with the local community for scant resources, the Rohingya are reportedly being blamed for growing tensions with host communities.[9]

It is in this context, and in the quickly evolving current scenario, that we conducted a rapid needs assessment in both the Rohingya and host communities in Cox's Bazar to obtain systematic information on the most pressing needs among these two groups of people, with particular attention to the communities' demographic profiles, education, livelihoods, finances, and aid. This study establishes the parameters for a series of planned participatory studies among the Rohingya aimed at better understanding their needs, their aspirations for their future, and their attitudes as rights-holders. Host community information will help establish a baseline to monitor the impact of this large influx of refugees on local services, wages, and well-being, and to help target interventions to meet needs in both communities.

Methods

We conducted a randomized survey of 802 households between March 15 and March 18, 2018, to assess the basic needs, adequacy of services, and priorities among both the Rohingya and local Bangladeshi host communities in Cox's Bazar, Bangladesh.

We conducted our study in the Rohingya makeshift camps located in the Ukhia and Teknaf subdistricts of Cox's Bazar and among host community households located within a five-kilometer radius of these camps. We surveyed 402 Rohingya households and 400 host community households (see Figure 1). The sample size was powered to detect differences within each group at the 95% significance level; our sample size calculation assumed a conservative proportion estimate of 50%, with a 5% margin of error. We defined "household" as a person or group of persons who live together. Each survey was administered to one adult respondent (over 18 years of age) per household, after obtaining that person's consent.

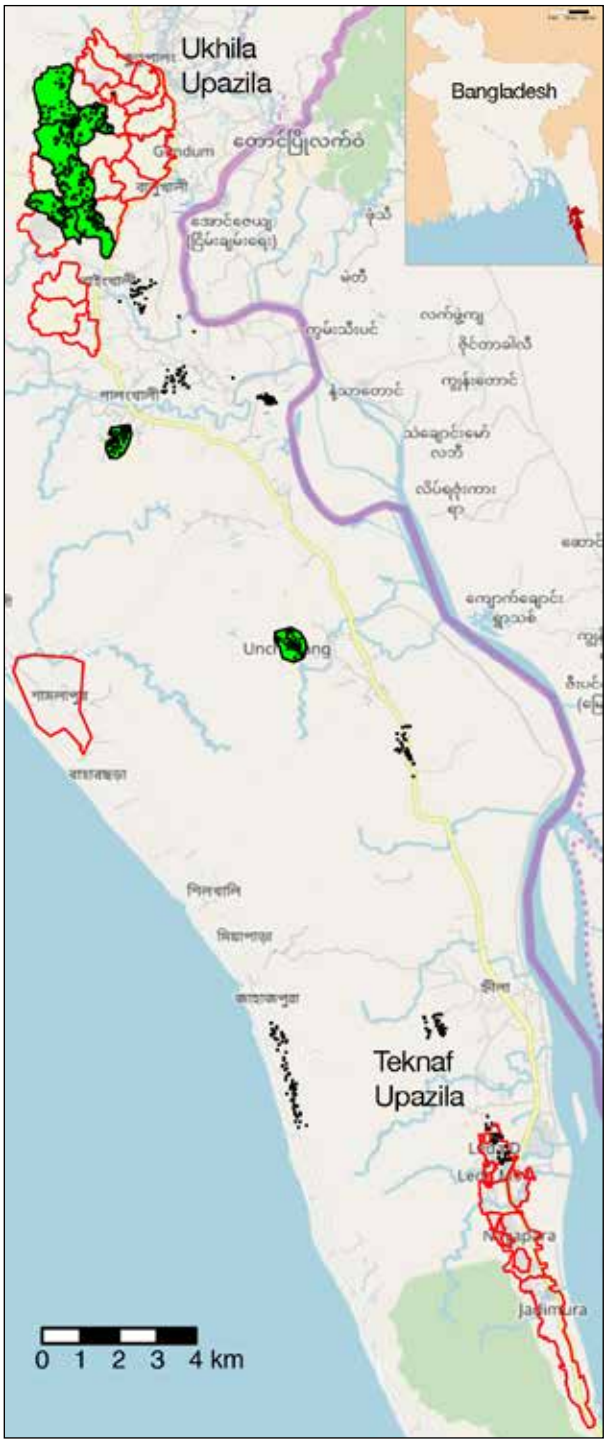
Sampling in the Rohingya communities

We used a two-stage random sampling strategy to select Rohingya households for our survey. Drawing from a complete list of Rohingya settlements in Cox's Bazar provided by BRAC, we restricted the sampling universe of Rohingya camps to settlements that (1) were designated as either a "makeshift settlement" or a "spontaneous site;" (2) had a population greater than 50 as of February 25, 2018; and (3) had no occupants prior to August 2017.[10] This initial selection resulted in nine camps in Ukhia (of which we randomly selected six) and two camps in Teknaf.

We identified Rohingya households within each camp using OpenStreetMap (OSM) layers for structures identified as "buildings." We then randomly selected 50 households within each of the eight selected camps by using the OSM "buildings" layer. These structures were marked with red dots, and their GPS coordinates were provided to the enumerators on geospatial PDF maps. If a marked structure had multiple households, enumerators used a random number generator to select from all households residing in the selected structure. When the selected structure was not a residential building, enumerators selected the nearest household to the right of the structure; if there were multiple households nearby, they used a random number generator to sample from the total number of houses. When there were no adjacent residential structures, enumerators chose randomly from a

pool of 15 additional preselected OSM buildings. This protocol was also followed when the selected structure had no occupants, if interviewees did not provide informed consent, or if the occupants did not match the sampling group (that is, if a sampled host community household was occupied by a Rohingya family or vice versa).

Fig 1. Sampled households in Cox's Bazar



Note: Red outlines represent all Rohingya camps, and green represents camps that were sampled from. Black dots represent all sampled households among both the Rohingya and host communities.

Sampling in the host communities

Ukhia and Teknaf subdistricts are divided into three unions each, making up of a total of 100 villages (unions are the rural administrative units under rural subdistricts).[11] We selected two villages from each union. Due to the unavailability of geospatial village boundary data, OSM could not be used for sampling. Enumerators randomly selected an initial household and then selected every 10th household thereafter to reach a total of 33 households in each of the 12 villages. Two additional households were selected in the two largest villages, resulting in a final sample size of 400.

Survey instrument

Our survey collected demographic information—age, gender, and educational attainment—for each household member. It also collected household mortality information for the last 12 months. The survey included additional questions on access to food and water, vaccination status of children, health care services, occupation, and livelihoods. No personal identifiers were collected. Our survey-based research study was granted exemption by institutional review boards at BRAC and the Harvard T.H. Chan School of Public Health per the US Federal Code of Regulation 45 CFR 46.101(b)(2).

Survey administration

BRAC hired 27 enumerators, all of whom were trained by our research team. They had good contextual knowledge of the Rohingya crisis, having worked in these or adjacent communities in the months prior to the survey. Our survey was administered in the Rohingya dialect. Data were collected using the CommcareHQ application on a tablet computer and, upon survey completion, were encrypted at source on the tablet. Every evening, the enumerators reported to a local BRAC office to upload the data to the cloud.

Statistical analysis

We used descriptive statistics and data visualization in RStudio (version 1.1.414) and Stata SE 15 to summarize the characteristics and responses of the study population.[12] Comparisons were drawn between the Rohingya and host community responses for key variables in relevant domains.

Results

Household demographics

The surveyed sampled population consisted of 1,828 individuals in 402 Rohingya households that had arrived after August 2017, and 2,119 individuals across 400 host community households. Table 1 provides descriptive statistics on household demographics for the two populations. Both populations had similar household sizes (median = 4 in Rohingya households; median = 5 in host community households). Rohingya households were younger (see Figure 1), with mean and median ages of 20 and 16 years, respectively, while host community households had mean and median ages of 24 and 18, respectively.

Rohingya households had a higher number of females (51.0%) overall compared to the host population (47.2% female); however, this ratio varied by age category (see Figure 2). Notably, a larger share of Rohingya households was headed by a female household member compared to households in the host communities (95% confidence interval for difference in proportions: 0.08, 0.19; p-value < 0.0001).

Mortality

Rohingya households reported 78 deaths in the 12 months preceding the survey; host community households reported 16 deaths. Of surveyed Rohingya households, 10.7% reported one death in the household, 2.5% reported two deaths, and 1.2% reported three deaths; in the host communities,

TABLE 1. Household demographics of sampled Rohingya and host community households

Household size	Rohingya (402 households, 1,828 individuals % (N, SE)	Host (400 households, 2,119 individuals) % (N, SE)
1	0.5 (2, 0.004)	0.5 (2, 0.004)
2	9.2 (37, 0.014)	3.5 (14, 0.009)
3	18.4 (74, 0.019)	11.0 (44, 0.016)
4	28.4 (114, 0.022)	19.3 (77, 0.020)
5	19.2 (77, 0.20)	23.0 (92, 0.021)
6	11.7 (47, 0.016)	20.3 (81, 0.020)
7	5.5 (22, 0.011)	13.3 (53, 0.017)
8	4.2 (17, 0.010)	4.3 (17, 0.010)
9	1.5 (6, 0.006)	2.8 (11, 0.008)
10	1.2 (5, 0.006)	1.3 (5, 0.006)
11	0.0 (0, 0.000)	0.5 (2, 0.004)
12	0.0 (0, 0.000)	0.3 (1, 0.002)
13	0.2 (1, 0.002)	0.3 (1, 0.002)
Head of household		
Female	28.1 (113, 0.022)	14.3 (57, 0.017)
Male	72.6 (292, 0.022)	86.5 (346, 0.017)
Other	0.2 (1, 0.002)	0.3 (1, 0.002)
How many people in your household have died in the last 12 months?		
0	85.6 (345, 0.018)	96.0 (384, 0.015)
1	10.7 (43, 0.015)	4.0 (16, 0.003)
2	2.5 (10, 0.008)	0.0 (0, 0.000)
3	1.2 (5, 0.005)	0.0 (0, 0.000)
Gender of deceased household member		
Female	35.9 (28, 0.054)	50.0 (8, 0.125)
Male	64.1 (50, 0.054)	50.0 (8, 0.125)

Note: N = total number of households in the sampled population; SE = standard error

no household reported more than one death. Figure 3 shows the distribution of age at death, by gender, for Rohingya households and host community households. Reported deaths in the Rohingya household were predominantly male (64.1%) and young (mean age at death = 38.7 years; median = 35 years; standard deviation = 24.2). The host community households reported equal numbers of male and female deaths, with deaths occurring at older ages (mean age at death = 56.1 years; median = 65 years; standard deviation = 35.2).

FIG 2. Population pyramids showing the age and gender distributions for Rohingya households and host community households

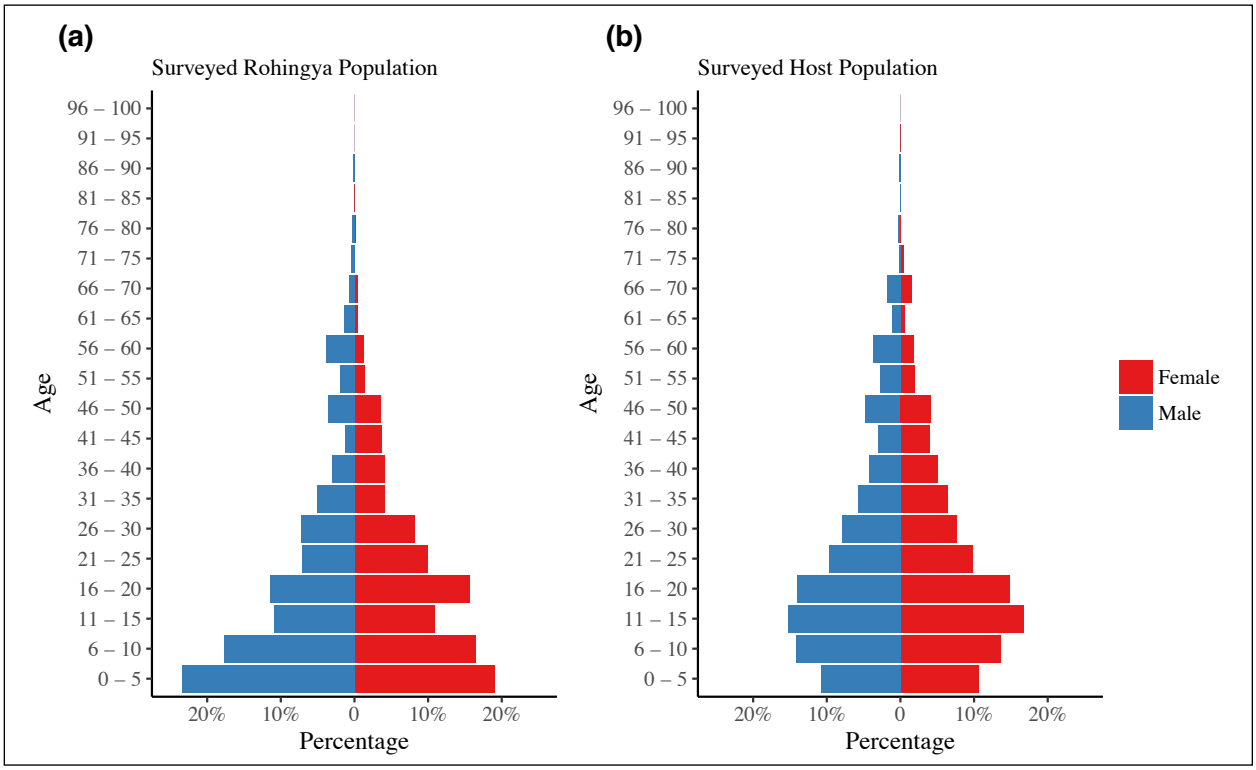
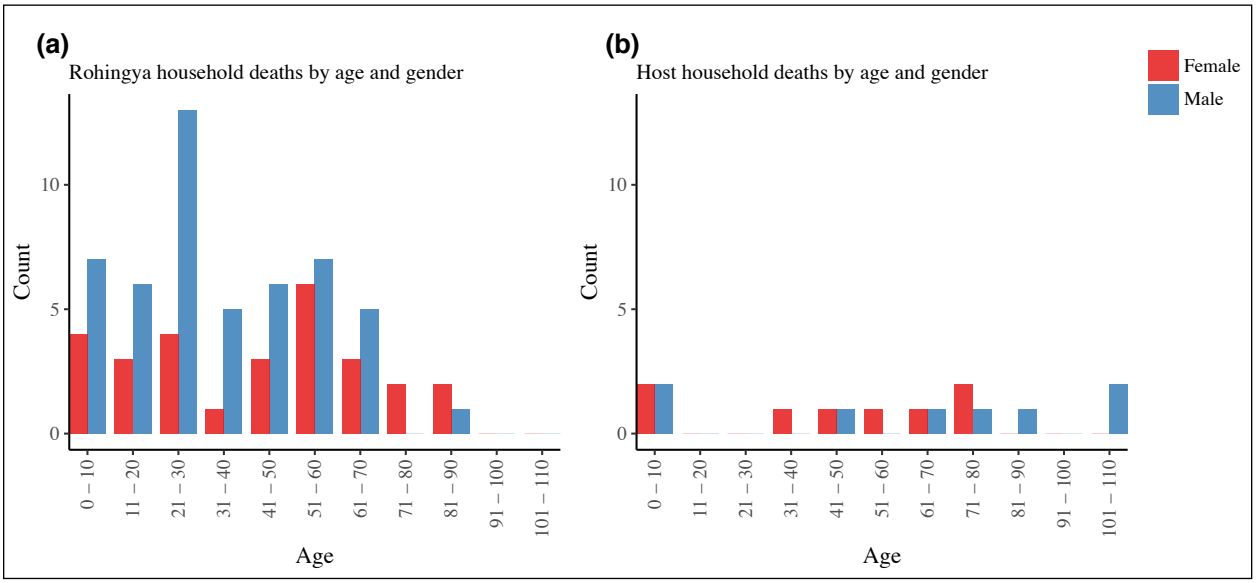


FIG 3. Frequency of reported deaths in Rohingya households and host community households, by age and gender



Education

A vast majority of Rohingya household members over the age of 15 (76.0%) reported having had no education, and 52.6% of Rohingya children under the age of 15 were not attending school. Of those children who were attending school, 88.2% of them attended learning centers or schools run by nongovernmental organizations. Among host community members, 43% of those over the age of 15 had received no education, and 33.6% of children under 15 were not attending school. Among school-going children, 53.2% attended government schools, 24.2% attended Islamic schools (known as *madrassas*), and 18.8% attended private schools. Figure 4 illustrates the distribution of educational attainment among adults in both populations.

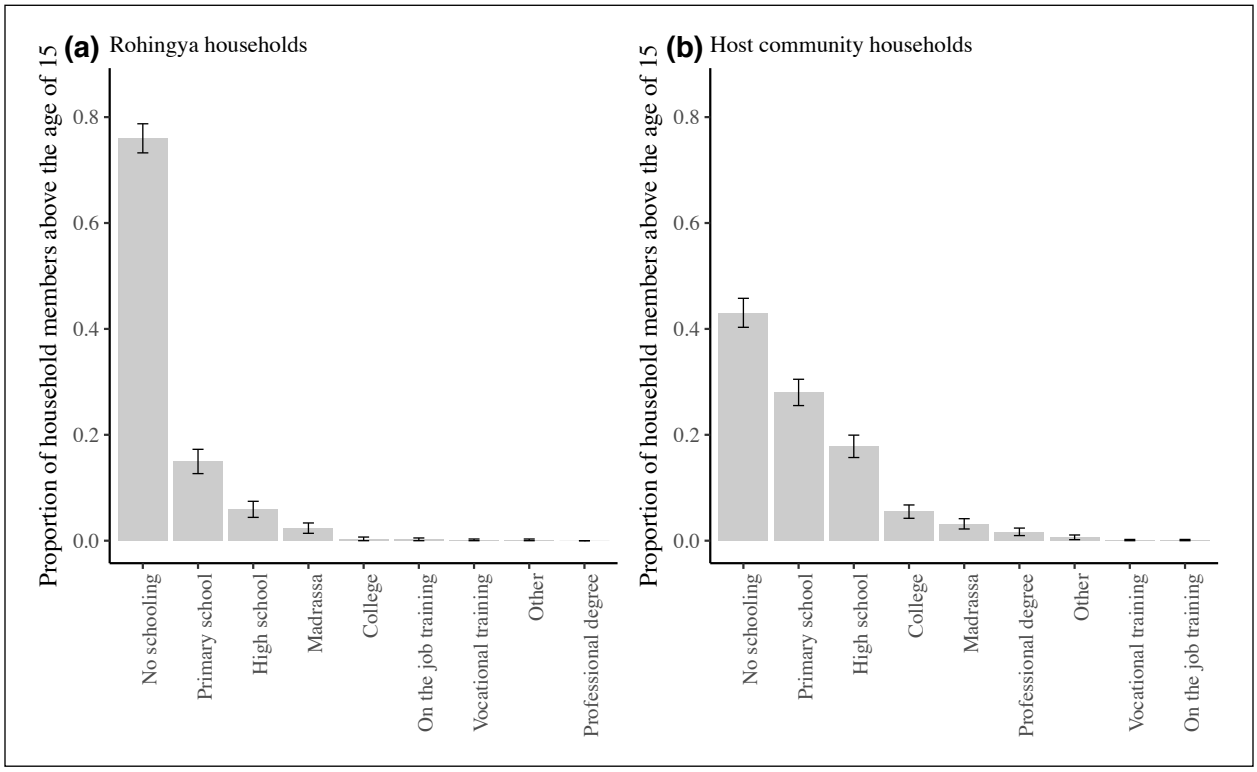
Household income and debt

Most Rohingya households (93.5%) reported a decrease in income over the previous 12 months. Among interviewed Rohingya households, the mean monthly income earned in Bangladesh was significantly lower than that earned in Myanmar (95% confidence interval for difference in means: -8405.6 taka, -2931 taka; p-value < 0.0001). In host community households, 49.5% reported a decrease in household income in the prior 12 months; however, there was no significant difference in the mean monthly income earned in 2018 compared to that earned in the previous two years (95% confidence interval for difference in means: -3022.1 taka, 1343.7 taka; p-value = 0.45). Figure 5 shows the change in income levels among both Rohingya and host community households.

Borrowing is common. In the Rohingya households, 35.1% were in debt. Of these, 72.2% had debts of less than 10,000 takas. The top three reasons for borrowing money were food, health care, and shelter. Regarding lenders, 97.2% were family and friends. No households reported borrowing from BRAC.

In the host community households, 38.8%

FIG 4. Proportion of Rohingya and host community household members over the age of 15, by level of schooling



Note: Bars represent proportions of all surveyed household members over the age of 15; error bars represent 95% confidence intervals. The majority of Rohingya household members (76%) reported having no schooling.

were in debt, among whom 65.4% owed more than 20,000 takas. They borrowed money mostly for work-related expenses, shelter, and health care. Among households in debt, 76.3% borrowed from family or friends, 19.2% from moneylenders, and smaller factions from banks, BRAC, and other micro-finance institutions (see Figure 6).

Our survey also asked respondents what they would do if they were to receive 15,000 takas in cash assistance (their answers were not limited to a single response). Among the Rohingya households, 51.7% said they would spend it on food, 32.8% on shelter, and 24.6% on clothing. A large proportion (42.8%) also reported that they would spend the money on "other" items not specifically listed. Meanwhile, in the host communities, 47.5% of households preferred to spend the money on work-related expenses, 22.8% on food, and 18.3% on shelter (see Figure 7).

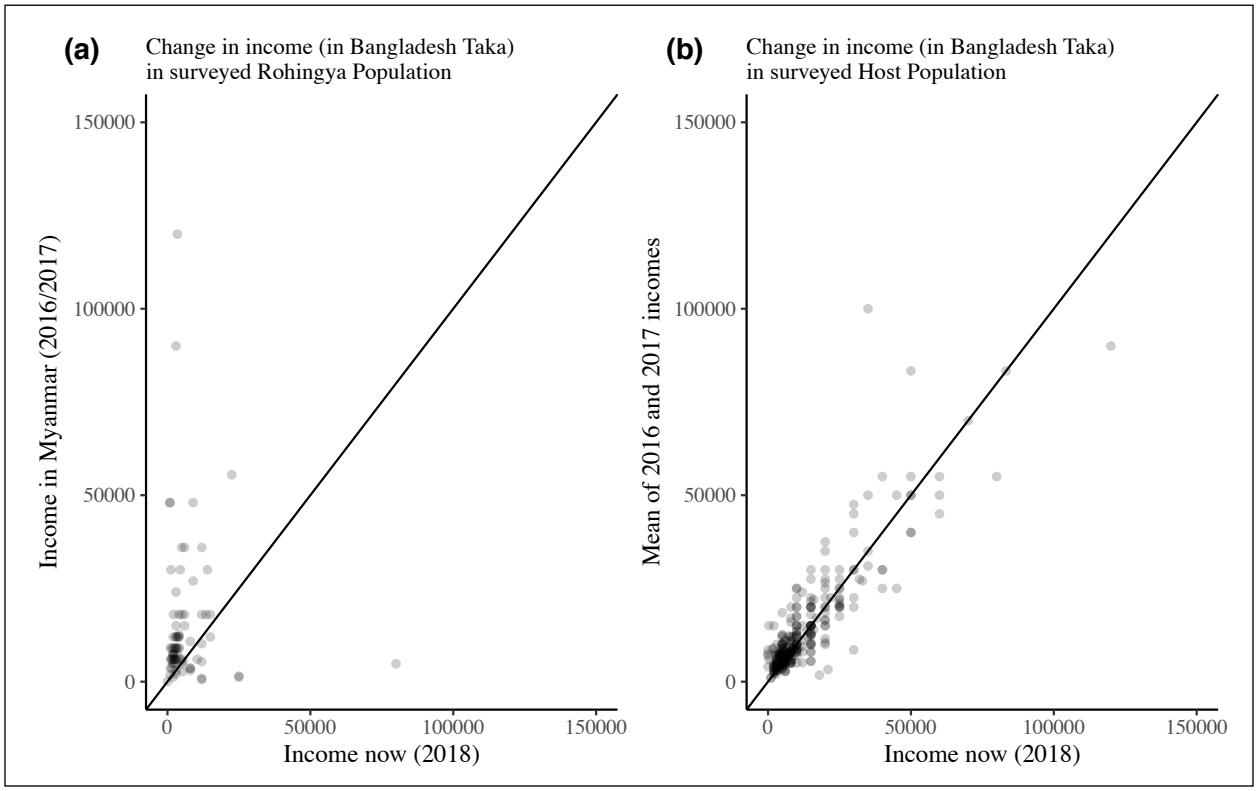
Water

The majority of households in both the Rohingya community (88.6%) and host communities (79.3%) used tube wells to obtain water for drinking, cooking, and bathing. The remaining Rohingya households sourced drinking water from wells (4.9%), rivers (0.5%), and other unspecified sources (5.7%). Among those households that did not source water from tube wells, 69.3% of host community households did not purify their drinking water, compared to only 35.6% of Rohingya households. The remaining households used conventional methods of boiling, filtering iodine tablets, or UV machines to purify their water.

Food security

When asked how many meals they ate the previous day, 62.9% of Rohingya households reported having three meals, while 35.8% reported having two. In

FIGURE 5. Reported current monthly income versus previous income for Rohingya households and host community households



Note: For Rohingya households, the survey asked about previous average monthly income in Myanmar, which spanned 2016 and 2017. For host community households, the survey asked about average monthly income in 2016 and in 2017 (average is plotted). The gray dots represent each response; the solid black line is the x=y line. At the time of data collection, 1,000 Bangladeshi taka = US$12.

the host communities, 84.8% of households reported having three meals, while 14.2% reported having two. One percent or less of all surveyed households reported only one or no meals the previous day. However, self-reported rates of food shortage were high: 58% of all Rohingya households and 39.5% of host community households reported experiencing food shortages. Even among households that reported having at least three meals the previous day, 47% of Rohingya households and 32.7% of host community households reported a shortage (see Figure 8).

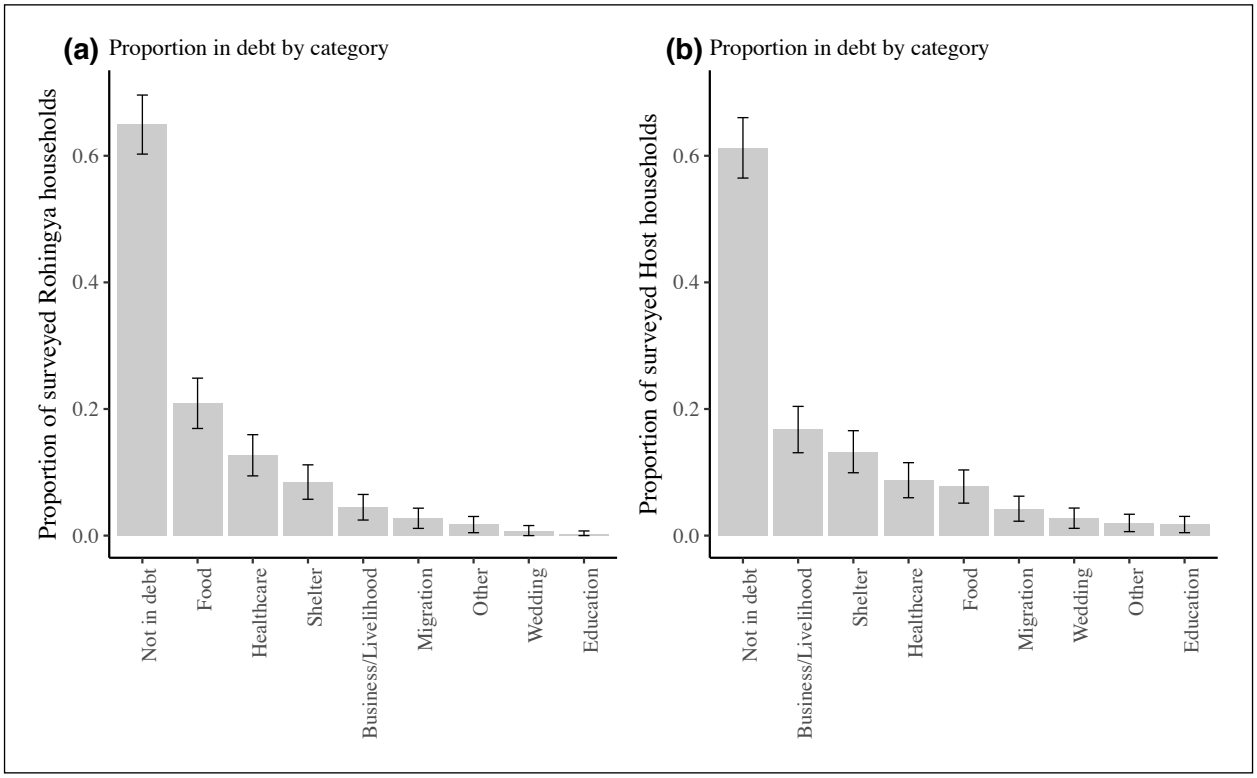
Vaccination

According to the recommended vaccination schedule for children, all children should receive nine doses of injectable vaccines and four doses of oral vaccines by the age of two.[13] Among the Rohingya households, of the 167 children aged two and younger, 61.7% had received no doses of injectable vaccines in Myanmar, and only 2.4% had received five or more doses in Myanmar. Even when older children are included, 42.9% of children under the age of four had not received any doses of an injectable vaccine in Myanmar, and only 2.8% had received five or more doses. For oral vaccines, 57.5% of children aged two and younger had received no doses in Myanmar, and only 3.6% had received the recommended number of oral doses (see Figure 9).

Several vaccination campaigns (for diphtheria, cholera, polio, and measles) have taken place in the Rohingya camps.[14] Among the 314 Rohingya children under the age of five, 88.2% had received at least one dose of an injectable vaccine since arriving in Bangladesh, and 82.4% had received at least one dose of an oral vaccine. However, among children who had received no doses of injectable vaccines in Myanmar, 24.8% received no injectable doses in Bangladesh; of those who received no oral vaccines in Myanmar, 29.6% had also not received any doses in Bangladesh (see Figure 10).

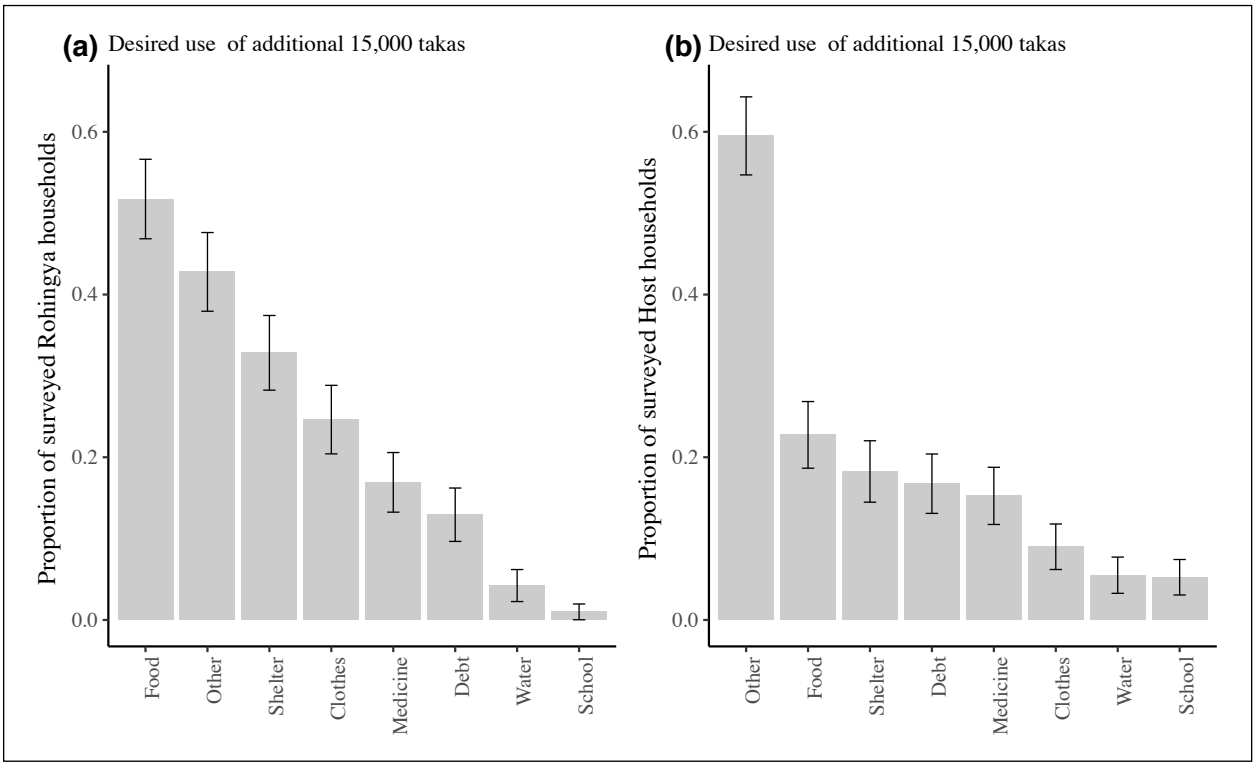
Among the host communities, of the 84

FIGURE 6. Proportion of Rohingya and host community households reporting being in debt, by category of debt



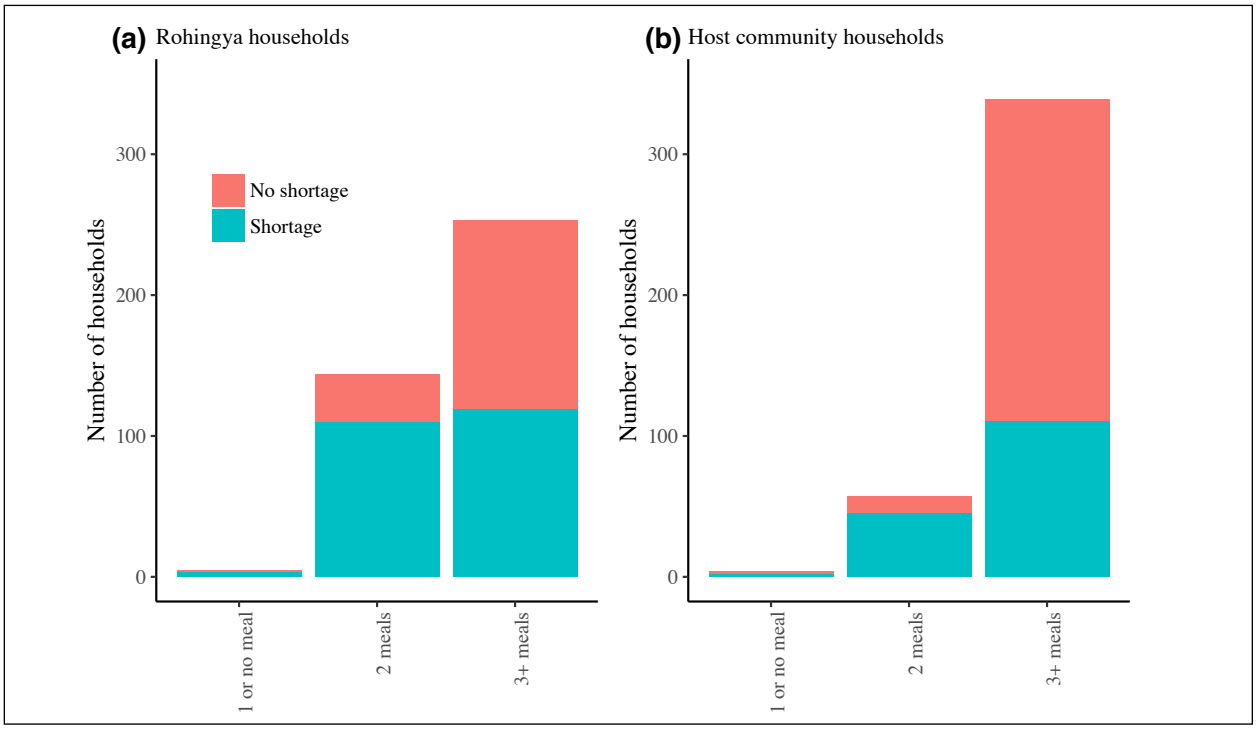
Note: Bars represent proportions of all surveyed households; error bars represent 95% confidence intervals. Among households reporting being in debt, the majority of Rohingya households reported being in debt for food, while the majority of host community households reported being in debt for expenses related to business or their livelihoods.

FIGURE 7. Desired use for additional money reported by Rohingya households and host community households



Note: Bars represent proportions of all surveyed households; error bars represent 95% confidence intervals. The majority of Rohingya households identified food as the main category in which they would spend additional money; for host community households, the majority responded that they would spend money on "other" items (which were primarily business-related expenses). For Rohingya households, the survey did not request a description for the "other" category.

FIGURE 8. Rohingya and host community households categorized by the reported number of meals the previous day and reported food shortage



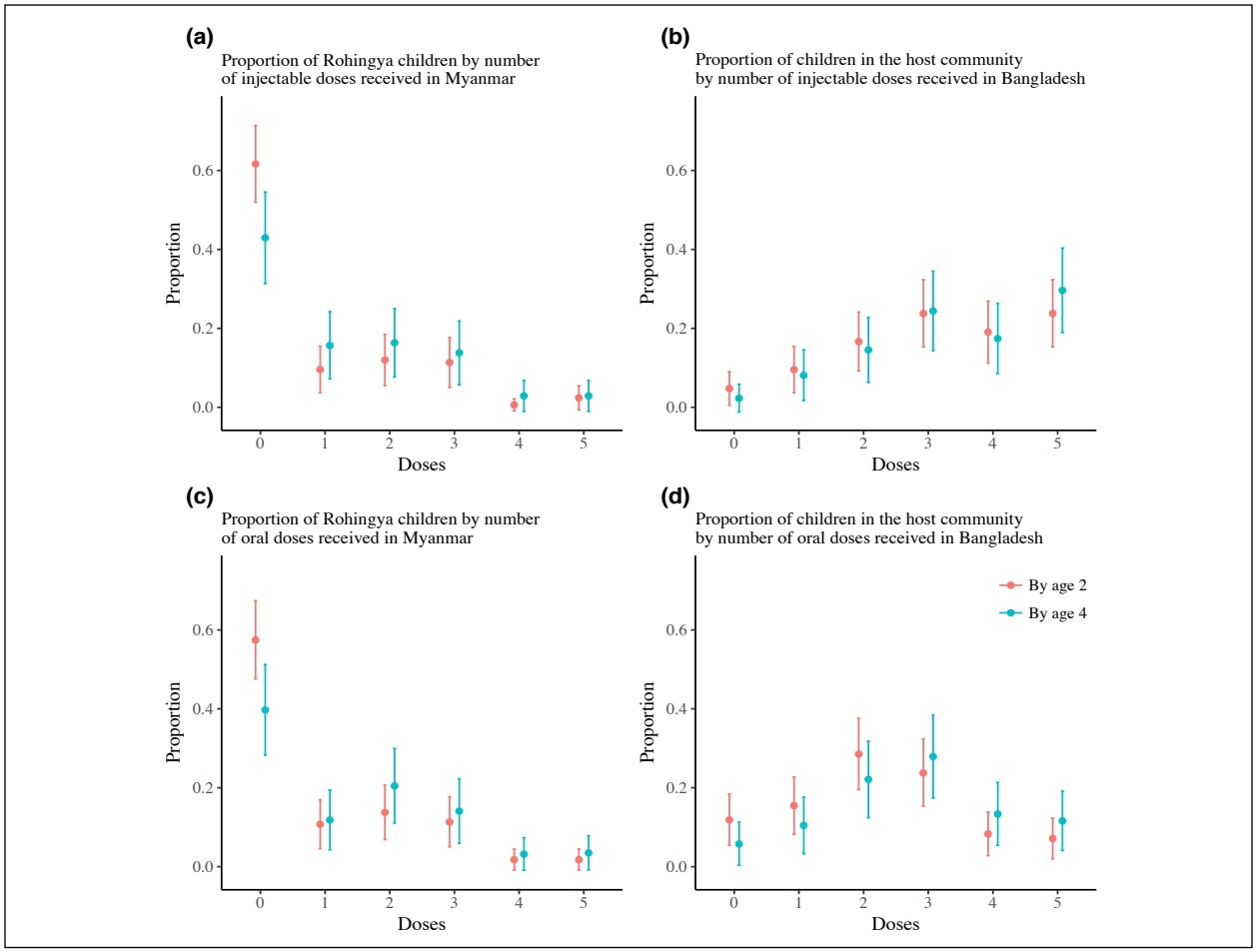
children aged two and younger, only 4.8% had not received any doses of injectable vaccines, and 23.9% had received five or more doses. For oral vaccines, 11.9% had not received any doses, and 15.4% had received the recommended number of doses. By age five, 24.9% of children had received the recommended doses of oral vaccines.

Health care access

Of all surveyed Rohingya households, 14.2% reported experiencing challenges in accessing health care. There was some variation across Rohingya sites, with the least number of households (5.9%) reporting difficulties at CXB 108 Chakmarkul, and the highest number (24%) reporting difficulties at CXB 219 Camp 19. Among those facing challenges in accessing care, 61.4% said that the nearest facility was too far, 12.3% said they could not afford care, and 40.4% cited other reasons. In the host communities, 32.5% of all surveyed households reported issues in accessing health care, with a wide variation (0 to 57.6%) among locations. Among those who reported difficulties, 70.2% stated that the health care facility was too far, 35.9% claimed they could not afford care, and 9.9% cited other reasons. Figure 11 provides a snapshot of the Rohingya and host community households reporting difficulties in access to care.

Of the 18.9% Rohingya households that reported a pregnancy in the prior year, the majority of pregnant women (56.6%) received no antenatal care. Of those women who gave birth in the previous 12 months, 73.7% did so at home without a certified birth attendant. In the host communities,

FIGURE 9. Proportion of children by ages two and four who have received injectable or oral doses among the Rohingya and host communities



11.3% of households reported a pregnancy during the last year, of whom 42.2% had at least one antenatal visit and 24.4% had two. Of those reporting a childbirth in the prior 12 months, 51.7% gave birth at home without a certified birth attendant.

Discussion

The results of this rapid needs assessment offer important insights into the most pressing challenges facing the Rohingya while also providing contextual information about the neighboring Bangladeshi communities hosting them. Our data underscore the gross violations and abandonment faced by the Rohingya in Myanmar.

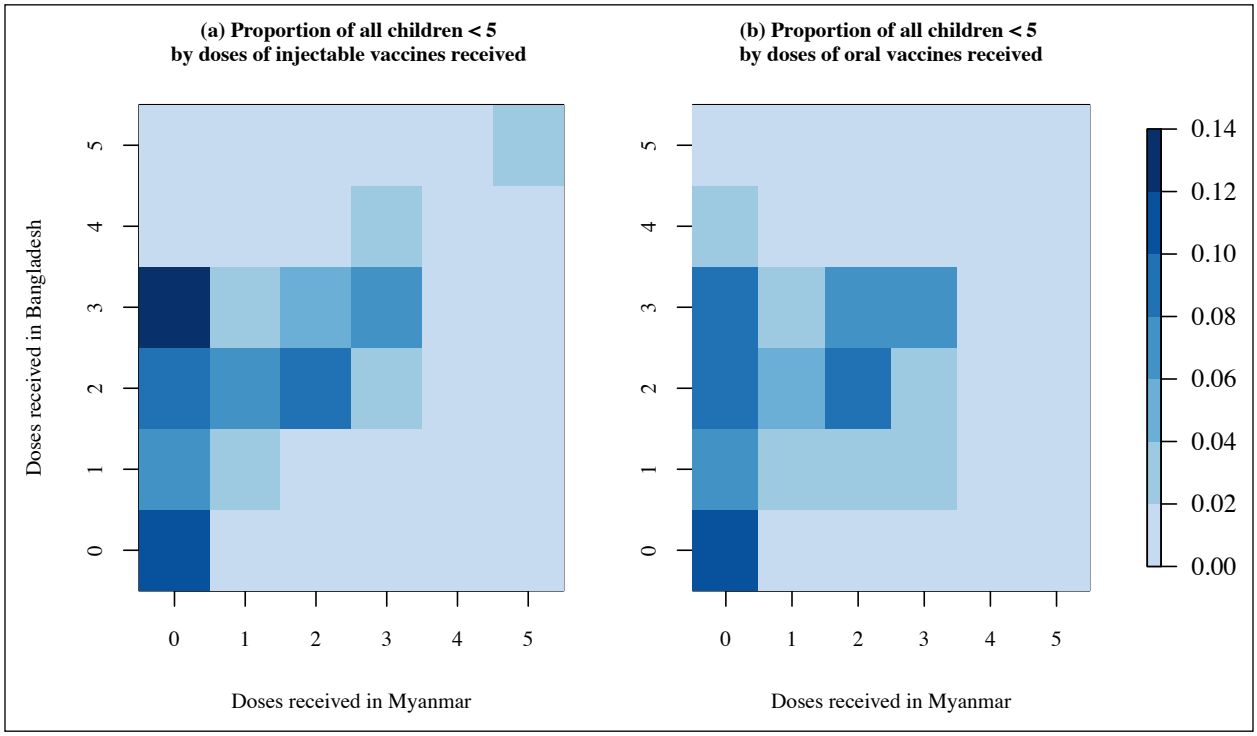
High mortality

The Rome Statute of the International Criminal Court defines the crime of genocide as

> *any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group . . . : killing members of the group; causing serious bodily or mental harm to members of the group; deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part; [among others].*[15]

The demographic pyramid representing Rohingya refugees demonstrates the loss of working-age men. In conjunction with the high number of household deaths reported in our survey, this pyramid shape speaks to a war-affected population with violent deaths of males. Our findings corroborate findings of systematic massacres of young men and boys as reported by other human rights and advocacy organizations.[16] Sampled Rohingya households reported nearly five times as many deaths as host community households, with a majority of them occurring among young men. In the Rohingya households, the median age for male deaths was lower than that for females, and the overall mean age at death in these households was lower than

FIGURE 10. Proportion of all Rohingya children under the age of five, stratified by the number of vaccine doses received in Myanmar and Bangladesh



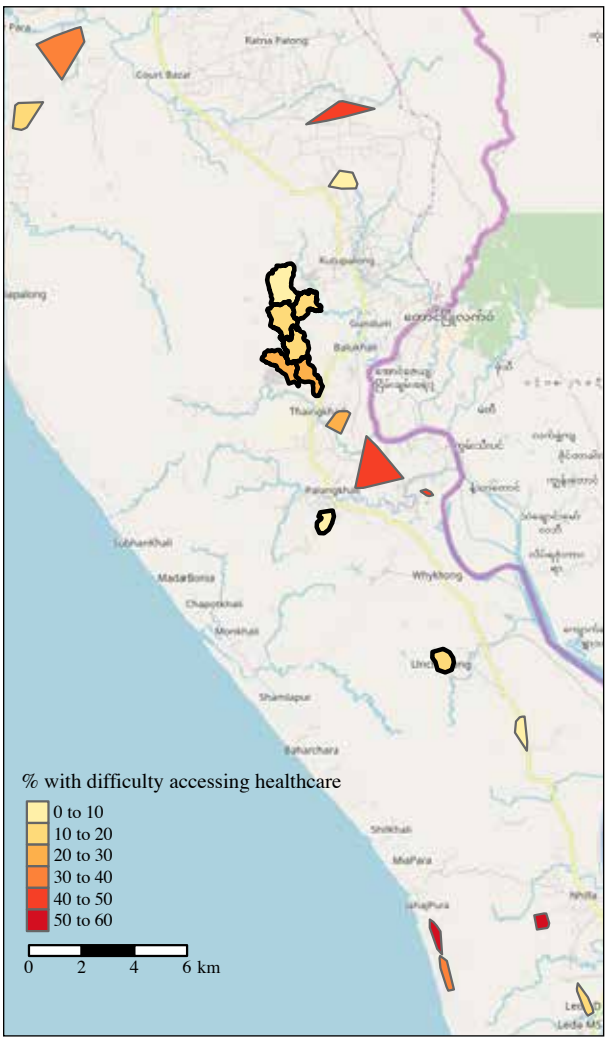
Note: Darker colors indicate larger proportions.

that in the host communities. This trend of high deaths among young Rohingya men is consistent with the targeted killings that have been observed as part of systematic ethnic cleansing and genocide elsewhere.[17]

Education

Literacy levels among Rohingya adults (those over 15 years) are very low, as is school enrollment. While we sampled only those who had arrived after August 2017, the numbers shed critical light on the need to prioritize access to formal schooling—an ongoing challenge among populations on the move.[18] Currently, BRAC provides primary education through 200 learning centers for over 21,000 students, available to all, with the rollout of additional centers planned in the near future. Contrary to concerns about Rohingya migrants seeking education in *madrassas*, our survey found that refugee children were not attending these institutions. However, based on our earlier surveys among the long-settled Rohingya in the region, *madrassa* attendance may eventually rise, especially if there are no viable alternatives. School access is a persistent challenge for many of the earlier arrivals; denied refugee status, they cannot access UNHCR-led services. Even those in the UNHCR camps have access only up to the eighth grade, consistent with national laws that provide for compulsory education up to the eighth grade.

Figure 11. Map of the Cox's Bazar region showing the percentage of households reporting difficulties in accessing health care in the Rohingya camps and local host communities



Note: Rohingya camps are outlined with thick black lines. Host community village boundary polygons were determined using the recorded household geolocations that lie on the convex hull of the set of all points for the village. Darker shades indicate higher proportions of households reporting difficulties accessing health care.

Bangladesh has ratified the Convention on the Rights of the Child. The country's education system is one of the largest in the world, with 21.9 million children in kindergarten and primary school. Two percent of the gross domestic product (and 14.4% of the national budget) is spent on education. A stated outcome of the government's Third Primary Education Development Program is to reduce "regional and other disparities" in terms of participation, completion, and learning outcomes. Despite these commitments, the need to expand access to schools and vocational training for both children and adults is evident in the host communities as well, where age-disaggregated data show that about one-third of Bangladesh's population falls in the 10–24 age group, with large gaps in basic education and employability.[19]

Livelihoods and debt

Rohingya households have become significantly impoverished, as expected during migration, with 79.9% of surveyed households reporting no current income. Among the host communities, contrary to the fear that the presence of Rohingya was driving down wages, our survey found small increases in the number of households reporting an income, as well as in the total income for some households.

Bangladesh's transition toward a country with a lower fertility rate and improved health services is reflected in its overall demographic profile, with a decreasing dependency ratio and a growing percentage of the population entering the labor market.[20] The Rohingya population will add to the dependency ratio in the country unless the Rohingya are allowed to participate in the labor market. There is growing and convincing evidence globally that legally integrating refugees into the labor force promotes dignity and self-reliance, while positively contributing to the local economy.[21] Our own studies of long-settled Rohingya migrants have shown that almost all eventually find some form of work, albeit in the informal sector, irregularly, and for low wages.

There is an urgent need to address and alleviate barriers to refugees' ability to legally seek work, including while they await decisions about their fate. Particular attention must be paid to involving women in income-generating activities, given the high ratio of female-headed households among the Rohingya population and the cultural barriers (in both Rohingya and host communities) against allowing women to work.

Bangladesh's existing restrictions preventing the Rohingya from being able to work and to borrow money only compound the economic burden inflicted on this community through the loss of property and possessions while fleeing Myanmar. These issues have led to the accrual of informal debt to family and friends. Rohingya debts are mostly below 10,000 takas and may reflect limited access to larger amounts through formal mechanisms of lending, including microfinance. The host communities, whose debts are often in excess of 20,000 takas, have better access to loans and use them primarily to support their means of livelihood.

Water

Our survey did not elicit any alarming deficits in access to water. Both groups procured water mainly from tube wells, which, if not contaminated at the source, provide water that does not require additional purification.

Food

We found high levels of food insecurity among the Rohingya, with more than one-third of these households reporting eating only two meals a day, and 32.7% of those that have three meals a day reporting a food shortage in their household. This food shortage among Rohingya refugees is also reflected in their prioritization of food over all else if provided additional cash assistance, as well as in their borrowing money to procure food, as reported in our survey. Currently, the Rohingya population that arrived in 2017 is reliant on humanitarian assistance for food, with the World Food Programme providing food vouchers that can be used to purchase from a pre-set list of food items, though these offerings lack dietary diversity.[22] The provision of cash assistance instead of food vouchers could allow the Rohingya to decide where they would like to allocate their money (for example, toward their own livelihood generation) and allow them to access a more diverse offering of foods than the current pre-set list.[23]

Vaccination

A high number of Rohingya children had received no vaccines while in Myanmar, as had been suspected after the recent diphtheria outbreak in the Rohingya camps in Cox's Bazar in December 2017.[24] Despite the large number of vaccination campaigns in the camps, a majority of Rohingya children have yet to receive vaccinations according to the prescribed universal schedule. The failure to vaccinate Rohingya children in Myanmar provides additional evidence of the discriminatory and unconscionable practices of Myanmar's government against the most vulnerable section of their society.

Health care access

Data on the observed (and wide) variation in health care access in the host communities will help the government and the aid sector plan services in the region, including the deployment of mobile clinics to reach areas where distances have been reported as prohibitive. Improving the utilization of antenatal care in both communities will require increased access and awareness.

Study limitations

While survey-based studies allow for rapid assessments in humanitarian emergencies, they suffer from inherent limitations associated with self-reported data, including recall and respondent biases.

In addition, our sampling approach in the Rohingya camps, which utilized OSM data, may be biased due to the limited availability of data on the presence of household structures from which to sample across locations. In the host communities, true randomization was hampered by the unavailability of a complete household census for these villages.

Our survey instrument was coded in Bengali on the tablets but administered in the Rohingya dialect; responses were recorded in Bengali. However, given that most questions were restricted to selecting from a list of possible responses, the translation of responses is not likely to have resulted in statistically significant errors.

The interpretation of our mortality data may be susceptible to systematic biases in our sampled Rohingya populations. For example, it is possible that only families where young, working-age men were killed left for Bangladesh, while others remained. These data may also be affected by recall bias favoring remembering male deaths or young adult deaths, as well as any inherent sex-preferences for males in the underlying population that may lead to a higher count of male deaths overall.[25] Our questions about Rohingya mortality were limited and did not include information on the cause, time, or location of deaths of household members. Given the consistency of our findings with reports on systematic discriminatory killings, further inquiry into these data would be beneficial.

Our questions (and the elicited responses) about vaccination also need further inquiry. It is important to know which vaccines the children have gotten, which they have not, and which need to be prioritized.

The study did not explore issues around identity, security, and safety facing the Rohingya, including questions about gender-based violence. It did not include further details about the high death rates among young men. Additional studies have been planned to address this gap.

Our findings indicate that an overwhelming number of Rohingya felt safe in Bangladesh. Among those who felt unsafe, most feared repatriation. Among the small percentage of people in host communities who felt unsafe, the majority feared the presence of the Rohingya. These sentiments need additional in-depth and focused inquiries among both groups.

Conclusion

The Rohingya are denied refugee status in Bangladesh. As a consequence, they are further denied many of the protections ensured through international law. The absence of legal registration precludes any formal mechanism of repatriation or of resettlement to a third, more hospitable nation. Accordingly, while some individuals have attempted the unsafe onward journeys (sometimes with fatal consequences) to locations such as Thailand, Malaysia, Indonesia, and the Middle East, the vast majority of Rohingya have been forced to seek work illegally, on the fringes of the informal sector.

Hundreds of thousands of new arrivals in the camps find themselves confined, with significant restrictions on work and schooling. Though Bangladesh's Constitution provides for the legal protection of non-citizens, it has not incorporated into domestic law article 25 of the Universal Declaration of Human Rights, which protects the right to an adequate standard of living.[26] It is in this legal vacuum that many Rohingya, whether refugees or legal residents, remain suspended indefinitely with little prospect of improvement. Denied the chance in Myanmar to fulfill their human capabilities, the Rohingya must not be consigned to inanition, sequestered in camps in Bangladesh.

The gaps in services identified by our data require renewed efforts to fulfill these human security needs. The general consensus among analysts is that many Rohingya will likely remain in camps in Bangladesh for the foreseeable future.[27] Most notably, however, other countries from the Association of Southeast Asian Nations seem to have abrogated responsibility for the Rohingya people.[28] The government of Bangladesh should

not be expected to take on this burden alone. The international community must provide the support needed to rehabilitate these refugees from campaigns of ethnic cleansing while insisting that the Rohingya be officially recognized as refugees. While the government of Bangladesh explores a range of placement options—including settling the Rohingya within Bangladesh, repatriating them to Myanmar, and supporting onward migration to a third country—it is of urgent importance that the Rohingya be furnished with tools of self-reliance. Solutions exploring relocation or onward migration will fall short unless they also include short-term measures aimed at allowing the Rohingya to find work and education while in Bangladesh. This population is burdened with high illiteracy rates and limited skill sets. While mounting evidence from around the world shows the prudence of formally integrating refugees into the labor force, doing so in Bangladesh will entail substantial upstream investment in imparting skills and education to migrant populations, with a particular focus on women.[29] These strategic interventions are likely to work best and cost least if migrant populations are integrated into the host community, as geographic isolation would render them unable to participate in or contribute to the local economy.[30] Such refugee integration efforts typically require expansion of services to the host community as well, in order to be equitable and to prevent further resentment among host communities.[31]

People seeking asylum must not be expelled or forced to return to situations where they are not safe. The principle of non-refoulement is a firmly established prohibition in international law.[32] Although the government of Bangladesh has taken steps to ensure that any instances of repatriation are safe and voluntary, the proposed repatriation efforts cannot be presumed to be uncoerced as long as evidence demonstrates that the environment in Rakhine State remains insecure.[33] Our data echo the international community's alarm at Myanmar's continued ethnic cleansing of the Rohingya from Rakhine State. Myanmar must be held accountable.

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Domestic and Family Violence in Post-Conflict Communities: International Human Rights Law and the State's Obligation to Protect Women and Children

SAMANTHA BRADLEY

Abstract

Post-conflict communities consistently experience high rates of domestic and family violence (DFV) against women and children. An end to violence in the public sphere is widely seen to precipitate the escalation of violence in the private sphere. This paper presents the argument that protecting women and children from DFV should be an essential public policy goal in post-conflict communities. Furthermore, the imperative for placing DFV on the post-conflict agenda is derived from states' obligations under international human rights law. Jurisprudence is clear that if a state has knowledge of DFV yet fails to take reasonable steps to ensure victims' safety and to investigate complaints, then that state may be violating the fundamental human rights to life, to freedom from inhuman and degrading treatment, to freedom from discrimination, and to health. Problematizing DFV as a violation of states' obligations under international human rights law, rather than dismissing it as a private sphere issue, should lay the groundwork for post-conflict states' conceptualization of the protection of women and children as a non-negotiable facet of peace-building agendas.

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Introduction

For women, an end to conflict does not always mean an end to violence. It is a well-documented phenomenon that post-conflict communities experience higher rates of domestic and family violence (DFV): when hyper-masculinized and traumatized male combatants leave the battlefield, often, for a myriad of reasons, their homes become new stages for violence.[1] Compounding this experience is the fact that post-conflict communities are predominantly poorly equipped to combat DFV in any way that meaningfully prioritizes the protection of women and children. Peace deals and state-building agendas are largely written by men, to the exclusion of women.[2] DFV is often not criminalized in post-conflict societies.[3] Additionally, post-conflict regression to patriarchal gender norms sees victimized women stigmatized by authorities when they find the courage to seek help.[4] Within this context, this paper argues that protecting women and children from post-conflict DFV should be a policy objective central to peace-building and state-building agendas. Furthermore, that the imperative for the post-conflict states' prioritization of the protection of women and children finds its roots in International Human Rights Law (IHRL), and states' inalienable obligations under IHRL.

This paper is structured into four parts. First, I provide an overview of scholarship regarding the phenomenon of post-conflict communities experiencing high rates of DFV. Secondly, I use two case studies, Bosnia and Herzegovina (BiH) and Timor-Leste, to demonstrate that post-conflict communities are also typically poorly equipped to both protect victims from DFV and combat the underlying causes of the violence.

Third, I evaluate what IHRL says, and how these laws interact with the realities of DFV experienced by women and children. I examine jurisprudence from international judicial bodies and highlight case law that clearly defines state obligations in respect to protecting vulnerable women and children from DFV. The four key IHRL norms and related jurisprudence that are evaluated are: the right to life, the prohibition on inhuman and degrading treatment, the prohibition on discrimination against women, and the right to health.

Finally, having outlined where the law stands, I review model policy documents created by international organizations and paint a picture of what prioritizing the protection of vulnerable women and children from DFV looks like, when incorporated into peace-building agendas.

Defining DFV

Violence committed against women and children can be defined in a number of ways, and laws across different domestic jurisdictions have their own definitions if these acts are criminalized.[5] This paper will utilize the definitions employed in Australia's *National Action Plan for Reducing Violence Against Women and Children*:

> **Domestic violence** refers to acts of violence that occur between people who have, or have had, an intimate relationship. […] Domestic violence includes physical, sexual, emotional and psychological abuse.
>
> **Family violence** is a broader term that refers to violence between family members, as well as violence between intimate partners […] it includes the broad range of marital and kinship relationships in which violence may occur.[6]

DFV in post-conflict communities

It is well recorded that for women, an end to conflict often does not mean an end to violence. Ni Aolain observes, "Feminist international legal scholars have long noted, sexual and gender-based violence rarely conforms to the timelines of peace treaties and ceasefires but endures past them."[7] Research confirms this: in general, post-conflict societies have higher rates of DFV.[8] For women and children whose male partners and relatives survive the conflict, DFV increases when the former combatants return to their homes.[9] The UN Security Council's Resolution 1325 on Women, Peace and Security, and subsequent associated resolutions, also implicitly acknowledge the vulnerability of women and girls to violence in post-conflict communities, and call for the implementation of international human

rights norms to protect women and girls from such violence.[10] Therefore, an end to violence in the public sphere is widely seen to precipitate the escalation of violence in the private sphere.

Research points to myriad reasons for this phenomenon. One explanation is that men exposed to the hyper-masculinity and horrors of war may in its aftermath have difficulty returning to non-violent society. Cockburn notes, "when men, brutalized by fighting, return home, they are liable to turn the home itself into a battleground."[11] Another explanation is to do with disarmament, demobilization, and reintegration, with ex-combatants often experiencing "difficulty making the transition to peacetime non-violent behavior after returning home."[12] Furthermore, research has demonstrated that "men exposed to torture and other human rights abuses are at a heightened risk of enacting IPV [intimate partner violence] when they return to their families,"[13] and that veterans who suffer from post-traumatic stress disorder and depression are more likely to perpetrate DFV than those with other conditions.[14] One study examined veterans in post-conflict Burundi, and found that 60% reported at least one incident of violence against their children, and 36% reported an incident of violence against an intimate partner.[15] In the Serbian context, studies have confirmed a relationship between masculinities magnified by conflict, DFV, and the evening news: "Women in Belgrade soon learned that the only way to avoid the almost inevitable violence after these programmes was to leave the house."[16] This research indicates that the masculinities forged by armed conflict, in combination with the psychological wounds incurred by combatants, contribute to ex-combatants having an increased propensity to perpetrate DFV when they return home to their partners and children.

Post-conflict and peace-building environments may also see communities idealizing a return to traditional gender norms that carry an inherent power disparity conducive to DFV. The patriarchal power structures of privilege and control that develop and thrive during conflict tend to carry over to post-conflict periods, to the overall detriment of women.[17] Kaufman and Williams observe, "the peace that emerges after conflict is often a gendered peace, one in which domestic violence often increases and women are expected to return to their traditional gender roles."[18] Furthermore, according to Pankhurst, it is normal for domestic abuse to increase in the post-war setting, both from partners returning home from the war, and from partners who remained at home. Even though men also suffer from high crime rates, as a group they are also the main perpetrators.[19] Researching DFV in post-conflict Timor-Leste, Hall noted that a return to traditional gender norms and roles in a post-conflict context created a loss of independence for women, and power dynamics that placed women at greater risk of experiencing DFV.[20] On this note, Maguire observed:

> Gender analyses of conflict and post-conflict situations have highlighted the danger, once a society is beginning to return to some form of stability […] of a return to what communities believe to be 'traditional' differentiated gender roles. Violence is a way of enforcing women's conformity to such demands.[21]

This body of research indicates that post-conflict communities regularly see a distortion of gender dynamics and a re-emergence of patriarchal power structures that may work to condone and perpetuate violence women experience in the private sphere.

Post-conflict communities as ill-equipped to combat DFV

In addition to post-conflict states experiencing high rates of DFV, these states are also uniformly ill-equipped to combat these issues. The protection of women and children may be deprioritized in favor of state-building initiatives preferred by the officials—usually male—who dictate peace agreements and state-building agendas. Furthermore, post-conflict communities lack laws criminalizing acts of DFV. Authorities may be prejudiced against victims of DFV as post-conflict societies see a return to traditional gender norms. I will employ two case studies of post-conflict communities to

demonstrate this phenomenon: post-conflict BiH, and post-conflict Timor-Leste.

DFV in post-conflict BiH

In the wake of the horrors of the conflict in the former Yugoslavia between 1991 and 1999, an increase in DFV was observed in post-conflict BiH, but the newly independent state lacked frameworks enabling effective responses to such violence. Of note is that the Dayton Accords that ended the Balkan wars in 1995 were the result of peace talks that did not include women, and used gender-neutral language.[22] In post-conflict BiH, "women were expected to focus primarily on their roles as mothers and wives."[23] Cockburn notes, "Perversely, the Dayton Peace Agreement did not diminish, but rather affirmed, patriarchal nationalism as a dominant ideology and social system in post-war BiH."[24] In 2010, a coalition of human rights organizations in BiH found that "violence against women, especially domestic violence, continues to be a widespread social problem in BiH."[25] A 2000 report commissioned by USAID also found that 20% of women in one BiH town had been victims of DFV.[26]

Cultural factors are believed to have contributed to rates of post-conflict DFV in BiH. A report found that DFV was "seen and tolerated as a 'socially acceptable behavior'" and, moreover "justified by the traditional and patriarchal conceptions of the role and status of women in BiH society."[27] Muftic and Cruz note, "research indicates that the vast majority of Bosnians believe that DV [domestic violence] is a private matter between a husband and a wife and, as such, the state has no right interfering in the affairs of family members."[28] Furthermore, victims of DFV are often seen to have contributed in some way to their victimization; this is a factor contributing to low reporting rates of DFV.[29]

In post-conflict BiH, legal, cultural, and support service frameworks all lack the capacity to provide an effective and victim-focused response to DFV. Starting with the legal domain, institutional and legal failures in post-conflict BiH leave women vulnerable. BiH did not adopt specific legislation regarding the protection of women and children from DFV until 2005.[30] Even though existing legislation provides for protection measures such as the removal of the perpetrator from the family home, the courts rarely order these measures.[31] Furthermore, when DFV cases are brought before the courts, "there is often a lack of clarity on the legal reasoning behind the way these cases are ultimately decided."[32] Rather than conducting their own investigations, prosecutors rely on the testimony of victims and witnesses; this practice has been criticized as placing unnecessary pressure on victims, "who often undergo these criminal proceedings without adequate social, psychological and legal assistance."[33] Inadequate legal responses to disclosures of DFV in BiH mean that victims have limited legal resources with which to ensure their immediate security.

There are also cultural norms in post-conflict BiH that inhibit victims' capacity to safely come forward and report their experiences of DFV. Muftic and Cruz found that most police officers in BiH perceived DFV as "a private family affair" and held negative attitudes toward the victims.[34] The writers further observed that, "In Bosnia, victim advocates assert that women are acutely aware of gender prejudices held by criminal justice professionals, service providers, and the public, and as such are deterred from seeking assistance."[35] State responses to DFV, such as those led by the BiH Centre for Social Welfare, are similarly characterized by a "lack of focus on victim safety."[36] This means both that there are patriarchal power dynamics that disenfranchise female victims of DFV, and that law enforcement officials do not receive adequate training regarding DFV to enable them to overcome these cultural dynamics in their work.

BiH also lacks support services to assist and secure the safety of victims of DFV. A 2011 report provides that BiH lacked services to support victims of DFV: all safe houses were run by NGOs, rather than the state, and were reliant on donor funding rather than state funding.[37] A 2013 report of the UN special rapporteur on violence against women expressed concern that the state Centre for Social Welfare has a focus on family reunification, including in cases of DFV, and often will intervene in situations of DFV and mediate for the victim to

return to the home of the abuser, or for the victim to allow the abuser back into her home.[38] Available shelters are also unable to support victims without a referral from state authorities, meaning that victims may be unable to access emergency accommodation without making an official complaint about the crimes.[39] Therefore, post-conflict BiH lacks the critical infrastructure and resources necessary to provide victims of DFV with safety and security when they find the courage to flee or to report the violence they experience.

DFV in post-conflict Timor-Leste

During decades of occupation leading up to a brutal conflict in 1999, many Timorese women and children lived alone, while men joined resistance movements in the jungle. After the 1999 crisis, when men rejoined peaceful society in the newly independent state of Timor-Leste, many brought the violence home with them. A 2015 study found that more than 33% of ever-married Timorese women experienced DFV at the hands of their most recent partner.[40] Hall points out that "The terminology of 'post-conflict' is problematic as it hides the reality of conflict for many East Timorese women who endure domestic violence."[41] In 2001, 40% of all reported crime in Timor-Leste was related to DFV.[42] Furthermore, 43% of respondents to an International Rescue Committee survey reported that they had experienced at least one incident of DFV in the preceding year.[43] A 2003 survey also found that 50% of women felt unsafe in their intimate relationships, and furthermore, that 25% had experienced violence from an intimate partner.[44]

High rates of DFV in Timor-Leste are believed to be an echo of the conflict. Relevantly, Niner observes, "It is a generally accepted notion in East Timor that the violence of the occupation and the associated trauma has resulted in a more violent society today."[45] Meiksin also observes that the state's history of conflict is a key ingredient in contemporary rates of DFV.[46] Surveys have further found that Timorese women linked higher rates of DFV with men's increased alcohol consumption post-conflict, in comparison to prior to the conflict.[47]

Post-conflict Timor-Leste is highly ill-equipped to protect women and children from DFV, with legal and cultural barriers to effectual response frameworks, as well as a tangible lack of emergency support services for victims.

Laws in post-conflict Timor-Leste have a limited capacity to protect women from DFV. Historically, DFV was not criminalized under either East Timorese customary law, or under Indonesian law during the occupation from 1975 to 1999.[48] DFV was only criminalized in Timor-Leste in 2010 under the new *Law No. 7/2010*.[49] This law is considered highly problematic as victim-consent is a requirement for prosecution, which in practice means that it is "difficult to ascertain whether the complainant is freely withdrawing his/her consent and whether he/she is subject to pressure from other individuals."[50] Contemporary Timorese legal frameworks also have limited protection mechanisms available to women, such as through personal protection orders that would enable a court to prohibit a perpetrator from approaching or contacting a victim.[51] A focus on prosecution rather than protection in Timor-Leste leaves victims of violence vulnerable, and with limited legal options to facilitate their immediate security.

Cultural norms stigmatizing DFV in Timor-Leste mean that very few victims report violence. It is estimated that three-quarters of DFV incidents remain unreported, with low rates of reporting being linked with cultural attitudes that DFV is a private issue.[52] A 2013 UNDP report found that women often failed to report violence because they feared alienation, noting "women who do not enjoy the support of their families are unlikely to pursue their case through the formal system fearing a rupture of socio-economic support systems and potentially serious repercussions from local authorities and the community."[53] Without widespread community condemnation of DFV, victims fear that reporting violence may place them at greater risk.

A further issue in Timor-Leste is a lack of support services available to assist victims. There are few safe houses and other support services available, and those that do exist are run by civil society organizations rather than the state (and

are also funded by donors rather than the state).[54] The UNDP report thereby recommends the government prioritize the funding of emergency and DFV shelters, and to fund training and microfinance programs within shelters to assist victims in achieving financial independence.[55] An absence of emergency support services designed to assist victims of DFV in Timor-Leste means that victims lack safe spaces that support disclosure of violence, and that facilitate victim security when violence is disclosed.

IHRL and the state's obligation to protect women and children

IHRL, as is derived from declarations, treaties, and customary international law, creates an imperative for post-conflict states to incorporate norms of protection for women from DFV into their peace-building frameworks.

IHRL creates responsibilities for states in relation to four essential human rights norms: the right to life, the prohibition on inhuman and degrading treatment, the prohibition on discrimination, and the right to health. Human rights judicial bodies have provided extremely clear jurisprudence on how these rights interact with the state's positive obligations to protect women and children from known perpetrators of DFV, and the circumstances in which a state will be imbued to have violated these rights.

The right to life

Where authorities are put on notice that a person is a victim of life-threatening DFV and fail to take reasonable measures to protect them, case law has demonstrated that this amounts to a violation of the right to life on the part of the state. The right to life is enshrined in both Article 3 of the Universal Declaration of Human Rights (UDHR), and Article 6 of the International Covenant on Civil and Political Rights (ICCPR).[56] It is further found in Article 2 of the European Convention on Human Rights (ECHR) and Article 4 of the American Convention on Human Rights (ACHR).[57]

The European Court of Human Rights (ECtHR) has considered the scope of the obligations created by the right to life in the context of serious and life-threatening DFV that has been reported to authorities. In *Kontrova v. Slovakia*, the ECtHR set out state obligations at the time the DFV is reported to police and held that by failing to respond to the criminal complaint appropriately, Slovakia violated the right to life at the point of the victims' deaths.[58]

> *The police had an array of specific obligations. These included, inter alia, accepting and duly registering the applicant's criminal complaint; launching a criminal investigation and commencing criminal proceedings against the applicant's husband immediately; keeping a proper record of the emergency calls and advising the next shift of the situation; and taking action in respect of the allegation that the applicant's husband had a shotgun and had made violent threats with it.*[59]

Furthermore, in *Branko Tomašić and Others v. Croatia,* the ECtHR held that the right to life becomes a positive obligation for states in certain circumstances:

> *A positive obligation will arise where it has been established that the authorities knew or ought to have known at the time of the existence of a real and immediate risk to the life of an identified individual from the criminal acts of a third party and that they failed to take measures within the scope of their powers which, judged reasonably, might have been expected to avoid that risk.*[60]

A key element of the case law is the requirement for states to take "reasonable steps" or "appropriate steps" to protect victims, once a state can be imputed to have knowledge of the violence. In *Civek v. Turkey,* the ECtHR held that Turkey's failure to take measures reasonably available to them in order to prevent the victim's murder at the hands of her husband, after they had been put on notice of the serious threat posed to the victim's life, amounted to a violation of Article 2.[61] In *Talpis v. Italy*, the ECtHR furthermore held that there was a violation of Article 2 of the ECHR: the police's failure to take effective action on the complaint lodged by the applicant, created a situation of impunity conducive to further acts of violence,

including the act that resulted in the murder of the applicant's son.[62] The ECtHR has also found that the obligations created by the right to life also extend to an obligation to carry out an effective investigation into a DFV-related death.[63]

The case law outlined above demonstrates that if states have knowledge of DFV but fail to take reasonable steps to protect the victims and investigate the crimes, this may be a clear violation of the positive obligations created by the IHRL norm of the right to life.

Prohibition on inhuman and degrading treatment

Courts have furthermore held that where a state has knowledge of DFV but fails to take reasonable steps to protect the victims, this may amount to a violation of the IHRL norm of the prohibition of inhuman and degrading treatment. The prohibition on inhuman and degrading treatment is linked to the prohibition on torture and is enshrined in Article 5 of the UDHR, Article 7 of the ICCPR, Article 5 of the ACHR, and Article 3 of the ECHR.[64] The prohibition is also found in Article 16 of the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.[65]

The ECtHR has held that failing to provide protection to a mother and children experiencing DFV was a violation of the prohibition on inhuman and degrading treatment under Article 3 of the ECHR.[66] The ECtHR has construed the prohibition on inhuman and degrading treatment as a positive obligation imposed on states. *Eremia v. The Republic of Moldova* provides:

> *[…] Article 3, imposes on the States positive obligations to ensure that individuals within their jurisdiction are protected against all forms of ill-treatment prohibited under Article 3, including where such treatment is administered by private individuals. This obligation should include effective protection of, inter alia, an identified individual or individuals from the criminal acts of a third party, as well as reasonable steps to prevent ill-treatment of which the authorities knew or ought to have known.*[67]

The case of *E.S. and Others v. Slovakia* also holds that Article 3 of the ECHR imposes on states a positive obligation to take adequate steps to protect victims of DFV, where the state has knowledge of that violence.[68] The ECtHR has also held that failure to conduct an effective investigation into a DFV complaint constitutes a violation of Article 3.[69]

The threshold for cruel, inhuman, and degrading treatment is lower than that for torture, and "the distinctions depend on the nature, purpose and severity of the treatment applied."[70] In *Rumor v. Italy,* the ECtHR held that "ill-treatment must attain a minimum level of severity if it is to fall within the scope of Article 3."[71] Furthermore, whether or not DFV meets the threshold such that it constitutes inhuman and degrading treatment is a question of "the nature and context of the treatment, its duration, its physical and mental effects and, in some instances, the sex, age and state of health of the victim."[72]

The above case law means that, if a state has knowledge of a DFV situation, but fails to take reasonable steps to protect the victim so that she is not forced to remain in the situation, then this is a clear violation of the positive obligation of the state to not subject its citizens to inhuman and degrading treatment.

Prohibition on discrimination

Victims of DFV also often face discrimination from the state: in the form of police who do not respond adequately to complaints, and in the form of laws that do not exist or do not provide adequate protection from violence. A prohibition on discrimination is created by a number of human rights instruments. Article 7 of the UDHR and Article 26 of the ICCPR both provide that all persons are equal before the law and prohibit discrimination.[73] Article 14 of the ECHR and Article 24 of the ACHR also prohibit discrimination.[74] The Convention on the Elimination of Discrimination Against Women (CEDAW) also codifies the prohibition on discrimination against women in a number of respects: for example, Article 2 imposes on states an obligation to adopt appropriate legislation and sanctions prohibiting all discrimination against women, and Article 5 implores on states the obligation to take

appropriate measures to modify social and cultural patterns and norms that prejudice women.[75]

A.T. v Hungary was the first DFV complaint to be brought before CEDAW's Committee, and, notably, held that DFV is a form of gender-based discrimination and that states have a positive obligation to take appropriate actions to prevent and respond to complaints of DFV.[76] The orders set out for Hungary provide a blueprint for states' obligations under CEDAW in respect to protecting women and children from DFV:

> *(b) Assure victims of domestic violence the maximum protection of the law by acting with due diligence to prevent and respond to such violence against women; […] (d) Take all necessary measures to provide regular training on the Convention […] thereto to judges, lawyers and law enforcement officials […] (f) Investigate promptly, thoroughly, impartially and seriously all allegations of domestic violence and bring the offenders to justice in accordance with international standards; (g) Provide victims of domestic violence with safe and prompt access to justice, including free legal aid where necessary, in order to ensure them available, effective and sufficient remedies and rehabilitation […].*[77]

The ECtHR has furthermore held that authorities' failure to respond to reported DFV effectively condones such violence, and therefore constitutes discrimination against women. In *Opuz v. Turkey,* the court held that "the state's failure to protect women against domestic violence breaches their right to equal protection of the law and this failure does not need to be intentional."[78] Furthermore, the court held that "the general and discriminatory judicial passivity in Turkey created a climate that was conducive to domestic violence."[79] In *Eremia v. Moldova,* the court noted that, "the authorities' actions were not a simple failure or delay in dealing with violence against the first applicant, but amounted to repeatedly condoning such violence and reflected a discriminatory attitude towards the first applicant as a woman."[80] A state's failure to adequately respond to DFV was also found to violate the prohibition on discrimination in *Jessica Lenahan v. United States*, heard in the Inter-American Commission on Human Rights.[81]

The above case law demonstrates that if states do not respond to complaints of DFV in a way that prioritizes the protection of women, and if states do not have adequate laws in force that facilitate the legal protection of victims, then they may be in violation of the IHRL norm of the prohibition of discrimination.

The right to health

Where states lack the capacity to respond adequately to the health needs of victims of DFV, they may fall further afoul of their international obligations in respect to the right to health. The right to health is enshrined in Article 12 of the ICESCR, and provides that all persons are entitled to the enjoyment of the highest attainable standard of physical and mental health.[82] Article 12 of CEDAW also provides that state parties should "eliminate discrimination against women in the field of health care," and Article 25 of the UDHR stipulates that, "everyone has the right to a standard of living adequate for the health and wellbeing of himself and his family."[83] The Convention on the Rights of the Child and the Convention on the Rights of Persons with a Disability also contain provisions enshrining a right to health.[84] The African Charter on Human and Peoples Rights furthermore contains a right to the highest attainable standard of physical and mental health.[85] A right to health is not contained within the ECHR; however, the ECtHR has read into Article 2 (right to life) an obligation of state-agents to prevent placing the health of persons at grave risk.[86] Therefore, not only is the right to health extensively codified by the above outlined international instruments, but it may potentially be included in the scope of other rights where it is not codified, as the ECtHR has demonstrated.

Arguably, in the context of DFV occurring in post-conflict communities, the right to health creates an imperative for states to create policy and infrastructure to ensure that victims' immediate and long-term health needs are met, as well as to prevent the continuance of violence. There is a limited amount of case law in this area. In *EIPR and Interights v. Egypt*, the Committee to the African

Charter on Human Rights and People's Rights examined gender-based violence (not specifically DVF) as being a violation of the right to health. The Committee observed the right to health "is crucial to the realization of other fundamental rights and freedoms and includes the right of all to health facilities, as well as access to goods and services, without discrimination of any kind."[87] Of the scope of the right, the Committee held that "States have a legal obligation to protect the right to health of its citizens, including *inter alia* taking concrete and targeted steps towards the full realization of the right, and adopting legislation or other measures to ensure equal access to health-related services and health care."[88] The Committee held that there was a violation of Article 16(1) of the Charter, because the trauma and injuries sustained by the victims affected their health adversely. The Committee also held that there had not been a violation of 16(2) of the Charter as "the victims received medical treatment after the injuries sustained."[89] This decision does pave the way for further judicial consideration of the right to health in the context of DFV, and in respect to how states are obligated to respond to such violence in order to observe the right.

Protecting women and children as a peace-building objective

The obligations created by IHRL, outlined above, create an imperative for measures to protect women and children from DFV to be built into peace-building frameworks. If states fail to implement such measures, they are in violation of key human rights norms. Furthermore, Krause and Branfors' empirical study demonstrates that women's involvement in peace negotiations contributes to the long-term durability of peace.[90] Here, I argue that the legal obligations of states created by IHRL point to an imperative for four key schools of policy and legislative measures to be integrated into peace-building frameworks in post conflict communities:

1. The state-led creation and funding of emergency support services for victims of DFV, including emergency accommodation, legal assistance, and health services;
2. Legal steps to protect women, such as the modernization of laws to bring legislation in line with international recommendations and standards such as those presented by the UN Handbook for Legislation on Violence Against Women (UN Handbook);
3. Training of law enforcement officials in how to appropriately and sensitively respond to complaints of DFV, as well as the setting of expectations for the investigation of complaints; and,
4. The implementation of wide-ranging policy frameworks to combat social and cultural attitudes that may create environments of power disparity between genders, and therefore be conducive to violence against women.

Funding and creation of emergency support services

Case law outlined above draws attention to the fact that if states do not have the capacity to step in to protect women from the perpetrators of DFV, then they risk violating their obligations under IHRL. It is imperative that victims of DFV have support services readily available within their communities to assist with their emergency housing, legal, and health needs. Such services enable victims' safety by responding to their immediate and critical needs, and by ensuring that women do not remain in dangerous situations after reporting violence to authorities. Australia's National Action Plan to address DFV provides that "Women and their children need to receive holistic support including health, housing, education, employment and legal assistance" in the aftermath of disclosures of violence.[91]

States need to develop measures to provide safe housing to victims both in the weeks immediately following the disclosure of violence, and in the years after it. Spinney and Blandy find that victims of DFV are vulnerable to homelessness in two key ways: "first, because violence disrupts and violates the sense of safety and belonging that is associated with the home and second, because when

women and children make the decision to leave a DFV situation, they are usually required to leave their homes."[92] While refuges are critical in providing a safe space supporting women to leave their homes in a hurry, research demonstrates that states require programs that ensure long-term housing security for victims who are escaping DFV.[93] Some programs in Australia have focused on providing support systems to victims to enable them to stay in their own homes rather than flee to refuges. These programs involve "risk assessment, safety planning and upgrading security in the victim's home, court support, liaison with police and other services, referrals to legal advice and counseling to address financial and other issues."[94]

Victims of DFV also require access to legal advice and assistance in the aftermath of disclosures. Lawyers are able to assist victims with urgent issues such as obtaining protection orders against the perpetrator, and any family law issues that need to be addressed immediately regarding the custody of children. The UN Handbook recommends that "Legal aid, including independent legal advice, are critical components of complainants/survivors' access to, and understanding of, the legal system and the remedies to which they are entitled."[95] In Bulgaria, research has demonstrated that when a victim of DFV applies for a personal protection order, her application is more likely to be successful if she has legal representation.[96]

It is also important that victims receive treatment for any physical and psychological health issues they are experiencing. A 2017 Australian longitudinal study found that women survivors of DFV "were more likely to report poorer mental health, physical function and general health, and higher levels of bodily pain" decades after the violence itself had stopped.[97]Additionally, an Australian study in 2004 found that DFV was the "leading risk factor contributing to death, disability and illness in Victorian women aged 15 to 44 years."[98] The World Health Organization (WHO), in their 2013 report *Global and regional estimates of violence against women*, highlighted the imperative of the provision of health services to women who have experienced violence.[99] The UN Handbook also recommends that "survivors of violence against women require timely access to health care […] to respond to short term injuries, and address longer term needs."[100]

Changing the law

Case law presented above demonstrates that if post-conflict states do not have appropriate laws both criminalizing acts of DFV, as well as allowing for protective orders to be put in place to provide immediate security to victims, then they are contravening their obligations under IHRL. Resolution 1325 also calls on states, when negotiating and implementing peace agreements, to adopt a gender perspective and include measures to protect the human rights of women and girls as they relate to the constitution and the judiciary.[101]

Peace-building processes often see the implementation of temporary laws designed to carry the state through transitional periods while authorities work towards developing new long-term legislation. In drafting legislation, private sphere issues such as DFV are often overlooked in favor of higher-profile public sphere state-building goals. For example, in post-conflict Cambodia, under the UN Transitional Authority for Cambodia (UNTAC) between 1992 and 1993, the Criminal Law and Procedure Act of UNTAC was in force, and contained no provisions prohibiting violence against women or DFV.[102] Laws specifically prohibiting DFV were not adopted in Cambodia until 2005.[103]

Peace-building processes should incorporate the voices of women in legislative drafting, and drafting should follow international standards set out for the protection of women. The UN Handbook includes minimum requirements for the development of laws to protect women from DFV.[104] Key recommendations are that states:

1. Establish specialized courts for the hearing of matters regarding violence against women, and ensure that officials at these courts receive special training and support.[105]
2. Incorporate a comprehensive definition of DFV, including physical, sexual, psychological and economic violence in their law.[106]
3. Ensure protection orders are available to survi-

vors of all forms of violence against women on the basis of verbal or written testimony of the victim.[107]

4. Ensure sentencing be both consistent and "commensurate with the gravity of the crimes of violence against women."[108]

Training of law enforcement officials

Case law demonstrates the imperative, under IHRL, of the training of law enforcement officials to respond appropriately to DFV complaints. Resolution 1325 also refers to the role of police in ensuring the protection of women and girls in peace-building processes.[109] International standards to employ when training police forces in post-conflict states can be found in the UNODC's *Handbook on effective police responses to violence against women*.[110] This handbook provides guidance for law enforcement agencies in relation to best practice for: the investigation of acts of violence against women; threat assessment and risk management; victim services and witness protection; responding to offenders; privacy and confidentiality, and police accountability and oversight.[111]

Changing cultural norms

The discussion above draws attention to the reality of post-conflict states often seeing a return to patriarchal cultural norms that may create an environment more disposed to DFV. Case law evaluated above also highlights the imperative for states to address underlying normative contributors to such violence. Research has demonstrated that changing cultural and community attitudes towards DFV can result in both a decrease in rates of DFV, and an increase in rates of reporting violence.[112] WHO, in a 2013 report, notes "the economic and sociocultural factors that foster a culture of violence against women," and "the importance of challenging social norms that support male authority and control over women and sanction or condone violence against women."[113] Diemer provides:

> *Attitudes influence early detection; inform responses to men's violence against women; determine whether violence is recognized; influence how victims are supported and whether perpetrators are held to account. […] attitudes are not fixed. They can be reshaped by exposure to new perspectives through peer groups, organizations and social institutions such as education and media.*[114]

Practical steps for facilitating changes to such sociocultural factors can be found in UN Women's *Handbook for national action plans on violence against women*. This handbook recommends states launch "attitudinal change" campaigns to encourage non-violent masculinities, challenge existing gender norms, and raise awareness regarding the unacceptability of DFV.[115] Noting the capacity of the media to influence public attitudes, it also recommends that states work with the media to "build the capacity of their professionals to avoid violence-supportive messaging and promote gender equality and non-discrimination."[116] Therefore, there are realistic measures that can be adopted in post-conflict communities to foster attitudinal change and create an environment that is both safe for victims to come forward, and that problematizes the issue of DFV as a public rather than a private issue.

Conclusion

DFV is a serious issue globally. However, research indicates that women and children in post-conflict communities are at greatest risk, with high rates of DFV in post-conflict states being a widely recorded phenomenon. This paper presented the argument that protecting women and children from DFV should be an essential public policy goal in post-conflict communities. Furthermore, that the imperative for placing combating DFV on the post-conflict agenda is derived from states' inalienable obligations under IHRL. Jurisprudence is clear that, if a state has knowledge of DFV, yet fails to take reasonable steps to ensure victims' safety and to investigate complaints, then that state may be violating the fundamental human rights norms of the right to life, the prohibition on inhuman and degrading treatment, the prohibition on discrimination, and the right to health. With these IHRL obligations in mind, there is a clear imperative for post-conflict states to incorporate the following

into peace-building frameworks:

1. The development and funding of emergency support services for victims of DFV;
2. The development of legislation both criminalizing DFV and facilitating the legal protection of victims;
3. The training of law enforcement officials in best practice relating to DFV response and protection; and,
4. The installation of long-term measures to facilitate cultural change, and address the toxic masculinities and power dynamics that may propagate DFV.

Problematizing DFV as a violation of states' inalienable human rights obligations, rather than dismissing DFV as a pandemic confined to the private sphere, should lay the groundwork for post-conflict states conceptualizing the protection of women and children as a non-negotiable facet of peace-building agendas.

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Human Subject Research: International and Regional Human Rights Standards

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Abstract

This article will place the discussion of human subject research within the larger context of human rights law, both at the international and regional level, and examine existing normative human rights frameworks that can be used to protect research subjects. The traditional approach has commonly focused on the ethical aspects of human subject research and little has been said about the implications of human experimentation on the enjoyment of basic rights. The difference between ethical principles and human rights is clearly determined by the non-enforceability of ethical norms and the legally binding nature of human rights obligations. A human rights approach to bioethics, and particularly to human subject research, can bring about a defined system and universally accepted set of rules in a field where sociocultural and religious diversity come into play.

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Introduction

During the Second World War and the Holocaust, Nazi researchers committed mass-scale atrocities against Jews and other prisoners under the name of medical research. The largest German Nazi concentration camp, Auschwitz, witnessed Josef Mengele's egregious experiments performed on Gypsy children, twins, dwarfs, and people with abnormalities. When the research came to an end, they were killed and their organs autopsied and analyzed.[1]

It took two years after the end of the war for 16 German physicians to be found guilty of nefarious crimes against humanity. The Nazi doctors' trial exposed torture, deliberate mutilation, sterilization, and murder.[2] Their trial led to the 1947 drafting of the Nuremberg Code, a set of guidelines governing research on humans, which included 10 principles focused on patient consent and autonomy. The Nuremberg Code, the first of its kind, was created to prevent a recurrence of the horrors committed in Nazi Germany, and it paved the way for the development of medical ethics and greatly influenced the evolution of human rights law.[3] The later Declaration of Helsinki, adopted in 1964, reaffirmed the need for informed consent in all research and warned that the "interest of science and society should never take precedence over considerations related to the wellbeing of the subject."[4] In 1978, the Belmont Report framed these issues into "broader ethical principles [to] provide a basis on which specific rules may be formulated, criticized, and interpreted," and focused on three main principles: respect for persons, beneficence, and justice.[5]

While experimentation with human subjects is widely practiced, it is often done without due regard to the human rights of participants. For example, recent cases include oxygen experiments conducted on premature babies without the parents' knowledge, and studies on whether cooling kidneys before a transplant would result in fewer complications, conducted without adequate assessment of the risks to transplant recipients.[6] With the advent of new technologies, the links between ethical principles and human rights in research involving human participants become particularly relevant. For instance, new gene editing technologies, such as CRISPR-Cas9, pose serious risks and challenges to the protection of peoples' human rights and basic ethical principles in terms of, for instance, human dignity, informed consent, and the rights of future generations.[7] Some companies have already sought permission from European regulators and are planning to seek approval from the US Food and Drug Administration to begin CRISPR clinical trials in humans for metabolic, autoimmune, and neurogenerative diseases, among others.[8]

This article will place the discussion of human subject research within the larger context of human rights law, at both the international and regional level, and examine existing normative human rights frameworks that can be used to protect research subjects. The traditional approach has commonly focused on the ethical aspects of human subject research and little has been said about the implications of human experimentation on the enjoyment of basic rights. With the Nuremberg Code, the Helsinki Declaration, the Belmont Report, and the International Ethical Guidelines for Biomedical Research Involving Human Subjects as the instruments to be followed, there is a noticeable need for legally enforceable norms to protect the rights of research participants. The difference between ethical principles and human rights is clearly determined by the non-enforceability of ethical norms and the legally binding nature of human rights obligations. A human rights approach to bioethics, and particularly to human subject research, can bring about a defined system and universally accepted set of rules in a field where sociocultural and religious diversity come into play.[9] In the era of the Sustainable Development Goals (SDGs), health research is a primary and vital goal. Target 3.b supports "the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries."[10] In this context, human subject research is necessary and even desirable to achieve Universal Health Coverage (UHC) and the full realization of the right to health.[11] The enjoyment of the right to health is recognized in core human rights treaties as a fundamental human right.[12]

Nonetheless, human research is not exempt from restrictions necessary to guarantee respect for human rights. States must protect people from potential harms arising from and during scientific research. States have the obligation to protect people from being used or exploited in harmful scientific experiments, as well as the obligation to set safeguards to prevent harm caused by research or experimentation.

This article proceeds as follows. First, I describe the international standards for human subject research in the light of norms enshrined in human rights treaties. Next, I briefly examine the regional standards in the Inter-American System of Human Rights, the European System of Human Rights, and the African System of Human Rights, with particular references to cases and relevant normative frameworks. Then, I present core issues regarding human subject research and delve into the crucial question of derogations of human rights obligations in the context of public health emergencies, and the implications for human subject experimentation. I conclude with a brief reflection on the potential of using international human rights law to protect human research subjects.

International standards for human subject research

The Universal Declaration of Human Rights (UDHR) was adopted in 1948, proclaiming that "All human beings are born free and equal in dignity and rights…endowed with reason and conscience" and recognizing that "No one shall be subjected to torture or to cruel, inhuman or degrading treatment."[13] While not legally binding, the UDHR set the ground for the adoption of the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant of Economic, Social and Cultural Rights (ICESCR).[14]

The ICCPR provides that "no one shall be subjected without his free consent to medical or scientific experimentation."[15] When analyzing its drafting history, one can clearly identify that Article 7 was the result of the broad consensus of participants to explicitly include the prohibition as a response to the atrocities committed in concentration camps during the Second World War.[16] The UN Human Rights Committee later interpreted Article 7 as requiring "special protections" and provided that the prohibition in article 7 relates not only to acts that cause physical pain but also to acts that cause mental suffering to the victim. Moreover, the prohibition extends to corporal punishment, including excessive chastisement ordered as punishment for a crime or as an educative or disciplinary measure.[17]

On the other hand, Article 12 of the ICESCR calls states to prevent, treat, and control epidemic, endemic, occupational, and other diseases to achieve the full realization of the highest attainable standard of physical and mental health.[18] This, in turn, requires "the promotion of medical research and health education" and "fostering recognition of factors favoring positive health results, e.g., research."[19] However, this obligation is not limitless. The right to health is intimately related to and dependent upon the realization of other human rights, such as the "right to be free from torture, non-consensual medical treatment and experimentation."[20]

As will be examined later, the Convention on the Rights of the Child (CRC) requires States parties to ensure that the views of the child are given "due weight… in all matters affecting the child" and that parents and guardians act in the "best interests of the child."[21] Moreover, particularly relevant when it comes to the selection of vulnerable groups as research participants, the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) establishes the obligation of States parties to "establish legal protection of the rights of women…and to ensure…the effective protection of women against any act of discrimination."[22] The Committee on the Elimination of Discrimination Against Women recognized that women "have the right to be fully informed, by properly trained personnel, of their options in agreeing to treatment or research, including likely benefits and potential adverse effects of proposed procedures and available alternatives."[23]

The Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Pun-

ishment (CAT) defines "torture" as "any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession."[24] Certainly the phrase "for such purposes as obtaining from him or a third person information" may be considered as including human subject research and likewise, as will be shown later, the lack of informed consent for research participation may be seen as a form of coercing the participant, in the terms outlined in Article 1.1. Moreover, Article 16 sets the state's obligation to prevent cruel, inhuman, or degrading treatment which do not amount to torture as defined in Article 1, under its jurisdiction.

It is true, however, that to be considered a violation of Article 1.1 or Article 16, the research must be conducted "by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity," which is often not the case. Still, even in cases where government officials are not involved, an argument could be made that a state has a due diligence duty to prevent torture or other ill-treatment that occurs within its territory or under its jurisdiction, even when it is not conducted by persons under its direct control or public authorities.[25]

With regards to persons with disabilities, the Convention on the Rights of Persons with Disabilities (CRPD) recognizes that States must provide them with equal recognition of legal capacity and protection against non-consensual experimentation, as well as prohibit exploitation and respect physical and mental integrity.[26]

Lastly, in the field of humanitarian law, the legal framework includes the Geneva Conventions that specify the prohibition of biological experiments on wounded or sick members of armed forces and the ban on medical or scientific experiments on prisoners of war not justified by the prisoner's need. Moreover, its Additional Protocols applicable to victims of armed conflict forbid experiments on wounded, sick, or shipwrecked persons even with their consent, and on persons who are interned, detained, or held.

Regional standards for human subject research

Inter-American system of human rights

While there is no specific Inter-American instrument devoted to human subject research, the protection of research participants is ensured through other norms. Under the Inter-American system of human rights, the American Declaration of the Rights and Duties of Man (ADHR) and the American Convention on Human Rights (ACHR) are the two most relevant instruments. Although not a legally binding instrument, the Inter-American Court of Human Rights held in its Advisory Opinion OC-10/89 of 1989 that recognizing the ADHR not being a treaty "does not, then, lead to the conclusion that it does not have legal effect" on members of the Organization of American States (OAS).[27]

The ADHR recognizes the right to the preservation of health and to well-being, as well as the equality of all persons before the law "without distinction as to race, sex, language, creed or any other factor."[28] For its part, the ACHR establishes the right of every person "to have his physical, mental and moral integrity respected." It also establishes that no one shall be subjected to torture or to cruel, inhuman, or degrading punishment or treatment."[29]

The ACHR, while raising most of the principles contained in the ADHR to a treaty-level protection, reduced the ESC rights to a single provision recognizing that

> *States Parties undertake to adopt measures… with a view to achieving progressively, by legislation or other appropriate means, the full realization of the rights implicit in the economic, social, educational, scientific and cultural standards set forth in the Charter of the Organization of American States.*[30]

The ESC rights were later captured in the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, which provides that everyone "shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental

and social well-being."[31]

However, according to Article 19(6) of the Protocol, only violations of the right to unionization and the right to education may give rise to individual petitions before the Inter-American Court of Human Rights, meaning that other rights, such as the right to health, were practically excluded from the scope of protection of the Inter-American human rights system. For years, the justiciability of ESC rights within the Inter-American system was the subject of scholarly debate regarding whether Article 26 of the ACHR allows for circumvention of Article 19(6) and opens up the door for the direct justiciability of ESC rights.[32]

Until 2017, the Inter-American Court had examined the indirect violation of ESC rights under provisions of the ACHR that enshrine civil and political rights. One clear example of this "indirect violation analysis" relevant to the ambit of human subject research concerns a 2016 decision from the Inter-American Court, wherein it addressed the question of informed consent in relation to forced sterilization as a violation of the right to humane treatment (Article 5), right to personal liberty (Article 7), right to privacy (Article 11), and right to freedom of expression (Article 13) and established that obtaining consent must derive from a communication process, through which qualified personnel present clear information without technicalities, impartial, accurate, truthful, timely, complete, adequate, reliable and informal.[33]

In August 2017, the court declared the direct violation of Article 26 for the first time.[34] And almost seven months after *Lagos del Campo*, the court clarified and expanded its interpretation of Article 26 in the context of the right to health.

In *Poblete Vilches v. Chile*, the Inter-American Court unanimously declared the international responsibility of Chile for not guaranteeing Poblete Vilches' right to health. The court ruled for the first time on the right to health as an autonomous right, in accordance with Article 26 of the Convention. In turn, although in the context of the provision of health services, the court recalled its previous decision in *I.V. v. Bolivia* and recognized the relationship between obtaining free and prior informed consent, and the autonomy and self-determination of the individual, as part of the respect and guarantee of the dignity of every human being. Moreover, the court considered obtaining informed consent as a fundamental mechanism to achieve respect and to guarantee different human rights recognized by the ACHR, which may have relevant implications for human subject research.[35]

Box 1. Example 1 of human rights violations in human subject research: US syphilis experiment in Guatemala

Between 1946 and 1953, researchers from the United States and Guatemala conducted, with the support of public institutions, non-consensual medical experiments on some of the most vulnerable populations in Guatemala under the excuse of contributing to the advancement of science.

People from Guatemalan marginalized populations were subjected to non-consensual experiments, including intentional exposure to syphilis, gonorrhea, and chancroid, which caused them permanent damage. The experiments specifically targeted prisoners, soldiers, patients in a state-run psychiatric hospital, children in orphanages, and sex workers, among others. With the exception of sex workers, who were included in the experiments to have intercourse with prisoners and soldiers, the groups of individuals that were targeted lacked mobility and could be kept in an area that would facilitate observation for the duration of the experiments.[36]

The experiments, funded by a grant from the US National Institutes of Health (NIH) to the Pan American Sanitary Bureau, involved multiple Guatemalan government ministries and a total of about 1,500 study subjects. The findings were never published. During the experiments, sex workers were infected with venereal diseases and then provided for sex to subjects for intentional transmission of the disease; subjects were deliberately inoculated by injection of syphilis into the spinal fluid that bathes the brain and spinal cord, under the skin, and on mucous membranes; an emulsion containing syphilis or gonorrhea was spread under the foreskin of the penis in male subjects; the penis of male subjects was scraped and scarified and then coated with the emulsion containing syphilis or gonorrhea; a woman from the psychiatric hospital was injected with syphilis, developed skin lesions and wasting, and then had gonorrheal pus from a male subject injected into both of her eyes and; children were subjected to blood studies to check for the presence of venereal disease.[37]

Susan Mokotoff Reverby, a professor at Wellesley College, discovered information about these experiments in 2005 while researching the Tuskegee syphilis study and shared her findings with United States government officials.[38] In October 2010, the US government apologized formally, observing that the violation of human rights in that medical research was to be condemned, regardless of how much time had passed.[39]

European system of human rights

Europe has pioneered human subject research and clinical trials. In 1997, the Council of Europe adopted the Convention for the Protection of Human Rights and Dignity of the Human Beings with regard to the Application of Biology and Medicine ("Oviedo Convention") in Oviedo, Spain, which brought together the bioethics and the legal realms for the first time on a single legally binding instrument.[40] The Oviedo Convention lays out minimum basic norms governing biomedical activities and does not exclude the possibility of granting wider protections.[41]

The notion of dignity is the cornerstone of the Oviedo Convention and, as such, primacy is afforded to the interests and welfare of the human being over the interests of society or science.[42] Moreover, as a general rule, any intervention in the health field "may only be carried out after the person concerned has given free and informed consent to it."[43] In relation to scientific research, Chapter 5 of the Convention delineates the standards that must be followed to ensure protection of persons undergoing research.[44]

The Additional Protocol to the Convention on Human Rights and Biomedicine concerning Biomedical Research, adopted in 2005, further expands the protection of human beings involved in research activities. It reaffirms the primacy of the human being over societal or scientific interests, and outlines the need for having an independent ethics committee in place "to protect the dignity, rights, safety and well-being of research participants."[45] Moreover, it describes the information that must be provided to the research participants, and the obligation to secure prior, free, and informed consent from each participant.[46]

Other instruments may also be invoked to protect the rights of research participants. The European Convention on Human Rights prohibits torture, or inhuman or degrading treatment.[47] The European Social Charter recognizes the right to protection of health, and the right to special protection of children and young persons.[48] The Charter of Fundamental Rights of the European Union recognizes the inviolability of human dignity and the right of everyone to have his/her physical and mental integrity respected. In particular, the Charter of Fundamental Rights of the European Union acknowledges that in the fields of medicine and biology the free and informed consent of the person concerned must be respected.[49]

African system of human rights

Under the African System, the African Charter on Human and Peoples' Rights recognizes that "human beings are inviolable [and] every human being shall be entitled to respect for his life and integrity of his person." In 1996, the Organization of African Unity adopted a Resolution of Bioethics in which it pledged to promote within the continent "the obligation to obtain the free and enlightened consent of any one to submit himself/herself to bio-medical research."[50]

Vulnerable populations that may become research subjects are afforded special protection in Africa. For instance, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa ("Maputo Protocol") recognizes the right to dignity of every woman and, particularly relevant to the context of human subject research, prohibits "all medical or scientific experiments on women without their informed consent."[51] With regards to children, the African Charter on the Rights and Welfare of the Child protects children's right to survival and development, their right to health, and their right to protection against abuse and torture.[52]

Core issues regarding human subject research

Basic ethical principles such as respect for persons, beneficence, and justice are common to most ethical codes in the world, and in turn inform and are linked to (1) the notion of informed consent, (2) the assessment of risks and benefits, and (3) the selection of human subjects and discrimination. I will examine these three core issues in the next section.

Respect for persons: Informed consent

The ethical principle of *respect for persons* demands that subjects enter into the research voluntarily and with adequate information.[53] To be operative, this ethical principle has often been articulated under the notion of "informed consent," usually formulated in terms of rights.[54] The requirement of informed consent is critical to protecting people unfamiliar with medicine or research protocols from manipulation and exploitation.[55]

In the context of human subject research, consent is considered to be free and informed when it is given on the basis of objective information from the researcher and includes not only the nature of the research, but also its potential consequences and risks involved, as well as its alternatives. Free and informed consent is also given in the absence of any type of pressure or coercion from anyone who may influence the participants' independent decision.[56] In order to enable potential subjects to make reasoned decisions on matters that will greatly affect them, informed consent must be obtained prior to any experimentation. In addition, the information must be sufficiently clear and suitably worded for the proposed subject.[57] This requirement is crucial and may be difficult to satisfy when seeking to obtain consent from persons with limited education or those unfamiliar with science.[58]

From a human rights standpoint, informed consent is a fundamental aspect of the respect for autonomy and human dignity of the person and is the very first criterion by which to assess the lawfulness of any experimentation. As such, the principle of autonomy is crucial as it represents the decision-making power of the research participant and the recognition of her/him as an autonomous moral subject.

By formulating the notion of *respect for persons*—as well as other ethical principles—using the terminology of rights recognized in legally binding human rights instruments, rights holders and duty-bearers benefit from clarity on the legal responsibility and the scope and content of the right to informed consent.

Beneficence: Maximizing benefit and minimizing harm—the case of public health emergencies

The principle of *beneficence* requires the best interests of the research subject to be front and center in order to do no harm, or at least to minimize the possibility of harm while maximizing benefits.[59] Emergency response is the most challenging and sensitive area in the beneficence debate: where the need for immediate governmental action against an imminent health threat must be balanced against possible risks and harms to research participants.[60] Human rights law offers a solution in these cases under the notion of "derogation under state emergency."

Oftentimes, disease outbreaks can pose major risks to countries, which in turn may lead governments to declare a public health emergency. A public emergency has been defined as one that is imminent or already occurring, whose effects involve the entire nation and threaten the continued organized life of the community, and where normal measures or restrictions for the maintenance of public safety or health are inadequate.[61]

Several human rights treaties, as well as general principles of law, recognize the right of States to derogate from human rights norms during a national emergency.[62] Non-compliance with certain human rights obligations is permitted during a grave emergency under the principle of exceptional threat.[63] However, a series of limitations must be observed in order to prevent abuse when declaring an emergency, in particular when such emergency may require human subject research to be conducted.

A derogation is only acceptable if necessary and proportional to the emergency at hand. Therefore, the first limitation to the derogation from human rights is the necessity of said measure.[64] Moreover, the derogations must be proportional to the factual circumstances. In other words, the duration, severity, and geographic scope of derogations is limited to measures strictly required by the situation.[65] States shall demonstrate the proportionality by linking the emergency and the derogations and proving that no less restrictive measure is available.

However, certain rights are non-derogable. For instance, the principle of non-discrimination is considered "functionally non-derogable in the sense that it is never strictly necessary to violate the ban on arbitrary discrimination in order to meet an actual threat."[66] In that sense, the Human Rights Committee has considered that even in situations of public emergency such as those referred to in article 4 of the [ICCPR], no derogation from the provision of article 7 [prohibiting medical or scientific experimentation without free consent, as well as torture or other cruel, inhuman or degrading treatment] is allowed and its provisions must remain in force.[67]

Justice: Selection of human subjects and non-discrimination

Justice requires that vulnerable people should not be inappropriately targeted as experimental subjects and "gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects."[68] In practice, this principle relates to the fundamental principle of non-discrimination, since "all human beings are born free and equal in dignity and rights."[69]

In selecting human participants for research, respect is necessary for people who may not be able to choose freely or who have diminished capacity. Some people may have diminished autonomy due to mental illness or age. Others may find it difficult to voluntarily and freely consent because they are subject to authority (for example, prisoners, members of the military), or because their condition may place them at increased risk (for example, pregnant women).[70] Vulnerable populations might also include marginalized populations, such as indigenous peoples, people living in extreme poverty, racial minorities, or people living with HIV/AIDS.

In the case of prisoners, for instance, given their imprisonment, they are usually subject to human rights abuses and are unable to refuse experimentation. In light of this situation, protections against the use of prisoners for medical experimentation have been widely established under international law.[71] Children are also protected as a vulnerable group for cases of research and experimentation. Children "shall in all circumstances be among the first to receive protection and relief" and "be protected against all forms of exploitation."[72] Also, medical experimentation on mothers is subject to special care and assistance, since it can endanger their health and that of their child.[73]

The recognition of the principle of non-discrimination as a cornerstone in human subject research is grounded on the notion of the unequal power dynamic between the researcher and the individual subject, which may be exacerbated in cases of structural inequality that are the "consequence of a situation of social exclusion or "subjugation" of [vulnerable groups] by others, in a systematic way and due to a complex set of social practices, prejudices and beliefs."[74] In this line, both the Special Rapporteur on the right to health and the Special Rapporteur on torture have recognized that structural inequalities may be exacerbated by social and economic factors, stigma, and discrimination, which could impair the informed consent of vulnerable groups.[75] In cases involving vulnerable populations, careful scrutiny is necessary to ensure that they are not involved in the research merely because their vulnerability makes them easier to manipulate.

The principle of non-discrimination is violated when differential treatment lacks an objective and reasonable justification. In the context of human subject research, the selection of groups of people according to their level of exposure to certain disease vectors—as may be bodily fluids—would be considered "objective and reasonable justification." Restricting the experiments to vulnerable populations—prisoners, women, children, people living in poverty—without a rational link between them and the factors contributing to the spread of a disease may violate the principle of non-discrimination, as these populations are often powerless, impoverished, or politically underrepresented, leaving them unable to question the methods or procedures or challenge the project.

Framing the selection of research participants as a human rights issue protects vulnerable populations as it clarifies freedoms, entitlements, and duties in this realm, provides a normative foundation for claims, and facilitates the accountability process.[76]

Box 2. Example 2 of human rights violations in human subject research: Postobon lab testing on Colombian children

On February 13, 2018, the *Liga contra el Silencio*—an alliance of journalists and media that fights censorship in Colombia—reported that Colombia's largest beverage company, Postobon, distributed drinks containing uncertified chemical supplements to more than 3,000 children from La Guajira, one of the poorest departments of Colombia, and conducted lab tests on some of the children to evaluate the effects of their products.[77]

According to sources from the company, the objective was "to determine the physical changes of the development and the biochemical changes derived from the consumption of this drink fortified with vitamins and minerals, in a representative sample of children who receive the drink." Postobon said its intention was "to evaluate the acceptance, use and consumption of the drink in its two presentations, as well as training in nutrition to parents of the 220 children of educational institutions."[78]

Colombia's Ministry of Health requested information from Postobon about the authorization protocol for the research, but it has not been provided. It is unclear whether the company requested parental/guardian consent for conducting this research. It is also unclear whether the company took steps to minimize harms and maximize benefits to the participating children, and whether the company had obtained consent for the scientific experimentation.

Conclusion

International and regional human rights law offers many normative foundations for the protection of human subject research. International and regional human rights treaties explicitly provide for rights—such as the right not to be subjected to torture or other forms of cruel, inhuman, or degrading treatment—that may be used to better protect the rights of research participants.

Human rights law promotes states' accountability on the adoption of positive measures ensuring the protection of research participants. Moreover, it obliges states to adopt legislative and administrative measures and, in cases of violations, it gives the research participant the ability to claim the enforcement and protection of those rights through judicial recourse.

Moreover, human rights standards provide a perfect avenue to address structural injustice and institutional and national responsibility in cases of human experimentation. Bringing ethical principles and human rights standards together can help bring compensation and relief to surviving participants or family members. Such standards can also serve to advance a reconciliation process at the national and international levels in cases of abominable experiments on humans, such as those that occurred in Nazi Germany, and to prevent future misconduct.

This article demonstrates the different ways in which the current state of international human rights law affords protection to research participants both at the international and regional level and reinforces principles and guidelines long enshrined in documents delineating ethical principles.

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Strategic Litigation to Advance Public Health

TAMAR EZER AND PRITI PATEL

Abstract

The HIV movement has relied on strategic litigation as an important tool to develop and enforce legal protections critical to health. This experience contains lessons on the potential of strategic litigation to advance public health more generally. Beyond impacting laws and policies, strategic litigation can change practice, breathing life into existing legal rules never implemented. While cases may target a particular law, policy, or practice, indirect impacts beyond a particular court decision on future cases, other branches of government, and the public record may be just as important. Each case is only one step towards change, and a judgment can be helpful in laying groundwork and in other contexts. Strategic litigation can also shape public discourse on issues relevant to health through development of the court's record, integration of expert testimony, and the use of media advocacy. It provides a means to harness the law's potential to construct reality and historical truth, creating an opening for the narratives of marginalized and affected communities. Strategic litigation and social movements can also have a reciprocal relationship, strengthening each other. Connection to a movement gives a case a political dimension, and social movements can assist in identifying issues, supporting clients, mobilizing communities, engaging media, and following up on the implementation of judgments. Strategic litigation, in turn, can galvanize social movements, creating events around which mobilization and media engagement can occur and facilitating coalition-building and the development of leadership.

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Introduction

The impacts of law on health have long been recognized.[1] This is particularly true in the context of HIV. The Global Commission on HIV and the Law has documented the positive role that strong legal protections can play.[2] In its view, changes to the legal and policy environment could lead to one million fewer HIV infections by 2030.[3] The World Health Organization (WHO) and the United Nations (UN) have likewise highlighted the importance of law to address HIV.[4] Moreover, laws focused on protecting the rights of marginalized populations are critical for HIV prevention and treatment.[5] According to UN Development Programme (UNDP) administrator Achim Steiner,

> *Equality, inclusion and non-discrimination are at the heart of the 2030 Agenda for Sustainable Development. Laws and policies that protect rather than punish, combined with programmes that reduce stigma and discrimination, exist and need to be scaled up if we are to achieve our goal of ending the AIDS epidemic by 2030.*[6]

Consequently, the HIV movement has relied on strategic litigation as an important tool to develop and enforce legal protections. In this paper, we take a rigorous look at cases in the context of HIV, drawing lessons to benefit future work, as well as strategic litigation in other health contexts.[7] The paper takes a broad view of HIV-related cases, and includes litigation to protect the rights of groups with greater HIV vulnerability, including sex workers, transgender persons, and men who have sex with men (MSM). Many of the cases discussed in this article, involving populations disproportionately impacted by HIV, relate to rights and claims that go beyond the group's vulnerability to HIV, but also include an articulation of the rights of a marginalized population.

Strategic litigation has varied definitions. In this paper, we define strategic litigation expansively as litigation with an intended impact beyond a particular case to influence broader change at the level of law, policy, practice, or social discourse.[8] This definition recognizes that change is not always aimed at the level of law or policy, but sometimes at enforcement and practice or raising the visibility of an issue and changing attitudes. Moreover, strategic litigation is most powerful when embedded in broader advocacy.

This paper thus analyzes the benefits of strategic litigation and lessons from the HIV field along three dimensions.[9] First, we delve into the more traditional aim of influencing law, policy, and practice. This reveals, however, that while cases may target a particular law, policy, or practice, indirect impacts beyond a particular court decision on future cases, other branches of government, and the public record are also critical. Next, we examine the role strategic litigation can play in shaping public discourse on issues relevant to health through development of the court's record, integration of expert testimony, and use of media advocacy. Finally, we interrogate the relationship between strategic litigation and social movements and how each can strengthen the other.

One or both of the authors were involved in most of the cases discussed in this paper through the provision of both financial and technical support as either the former Deputy Director of the Law and Health Initiative of the Open Society Public Health Program (Ezer) or as the former Deputy Director of the Southern Africa Litigation Centre (Patel). The cases discussed in this paper have been selected due to their relevance to the topic and the authors' personal experience with and understanding of the impact of the cases.

Before delving into the benefits of strategic litigation, it is important to recognize that strategic litigation is resource-intensive and brings risks, and the strategic value of a particular case is context-dependent, requiring an understanding of the specific legal, political, and social environment. Risks to consider before engaging in litigation include potential harm to clients and the affected population, the possibility of a negative legal outcome, and political and social backlash. At the same time, risks can be mitigated. Clients and affected communities should be made fully aware of any potential for harm, and precautions can be taken to minimize danger. It is possible to plan for next steps in case of a negative legal outcome, and it is crucial to assess if

even a negative outcome can help advance an issue in positive ways. For example, in Malawi, in *R. v. Monjeza and Another* the criminal prosecution of a man and transgender woman seeking a same-sex marriage resulted in both individuals being sentenced to 14 years in prison with hard labor, and resulted in psychological harm to both individuals, despite the community's best efforts to provide necessary psychological support.[10] However, media coverage and other advocacy related to the case have strengthened the lesbian, gay, and bisexual (LGB) movement in Malawi and increased public discussion of LGB rights, potentially paving the way for more effective future litigation and policy change.[11]

Changing laws, policies, and practices

Strategic litigation generally aims to change laws, policies, or practices. This is critical in the context of HIV, where many countries fail to provide legal protections for core rights, including the right to health and freedom from discrimination on the basis of health status.[12] Some countries further criminalize marginalized populations and drive them underground, limiting the effectiveness of public health programs.[13] Even when good laws exist, they are not always enforced.[14] Cases from the HIV context reveal the importance of planning for both direct and indirect impacts. Each individual case is only one step towards change—a judgment may be helpful in other health contexts, can lay the groundwork for additional litigation, and can motivate other branches of government to act. The court case itself, through building a public record, serves a vital role beyond the final judgment.

Examples abound of strategic litigation resulting directly in a positive change in law and policy impacting health. The classic case is *Minister of Health v. Treatment Action Campaign* (TAC), where the Constitutional Court of South Africa required the government to provide medication to prevent mother-to-child transmission of HIV (PMTCT) and reversed the government's policy of denying necessary medication to pregnant, HIV-positive women.[15] Monitoring implementation of the TAC decision has been a challenge, and access to PMTCT services varies widely across South Africa's provinces.[16] Nonetheless, the case increased access to medication significantly, saving lives. It is estimated that in 2010, the introduction of PMTCT prevented 19,500 HIV infections, saving more than one million life years.[17] According to a study in KwaZulu-Natal, between the 2001 TAC decision and 2006, infant mortality declined by 57% due to the availability of PMTCT programs and antiretroviral treatment.[18] More recently, in *Attorney General v. Tapela,* the Court of Appeal in Botswana struck down a government policy denying free HIV treatment to non-citizen prisoners, resulting in more HIV-positive prisoners obtaining access to necessary HIV treatment.[19] Such results can directly increase access to health services and treatment for marginalized populations.

However, strategic litigation can also play an important role in changing practice and breathing life into existing inadequately implemented laws and policies. For instance, the High Court in Botswana in *ND v. Attorney General* ordered the relevant government agency to change the gender marker on the identity document of a transgender man from female to male, ruling that the failure to do so violated his constitutional rights.[20] ND had argued that under the National Registration Act, the registrar can issue a person a new identity card if there has been a material change to their circumstances. In this way, strategic litigation is a test of the rule of law and its proper implementation, contributing to both its construction and consolidation. It can also prompt a more equitable interpretation of certain laws that may have a discriminatory impact. In 2011, the Supreme Court of Canada interpreted a provision of the Controlled Drugs and Substances Act (CDSA), which criminalizes drug possession, to exempt Insite, a supervised injection site, from the CDSA's application, and accordingly ordered the federal minister of health to provide Insite an exemption. The CDSA permits the federal minister of health to exempt drug possession from criminalization if it "is necessary for a medical or scientific purpose or is otherwise in the public interest." Insite had initially received that exemption,

but later the exemption was not renewed. The court held that the failure to exempt Insite threatened the health and life of people who inject drugs, thereby violating their constitutional rights.[21]

Court decisions in one country can also have relevance in other similarly situated countries. For instance, in Kenya in *R. v. Kenya National Examinations Council*, Audrey Mbugua Ithibu used a legal case seeking a change of her gender on a school certificate as a way to advance the rights of transgender persons more broadly.[22] The High Court cited a case from the Supreme Court of India and the Supreme Court of Nepal recognizing a third gender.[23]

Additionally, strategic litigation can result in a judgment helpful for health issues more broadly. For example, in banning the forced sterilization of women living with HIV, the Supreme Court of Namibia clarified the concept of informed consent under Namibian law.[24] The central issue in the case was what constituted informed consent. The government argued that the women's informed consent was given, while the women claimed it had not.[25] The Supreme Court held that "[i]nformed consent implies an understanding and appreciation of one's rights and the risks, consequences and available alternatives to the patient. An individual must also be able to make a decision regarding sterilisation freely and voluntarily."[26] This definition is a new and powerful tool that activists can use in seeking redress for other violations of informed consent.

Such cases point to a role for creative opportunism, using ordinary cases to push for change. Rather than waiting for the "perfect" case, advocates can use ordinary cases to change laws, policies, or practices. For instance, the *Center for Health, Human Rights and Development (CEHURD) and Others v. Nakaseke District Local Administration* case could easily have been a simple matter involving the negligence of an individual doctor, who was absent for eight hours during an obstructed labor; in fact, the trial court judge admonished the lawyers for not joining the doctor as a party in the suit.[27] However, CEHURD, which brought the case, recognized that it could be used to address larger systemic gaps affecting maternal health, including shortages in essential medical supplies and limited dedicated medical personnel. It thus anchored the case in constitutional rights, addressing the government's failure to provide basic maternal health care to pregnant women and creating an incentive for structural change, rather than punishment of individual doctors.[28]

This also reflects the importance of an incremental approach, where cases slowly build on each other to create change. An incremental approach is particularly useful when it comes to asserting the rights of marginalized groups. In Malawi, organizations seeking the decriminalization of sex work first sought to challenge the forced HIV testing of sex workers. The resulting judgment affirmed that sex workers are entitled to fundamental constitutional rights, which were violated when they were subjected to mandatory HIV testing.[29] Following this case, organizations challenged the offense of living on the earnings of prostitution, arguing that the offense did not prevent sex workers themselves from living on their earnings. In 2016, the High Court in Malawi found that section 146 of the penal code, which criminalizes living off the earnings of prostitution, prevents another individual from living on the earnings of their prostitution, but was designed to protect sex workers from exploitation by third parties.[30] Further, in 2017, Malawi organizations sought to challenge laws criminalizing being a rogue and vagabond, which have been used to harass sex workers. The High Court agreed and struck these laws down as unconstitutional.[31] These three decisions affirming the rights of sex workers have laid a solid foundation from which a challenge to the laws criminalizing sex work can be initiated.

Furthermore, strategic litigation can create a pressure point that spurs action from other branches of government. For example, the favorable judicial decision in Namibia's forced sterilization case on behalf of three women strengthened the overall bargaining position of women living with HIV in their negotiations with the Namibian government regarding investigating other claims of forced sterilization and compensation, as it affirmed that at a minimum the courts had found that at least three women had been subjected to forced sterilization.[32]

Likewise, when Uganda's parliament failed to act after the law reform commission recommended statutory changes to protect women's equal rights to inheritance, advocates applied additional pressure through legal action.[33] While their court case has not yet resulted in statutory reform, it was successful in nullifying certain discriminatory provisions of the Succession Act.[34]

Additionally, strategic litigation obliges governments to respond on the record to specific policies and practices at issue in the case. This can be useful in pressuring governments to change these policies and practices, even if the litigation itself is unsuccessful. For instance, in Canada, litigation initiated by a former prisoner, the Canadian HIV/AIDS Legal Network, and three other HIV organizations to challenge the federal government's refusal to permit access to sterile injection equipment for drug use in prisons established a record of the successes of these programs elsewhere, and of the Canadian government's failure to respond to multiple national and international recommendations for such programs. As a result, the government was called upon to provide evidence to support its prohibition of access to sterile injection equipment. The government filed affidavits attempting to justify its position based on security concerns, but the affidavits did not address the effectiveness of policies and practices of international programs enabling access. The government did finally confirm its position that all injection equipment for drug use (sterile or otherwise) is considered "contraband" and that this characterization is founded on security concerns—points not clearly communicated previously. Having this information, advocates are in a better position to respond to governmental arguments both in and out of court.[35]

Shaping public discourse

Strategic litigation can play an important role in shaping public discourse relevant to health. This takes place through the court process itself, and through the development of a public record, integration of expert testimony, and the use of media advocacy.

Strategic litigation is a powerful tool since it harnesses the potential of law to state reality and construct historical truth. Through the hearing of evidence and judicial recognition, litigation converts the stories of clients and affected communities into fact, captured in a public record. For marginalized groups, in particular, this is a valuable means to influence the historical narrative. For instance, as mentioned previously, when three women living with HIV in Namibia brought a case challenging their forced sterilization, the government's steadfast denial of this practice was forced to give way in the face of the women's testimony, which medical experts corroborated and the judiciary confirmed.[36] Strategic litigation can also enable marginalized groups to overcome popular or internalized assumptions that they are undeserving of rights protections. *R. v. Kenya National Examinations Council*, had an empowering effect not only on the plaintiff, Audrey Mbugua Ithibu, but on other transgender persons in Kenya. They drew inspiration from Audrey's assertion of her rights, testimony regarding her lived experiences, and affirmation by the court.[37]

Strategic litigation further provides an opportunity for engagement with health experts, impacting both the court's and public's understanding of an issue. For instance, in a case involving access to opioid substitution treatment (OST) in Russia, the government questioned the efficacy of the treatment as one of its central arguments for banning it. In response, the plaintiffs' lawyers secured opinions from medical organizations and experts to counter the government's claims about OST's potential harms. Working with the international medical community also focused attention on global standards and good practices, dispelling myths.[38] In *Attorney-General v. Tapela*, the non-citizen prisoners living with HIV in Botswana supported their argument that denial of HIV treatment violated their constitutional rights by including a submission from a well-respected epidemiologist outlining in medical terms what can occur if a person living with HIV is denied treatment and the relationship between HIV and tuberculosis.[39] The Court of Appeal relied on this

submission in finding that HIV treatment can greatly reduce the incidence of tuberculosis in prisons, where high rates of tuberculosis persist, thereby keeping all prisoners safer from illness.[40]

In many cases, media advocacy is an essential complement to strategic litigation that can impact public discourse significantly. As Mark Heywood, head of South Africa's AIDS Law Project and a founder of TAC, explains, the TAC case made good use of media coverage "to amplify stories of the human cost of denial of HIV medication to a national and international audience. The violation of the human right of access to treatment for HIV was made into a moral dilemma for society as a whole."[41] Media advocacy includes:

- sensitizing and building relationships with key journalists covering the issue;
- issuing press releases when key events occur and organizing press conferences;
- placing opinion pieces in influential newspapers and blogs; and
- using social media—including Facebook, Twitter, and blogs—to keep mainstream media and others apprised throughout the litigation.

In Namibia, organizations engaged the media when litigating cases of forced sterilization. In particular, they engaged local and international journalists to sensitize them to the problem, issued press releases, placed opinion pieces in regional and international media outlets, and held press conferences. Civil society organizations also used social media to disseminate regular updates on the court case, including tweeting from the courtroom and publishing regular updates on a blog dedicated to the issue.[42] This raised public awareness of forced sterilization not only in Namibia but throughout Africa. Since the litigation, more women have come forward to report they were forcibly sterilized in Namibia and in other African countries. In Kenya, for example, a group of women living with HIV and civil society organizations have sued medical institutions and the government for forced sterilization. Organizations in Lesotho, moreover, have published a report documenting the forced sterilization of women living with HIV.[43]

Media coverage can help translate what occurs in the courtroom for the benefit of the broader public. Health rights cases, in particular, can involve technical information and health-related jargon difficult for the average outsider to understand. Translating such information into plain language through media coverage can be critical to changing public discourse and raising understanding of issues. In a case involving a challenge to Kenya's Anti-Counterfeit Act, which limited access to generic HIV medications, the media advocacy sought to assist the public in understanding what was at stake in the case and how legislation that appeared to deal with counterfeit medications actually restricted access to affordable, HIV treatment.[44]

Strengthening movements

Strategic litigation has a reciprocal relationship with social movements. It can strengthen and help build social movements and, at the same time, often depends on them. Strategic litigation is generally most effective as part of broader advocacy. Connection to the community gives a case a political dimension—it becomes a matter for systemic change rather than just a problem for certain individuals. Social movements can assist in the following areas: identifying cases and supporting clients throughout the litigation process; documenting violations and providing a nuanced understanding of experiences; mobilizing communities to amplify the impact of litigation; engaging media; and ensuring accountability for the implementation of judgments. Strategic litigation, in turn, galvanizes social movements, creating events around which mobilization and media engagement can occur, and facilitating coalition building and the development of leadership.

Social movements play a crucial role in identifying cases and providing clients with ongoing support. Many countries have stringent rules regarding who can bring a lawsuit. This often requires that advocates seeking to challenge particular laws, policies, or practices find individuals directly af-

fected by them, who are willing to be involved in litigation. Grassroots organizations can assist in identifying appropriate plaintiffs and providing them with psychosocial support throughout litigation that is often lengthy. For example, in *Tapela*, a case challenging Botswana's policy of denying free HIV treatment to non-citizen prisoners living with HIV, the Botswana Network on Ethics, Law and HIV (BONELA) was able to identify two suitable plaintiffs as a result of its existing work on HIV in prisons. As a leader in the HIV movement, BONELA was known by the two plaintiffs, who wrote to them requesting assistance.[45] In Malawi, the Centre for the Development of People (CEDEP) worked closely with two individuals, Steven Monjeza and Tiwonge Chimbalanga, who were being criminally prosecuted for organizing their same-sex wedding ceremony, to provide them with psychosocial and other support. CEDEP visited them in prison, where they were being held during the trial, providing them with necessities including food and basic toiletries.[46] Among other support, CEDEP helped Chimbalanga obtain asylum in South Africa upon his release.[47]

Additionally, social movements can help in documenting and defining violations. In order to craft an appropriate remedy in HIV-related cases, it is often necessary to have detailed documentation of a violation to prove its occurrence and gravity. Grassroots organizations with strong links to the affected community can assist in this documentation process. In the Namibia sterilization case, the grassroots organizations' strong relationships with women living with HIV helped them identify and document additional cases of forced sterilization.[48] This is particularly true when addressing the health rights of marginalized populations, as members of the community may be skeptical of unfamiliar organizations and individuals eager to work with them. In *Canada v. Bedford*, a case challenging the criminalization of sex work-related activities, sex worker-led organizations had spent years working with sex workers in the community to document their experiences and violations suffered. During this time, they produced numerous reports and gained a deep understanding of how the laws impacted sex workers in their daily lives.[49] This documentation then formed the basis of the case focused on the risk of serious physical harm facing sex workers.[50]

Moreover, social movements can lead mobilization campaigns around litigation. Organizations specializing in litigation often lack the expertise and connections needed to mobilize affected communities and organize advocacy activities, such as marches and sit-ins. For example, in a case challenging the forced sterilization of HIV-positive women in Namibia, the Namibia Women's Health Network (NWHN), a grassroots organization addressing the needs of women living with HIV, mobilized women living with HIV around the case. NWHN ensured that the women were present in the courtroom during the case, organized marches on the days of the trial, established a website providing daily information on the litigation, and identified spokespeople to share with the media how forced sterilization affected their health and lives.[51] The Legal Assistance Centre lacked this mobilizing capacity and could focus its efforts on representing the three plaintiffs.[52]

Social movements also play a vital role in media advocacy. In many jurisdictions, lawyers are unable to communicate with the media due to professional restrictions. However, civil society organizations not directly involved in the litigation are well-placed to speak on the litigation's significance. For example, Zambia continues to implement the *sub judice* rule requiring lawyers to refrain from media commentary and preventing them from speaking publicly about ongoing court cases and on the view that only the arguments made in court should affect the case.[53] In a case challenging the mandatory HIV testing and subsequent dismissal of two former military employees, the Zambian AIDS Law and Research Network (ZARAN)—a civil society organization—was able to engage the media and public, while the lawyers could not speak publicly about the issues raised. ZARAN issued press releases, organized press conferences, and informed other stakeholders of the litigation.[54]

Furthermore, social movements can assist in ensuring the proper implementation of positive

judicial decisions, as implementation can require ongoing monitoring and, in some cases, returning to court to enforce positive judicial decisions.[55] In many cases, obtaining a positive judgment is only the midway point in advocacy. In Namibia, social movements have been critical in the long process of obtaining redress for women subjected to forced sterilization. Despite positive judicial decisions in three cases, a number of organizations report that since the litigation, medical personnel at public hospitals have asked women who seek sterilization to draft and sign an affidavit to that effect as a prerequisite to the procedure. The requirement that these women sign the affidavit before the police or a notary is an insurmountable hurdle for many women seeking the operation, as they are wary of the police and do not have the money to pay for a notary. Organizations have sought to address these hurdles through advocacy.[56]

At the same time, the involvement of social movements in strategic litigation can also strengthen them. Alicia Ely Yamin notes that with regard to HIV movements in particular, "Litigation did not so much displace social struggle—rather it became an integral tool of social struggle across a number of widely varying contexts."[57] This was the case with the TAC litigation in South Africa, which supported a larger campaign. Mark Heywood describes that it "caught the attention of young women with HIV and—for the first time in Africa—began to galvanize a social movement that was made up of people who were predominantly poor, black, and living with HIV."[58] The critical point is that "litigation was not left to lawyers, but used to strengthen and empower a social movement and backed by marches, media, legal education, and social mobilization."[59]

Court cases provide human stories and concrete events around which communities can mobilize, generating momentum and galvanizing media attention. Media interest intensifies—and advocacy opportunities are presented—when a case is filed, both during and immediately after the trial or hearing, and when a judgment is handed down. As key dates are generally known in advance, organizations can plan advocacy activities accordingly. In 2010, the trial in *R v. Monjeza and Another* helped mobilize and solidify the country's LGB movement.[60] Prior to the trial, which included a constitutional challenge to the criminalization of sodomy, the only LGB group in Malawi—CEDEP—had worked to raise awareness of the rights and health issues relevant to the LGB community, but had not carried out any significant advocacy campaigns and was not well known in the country.[61] Following the trial and the media engagement accompanying it, CEDEP was able to build a strong LGB movement and connect with other civil society organizations in Malawi. As a result, CEDEP has shown itself well-placed to speak out not only on issues affecting LGB persons, but also more generally on human rights and the rule of law.[62]

Similarly, in Canada, the case challenging the criminalization of sex work-related activities—*Canada v. Bedford*—helped foster a more cohesive and nationwide sex worker movement. Prior to the litigation, many Canadian sex worker communities banded together in their respective cities, but they did not coordinate efforts on a national level.[63] This changed over the course of the *Bedford* litigation. The powerful sex worker movement that resulted continues to collaborate on advocacy activities and responses to government action from coast to coast.[64]

Strategic litigation can also strengthen social movements by providing an opportunity for coalition building and connecting the experience of marginalized groups with issues of concern to the larger public. In Uganda, a series of cases aimed at addressing maternal mortality resulted in a coalition of about 150 organizations working to advance maternal health in the country and strengthened the connection between local and international advocates. This coalition continues to coordinate its activities on this issue long after the issuance of a number of favorable judicial decisions and has facilitated the development of unlikely allies, including between health service organizations and legal organizations.[65] In Kenya, the National Gay and Lesbian Human Rights Commission challenged the government's refusal to formally register their organization because the name was deemed "unacceptable" and because Kenya's penal code

"criminalizes gay and lesbian liaisons."[66] The case was part of a broader push by NGOs to address laws limiting their ability to engage in advocacy, enabling connection between the LGBT community and other groups.[67]

Finally, when strategic litigation is conducted in collaboration with affected communities, it can restore dignity and agency to these communities and contribute to the development of leadership. In a challenge to a ban on OST in Russia, the plaintiffs in the litigation have been motivated and empowered by their involvement in the case to carry out further advocacy activities on the rights of people who use drugs, despite the significant harassment they have faced because of their activism.[68] In Kenya, Audrey Mbugua Ithibu's case requesting that her gender marker be changed on her education certificate cemented her as a leader and representative of the transgender community in Kenya. She speaks publicly regarding being a transgender person in Kenya, and the need to strengthen and enforce the rights of transgender persons.[69] The *TAC* case, as Mark Heywood recounts, showed how "access to accurate information about health and linking this information to rights empowered marginalized people who began to assume both a public voice and visibility."[70]

Conclusion

This paper draws on lessons from the HIV field to explore the benefits of strategic litigation for health along three dimensions: (1) impacts on law, policy, and practice; (2) impacts on public discourse; and (3) impacts on movement building. It reveals the importance of taking a broader focus, which includes both direct and indirect impacts, and viewing strategic litigation within a larger context of future cases, actions by the various branches of government, and construction of a social discourse and historical record. Moreover, strategic litigation has a reciprocal relationship with social movements. Social movements often play a critical, complementary role to the litigation, and the litigation, in turn, strengthens them. Strategic litigation provides vital opportunities for advocacy, media engagement, coalition building, and the emergence of leadership. Strategic litigation can be a powerful tool to advance health, and it is to be hoped that an understanding of its functioning across the various dimensions can make it more effective.

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PERSPECTIVE

Contribution of the Health Ombud to Accountability: The Life Esidimeni Tragedy in South Africa

EBENEZER DUROJAYE AND DAPHINE KABAGANGE AGABA

Introduction

Between October 2015 and June 2016, 1,711 people were relocated from mental health facilities operated by long-term provider Life Esidimeni in the South African province of Gauteng to alternative facilities managed by multiple nongovernmental organizations (NGOs). The result of the change in providers, and the manner in which the transfers were managed, became a tragedy that culminated in the death of 144 mental health care patients and the exposure of 1,418 others to torture, trauma, and poor health outcomes.[1] The state was unable to ascertain the whereabouts of a further 44 patients.

The tragedy began in October 2015, when the then member of the Executive Council for health in the populous Gauteng province, which includes Johannesburg and Pretoria, announced the termination of a 40-year contract between the Department of Health and Life Esidimeni for the provision of mental health services.[2] The NGO facilities to which the patients were transferred were ill prepared and ill equipped for the influx of patients.[3] The tragedy drew further public attention in September 2016, when, responding to a question raised in Parliament, the member of the Executive Council for health said that about 36 former residents of Life Esidimeni had died under mysterious circumstances following their transfers.

South Africa's minister of health then requested that the newly established Office of the Health Ombud investigate the circumstances surrounding the deaths of mentally ill patients and advise on the way forward.[4]

Accountability and the health ombud

Accountability serves to constrain or limit power and prevent its abuse or misuse.[5] Mechanisms are required to track the actions of those in power, sanction any misuse of authority, and avert or redress abuses of power.[6] Accountability creates avenues by which those with responsibilities explain the interventions they have implemented and steps taken to remedy any gaps that have been identified.[7] To promote transparency around accountability, states are obligated to fulfill the right to access information and the freedom to form and belong to associations.[8] Within health systems, accountability is often exercised at several levels,

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including the legal, social, administrative, and political.[9] With regard to ensuring accountability in realizing the right to health of vulnerable groups, the *LC v. Peru* case emphasized the need for states to put in place legal avenues, national tribunals, and other public institutions to ensure accountability in the realization of women's rights.[10]

South Africa established the Office of the Health Ombud to promote accountability. The office is empowered to receive verbal and written complaints and to investigate and dispose of these complaints in an economical, fair, and expeditious manner.[11] Health ombudspersons are not unique to South Africa. England, New Zealand, and Australia, for example, also have health ombudspersons (who are sometimes also referred to as health commissioners). England appointed its first ombudsperson in 1973, New Zealand in 1994, and Australia in the 1980s (through the appointment of state-level health complaints commissioners).[12] An ombudsperson usually refers to an official elected by parliament or government with a mandate to represent citizens' interests and to investigate and deal with complaints concerning public (and sometimes private) agencies.[13]

In South Africa, the Office of the Health Ombud is an independent body established by the National Health Amendment Act of 2013. The office is functionally located in the Office of Health Standards Compliance (OHSC) and is assisted by persons designated by the OHSC.[14] The OHSC, which was also created by the National Health Amendment Act of 2013, has the overall mandate of promoting and protecting the health and safety of users of health services. Under the OHSC, the ombud office is officially designated as "Complaints Management and the Ombud."

The health ombud is responsible for addressing lapses and malpractices in the health setting with a view to protecting the rights of patients and users of the health care system.[15] For each complaint, the ombud is required to report his or her findings and recommendations back to the complainant and the health facility; to make recommendations for action to the chief executive officer of the OHSC, who must then ensure that the recommendations are implemented; and to conduct a thorough investigation with the assistance of OHSC staff by obtaining statements and evidence from relevant individuals.[16]

In June 2016, the first health ombud (Malegapuru William Makgoba) was appointed by the minister of health. In making the appointment, the minister emphasized that the ombud would act as a "public protector" for health, since he would deal with complaints from those who were dissatisfied with health service delivery.[17] The minister asserted that this move was prompted by the significant increase in claims of medical negligence and by a failure to address litigants' claims, which resulted in the government spending large sums of money on compensation. He stressed that the ombud office would not only receive and address complaints but also pursue effective enforcement and remedial measures.[18]

The health ombud's findings regarding the Life Esidimeni tragedy

Following a request from the minister of health, the Office of the Health Ombud conducted a thorough investigation that relied on evidence provided by numerous stakeholders, which culminated in the publication of a comprehensive report entitled *The Circumstances Surrounding the Deaths of Mentally Ill Patients: Gauteng Province*.[19] The office's investigation found that 94 patients (subsequently increased to over 100) died between March 23, 2016, and December 19, 2016, in three hospitals and 16 NGO facilities. The report notes that all 27 NGO facilities involved in the patient transfers operated without a license and that all of the patients who died did so under "unlawful" circumstances. Overall, about 95% of the deaths occurred in NGO facilities.[20]

The Office of the Health Ombud also found that the decision to terminate the contract with Life Esidimeni contradicted South Africa's National Mental Health Policy Framework and Strategy. Rather than the deinstitutionalization of patients being carried out gradually, as envisaged by the policy, it was rushed and disorganized, and functional community-based services were not in place.[21] The report stated that the cost rationale for termination

of the contract was not acceptable because it failed to respect the fundamental rights of the patients. Furthermore, the Gauteng Department of Health failed to develop a plan to ensure that the money that had been saved from the contract's termination was used for the benefit of the patients.[22] The investigation also found that the psychiatric hospitals to which some of the patients were moved cost almost twice as much as care at Life Esidimeni. Although some of the NGO facilities were far less expensive, the ombud observed, they offered substandard care and lacked certain vital health services, which ultimately led to the patients' suffering and death.[23] This is inconsistent with the government's obligation to realize the right to health of vulnerable people.

The ombud reported that the Gauteng Mental Health Marathon Project, as it became known, was done in a rush, with "chaotic" execution. The patients were transferred in an inhumane and degrading manner, with no written plan for their transportation. Some had their hands and feet tied throughout the move, some suffered trauma as a result of being moved without their families knowing where they had gone, and some were transferred without their clinical records and personal belongings.[24]

The report notes that most of the NGO facilities where the patients died lacked the necessary experience and capacity to deal with the situation. Conditions included overcrowding, poor hygiene, low-quality or insufficient food, a lack of qualified staff, and a lack of access to medicines and other supplies.[25] The causes of the deaths were unnatural and preventable and included chronic hepatitis, liver failure, pneumonia, uncontrolled seizures, and neuroglycopenic brain injury.[26]

Issues of noncompliance with health regulations were identified, including accommodating more patients than permitted by the operating license and NGOs being granted licenses to operate without being registered as legal entities or without adequate staffing. Some facilities were simply residential premises.[27]

The health ombud's recommendations

One of the key recommendations of the ombud was to overhaul the health care system for mentally ill patients. He also recommended disciplinary action against government officials for their complicity in the deaths of more than 100 patients.[28]

In responding to the recommendations, the government held a press conference in February 2017 in which the minister of health, Aaron Motsoaledi, announced that disciplinary processes had been initiated against several senior health officials.[29] During the arbitration process, it was reported that 1,418 patients who had suffered trauma and poor health but survived had been returned to Life Esidimeni facilities for continued care.[30]

Another recommendation of the ombud called for an "alternative dispute resolution process" led by a credible and experienced South African. This led to a comprehensive arbitration process that culminated in the acknowledgment by government officials of those who died or suffered as a result of the move from Life Esidimeni.[31]

In March 2018, the arbitrator, Justice Dikgang Moseneke, delivered an elaborate and stinging arbitration award.[32] In agreement with the health ombud report, the arbitrator asserted that the public officials behind the project had acted irrationally and had abused their power. He concluded that the project had been characterized by mismanagement, secrecy, a lack of accountability and transparency, and ulterior motives that remained unknown, all of which led to the suffering and death of mental health care users. The arbitration revealed that the human rights violations suffered by the patients had amounted to torture. Torture includes systematic acts that are not only unkind but also hateful and directed at bodily and psychological pain and harassment. As one expert witness stated:

> If you take a group who didn't know the move was coming, weren't prepared for it and are moved on the backs of trucks, tied with sheets without identity documents, without wheel chairs, that amounts to torture. And then they are moved into filthy dangerous environments as if they are not human … All those are features of actively torturing people in these institutions.[33]

The arbitrator further emphasized that by pre-

maturely terminating the Life Esidimeni contract without a reasonable alternative, the state violated mental health care users' rights, including the rights to life; to freedom from torture and cruel, inhuman, or degrading treatment; to human dignity; and to health and its underlying determinants (such as food and water). He noted that by exposing mental health care users to under-resourced NGOs, the state facilitated the abuse of users' rights by third parties.[34] He further asserted that the Gauteng Mental Health Marathon Project treated mental health care users and their families as recipients of—and not active participants in—decisions affecting their lives. Patients and families were not involved in the decision to move them from Life Esidimeni, and any attempts to contest the move were ignored or met with disdain.[35]

Having laid out the egregious violations, the arbitrator ordered the government to pay appropriate compensation to the families of those who died. This amount was to be in addition to the 20,000 rand (US$1,390) that the government had offered, leading to a total of 1.2 million rand (US$8,000), which was to be paid within three months.[36] While giving his ruling, the arbitrator pointed out that he was aware that several other potential claimants had not appeared before him and that if these individuals came forward, they were to be compensated in the same way, rather than requiring a new litigation process.[37] The arbitrator ordered the government to provide counseling and support services to all claimants who requested them. He also ordered it to construct a monument at its expense within 12 months of the publication of the award to commemorate the suffering caused by the project.[38] The provincial department of health was ordered to provide the Office of the Health Ombud and claimants with a recovery plan aimed at systemic change in the delivery of mental health care.[39] It was required to report to the ombud within six months.

The negative press and attention caused by both the ombud's report and the arbitration proceedings forced the resignation of the three senior officials who had been in charge of the Gauteng Mental Health Marathon Project.

In June 2018, the media reported that the Gauteng government had paid compensation to the families involved in the arbitration and was also providing counseling.[40] At the time of writing, inquiries and investigations by several state bodies—including the police, National Prosecuting Authority, and Special Investigations Unit—were underway to ascertain the possibility of filing criminal charges against those at the helm of the Gauteng Mental Health Marathon Project.[41] Disappointingly, it was recently reported that one of the public officials implicated in the tragedy had been reelected to the Provincial Executive Committee of the African National Congress, which drew the condemnation of many.[42]

While the health ombud's role in the Life Esidimeni tragedy has been applauded, his handling of a more recent case has come under criticism for being more critical of a whistle blower than of the complaints made by him.[43] The South African Medical Association has said that even if there were discrepancies in the whistle blower's complaint, by focusing on him, the ombud had discouraged others from coming out and reporting incidences of malpractice and human rights violations.

Nonetheless, with regard to the Life Esidimeni tragedy, the ombud played a crucial role in promoting health accountability in South Africa. His comprehensive report was instrumental in producing a chain of events leading to redress and compensation of the mental health care users who had suffered as a result of the project, including the families of those who had died.

Improving the accountability role

Monitoring and enforcing remedies

In practice, accountability entities tend to lean toward either monitoring the actions of duty-bearers or enforcing remedies. Monitoring focuses on gathering information and asking duty-bearers to justify their conduct.[44] Enforcement examines sanctions or remedial and corrective measures to meet standards, and it aims to ensure that remedies are fulfilled and improper behavior is addressed.[45]

Human rights commissions and bodies often tend to focus on monitoring and exposing human

rights violations.[46] Similarly, the health ombud often takes on a monitoring role and produces and disseminates reports arising from complaints. This is one element of access to information.[47] But the ombud's enforcement role can be limited.

The powers given to the health ombud by the National Health Amendment Act are, to a large extent, "recommendatory." The act empowers the ombud to conduct an investigation and then submit a report that includes his or her findings and recommendations to the chief executive officer of OHSC. If the OHSC fails to address the recommendations, the ombud may ask the minister of health to intervene.[48] The challenge with this arrangement is that the ombud's enforcement and remedial powers are dependent on an external source. This may pose a challenge if the chief executive officer of the OHSC or the minister of health do not prioritize the recommendations.

In Queensland, Australia, the ombudsperson has enforcement powers in certain cases. The Queensland Health Ombudsman Act of 2013 grants the ombudsperson the authority to take immediate action if there is a risk to persons and to safeguard public health and safety. The ombudsperson can suspend health practitioners, impose conditions on their registration, and prohibit or limit them from practicing.[49] In New Zealand and England, as the roles of the health ombudspersons have evolved, their investigative and disciplinary powers have been strengthened through legislation. They have the power to ask agencies to report back on steps that have been taken to implement the recommendations.[50]

In doing so, these countries have strengthened ombudspersons' accountability role by enabling them to enforce their remedies. Thus, it is hoped that the relatively new position of the health ombud in South Africa will eventually go beyond monitoring to include enforcement as well.

There is also the issue of the office's capacity to deal with complaints. After it was reported that in 2016/17 only 15% of investigations had been finalized by the ombud within six months of the complaints' filing dates, the budget for the complaints management process (which includes the Office of the Health Ombud) was slated to be increased from 14.8 million rand in 2017/18 to 20.5 million in 2020/21.[51]

Nature of complaints

Another element of the ombud's accountability role is the individualized and retrospective nature of the complaints that the ombud may receive. South Africa's health ombud is empowered by the National Health Amendment Act to receive both written and verbal complaints pertaining to any act or omission by the owner or an employee of a health establishment or a facility charged with providing health services. The ombud is then required to investigate each complaint fairly and expeditiously and then inform the complainant of his or her findings.[52] This is an individualized process involving the ombudsperson, the complainant, and the health establishment.

In commenting on New Zealand's complaints system, Ron Paterson notes that "an ombudsman is little more than the proverbial ambulance at the bottom of the cliff if all that is achieved is retrospective analysis of how and why a patient's rights were breached."[53] He illustrates that if a health provider implements the ombudsperson's recommendations by doing away with the shortcomings in the provider's practice, then it may be said that the ombudsperson's role has been realized at the individual level. Paterson explores how the resolution of such individual complaints can then be exploited to enhance health service delivery at a broader level. He proposes the utilization of the reports that are produced by the ombudsperson for educational purposes and for advocacy on behalf of health care consumers.[54]

In the case of South Africa, a series of issues contributed to the health ombud's taking up of the Life Esidimeni case. The arbitration award was a result of over two years of varied tactics, including rights education; advocacy; engagement with the government, the United Nations Special Rapporteur on the right to health, and watchdog bodies (such as parliamentary portfolio committees, the Mental Health Review Board, and the South African Human Rights Commission); and litigation by various actors, such as Section 27, NGO networks, mental health support and advocacy groups, professional

associations, and families of people using mental health services.[55] These strategies also ensured that the media never lost interest in the case, which prompted the minister of health to request the newly appointed ombud to conduct an investigation.[56] The release of the ombud's report led to a series of actions aimed not only at preventing similar deaths from occurring in the future but also at improving the mental health care system in general.[57]

The question that arises here is what happens with cases that are not picked up by the media, civil society, or the public. Will such cases remain "individualized" to the complainants and health establishments involved? This remains to be seen, as the Office of the Health Ombud is still relatively new and in the process of establishing its mode of operation. Still, it is vital that accountability entities such as the health ombud do not work in isolation. Accountability is the result of a concerted and dynamic effort by a series of actors using various strategies over time.

In order to enhance the ombud's educational role, the National Health Amendment Act also requires the ombud to prepare a report on the functions and affairs of its activities, which the minister of health then presents to Parliament.[58] In this way, accountability is not an isolated activity but rather an integrated one aimed at improving quality of health care for health consumers and at strengthening the health system. The enhancement of the accountability role of the health ombud is vital in the South African health system, which has a legacy of challenges related to its apartheid past, including inequalities and disparities in access to health exacerbated by large numbers of people living in poverty, a public-private divide, failure by health leadership to overcome mismanagement at the provincial and district levels, and a lack of health workers in public health facilities.[59]

Conclusion

South Africa's establishment of the Office of the Health Ombud is a commendable step toward improving health accountability in South Africa. The newly established health ombud played a critical role in promoting justice in the Life Esidimeni tragedy. However, not all of the ombud's recommendations have been fulfilled, particularly those involving criminal liability.

The ombud's enforcement and remedial powers need to be strengthened so that its recommendations are not stalled by people in positions of power. The complaints mechanism would be more effective if it focused less on individual complaints concerning past events and more on system failings. Consequently, the health ombud should aim not just to resolve individual claims but to use its educational and information-sharing roles to address the numerous challenges facing South Africa's health system.

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Does Information and Communication Technology Add Value to Citizen-Led Accountability Initiatives in Health? Experiences from India and Guatemala

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Abstract

Information and Communication Technology (ICT) may facilitate the collection and dissemination of citizen-generated data to enhance governmental accountability for the fulfillment of the right to health. The aim of this multiple case study research was to distill considerations related to the implementation of ICT and health accountability projects, describe the added operational value of ICT tools (as compared to similar projects that do not use ICT), and make preliminary statements regarding government responsiveness to accountability demands through ICT projects. In all three projects, the need for relationship building, continuous community engagement and technical support, and training for volunteers or service users was identified. Government responsiveness to the data varied, suggesting that political will is lacking in certain contexts. Despite these challenges, ICT initiatives provided an easy, accessible, and low-risk platform for reporting violations and demanding accountability from service providers and decision-makers. ICT-enabled citizen generated data can add significant operational value and some political value to project activities and goals, and may affect systems change when it is part of a broad-based, multi-level civil societal and governmental effort to improve health care quality.

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Introduction

Global and national health policy-makers and citizen activists agree that accurate data on health service coverage, equity, and quality is a vital public good that should inform health policy-making and health governance.[1] This assertion is echoed in human rights norms related to the right to information, the right to demand compliance and answerability from state actors, and the right to see one's priorities reflected in health policies.[2] However, it is possible that in some contexts, health providers, administrators, and politicians resist the aggregation, dissemination, and utilization of data because it could expose corruption, under-investment, and implementation failures.[3] Non-governmental organizations (NGOs) and activists may compile their own data on user experiences of health care, with a view to exposing critical gaps in government fulfillment of the right to available, accessible, acceptable, and good quality health services (hereinafter AAAQ).[4] As documented in the health and human rights field and in the growing field of social accountability, successful efforts to collect and leverage such data have led to improvements in various AAAQ attributes of health care, including respectful treatment and decreased absenteeism. Some efforts have set the stage for continued improvements by fostering individual and collective empowerment; and sustained changes in relations between marginalized communities and the government.[5] Many donors and advocates are optimistic about the role information and communication technology (ICT) might play in the collection and dissemination of citizen-generated data to enhance governmental accountability for health care services.[6]

The consensus definition of accountability encompasses answerability and enforceability. Governments are obligated to provide information and justification regarding policy and practice (answerability), and sanctions must exist for failure to comport with policy (enforceability).[7] Human rights actors stress the remedy component of enforceability, including, for example, restitution, compensation, rehabilitation, satisfaction, and guarantees of non-repetition.[8] In this paper, we adopt a right to health framework: governments should be accountable for the progressive realization of the right to health, including delivering AAAQ health services.[9] The emerging grey and peer-reviewed literature suggests that while ICT can be an effective tool for aggregating data to demand accountability, unbridled optimism regarding ICT for health accountability is not warranted.[10] Collecting and disseminating data is only one step in fostering state accountability; in order for government services to improve, the state must take concerted action and must have the capacity and willingness to do so in effective ways.[11] Nonetheless, ICT may be useful to citizen monitoring of public service delivery in specific settings. It could make data gathering and aggregation easier, thus adding operational value, and could augment the political cost and the perceived legitimacy of claims made by citizens, thus adding political value.

The comparative case study described here emerged from discussions within the Community of Practitioners on Accountability and Social Action in Health (COPASAH), a network of practitioners and organizations working in low- and middle-income countries. COPASAH fosters learning exchanges and conducts joint advocacy. This study was designed by practitioners from three COPASAH member organizations: Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud (CEGSS), Nazdeek, and SAHAYOG, with support from researchers at the Mailman School of Public Health at Columbia University.

Comprehensively assessing how ICT contributes to specific outcomes relating to the right to health is a long-term goal. Our research addressed the more intermediate goal of identifying and comparing operational questions that will shape the extent to which ICT adds value to efforts to enhance government accountability for health.

The aim of this paper is to describe lessons learned emerging from the comparative case study, including:

- considerations related to project implementation;
- the added operational value of ICT tools (including websites and mobile phones; as compared to similar projects that do not use ICT);

- challenges and adaptive program changes; and,
- government responsiveness to accountability demands through ICT projects.

We intend this paper to be a practitioner-led contribution to the growing peer-reviewed literature regarding citizen-led accountability and ICT. Most notably, between 2012 and 2017, Making All Voices Count (MAVC), an international funding and research consortium, supported an in-depth multi-country study specific to ICT for improving public service accountability.[12] Our research is unique in that we focus exclusively on the availability and quality of health services for low caste, tribal, and indigenous populations. These groups are among those most likely to experience non-AAAQ health care.[13] They are also potentially less likely to a) have information about their entitlements, b) view themselves as rights holders, and c) be technologically literate and therefore able to use ICT tools effectively to lodge complaints.[14] They are disproportionately removed from the human rights tools enabling them to report and seek remedy for violations of the right to health.

Methods

Study context

In the three projects considered in this paper, project volunteers or health service users from the community employed mobile phone technology (interactive voice response and/or text messages) to gather or report evidence from government health facilities regarding a pre-determined set of indicators of quality health care. These indicators were not meant to capture the entire concept of quality, but to portray attributes of care that communities had identified as important and that lay people could assess, such as disrespectful treatment and demands that patients make informal payments for health care. The data were then aggregated, mapped, and displayed through online platforms developed by the organizations. The projects all used the same basic theory of change: the implementing NGOs and the communities they serve would define their health care priorities, learn about relevant legal entitlements and standards, use ICT to document users' experiences against the standards, and deploy the data generated to demand government response. Consistent with the human rights principle of remedy, Nazdeek and CEGSS also sought restitution for aggrieved patients in some cases. All three organizations sought satisfaction and guarantee of non-repetition, such as public disclosure of the situation, acknowledgement of problems, or a change in legislation or policy.

The implementing organizations created opportunities for users to engage with the government health system collectively at multiple levels in order to demand that they address the identified problems. The implementing NGO complemented this collective engagement with ongoing advocacy such as one-on-one meetings with district health officials. The NGOs expected the health system to respond for two key reasons: (1) health facility leadership and other decision-makers would learn more about current challenges in health care quality, including the frequency of certain challenges and how they affected the community, and (2) health providers and leaders would be politically or professionally compelled to act because publicly displayed data regarding poor implementation of service delivery would engage the public, heighten political costs, and/or alert the formal health system hierarchy about problems. Though the basic theories of change were similar, the program activities differed in several key ways, reflecting the different orientations and organizational goals of the NGOs, as well as the very different contexts in which the efforts were undertaken.

CEGSS

CEGSS was formed in 2006 with an aim to use participatory approaches to improve indigenous Guatemalans' access to quality health care, particularly care that was culturally acceptable, non-discriminatory, and reflected community priorities. The project described in this study has been operational and evolving for 10 years; CEGSS changed it from a paper-based system to an ICT-enabled system in 2014. As part of this pro-

gram, CEGSS trained and supported indigenous Community Defenders for the Right to Health (CDRH) who visited health facilities regularly. During these visits, CDRH asked users if they had faced any obstacles to obtaining care. They also interviewed front-line health care providers and inspected facilities. CDRH conducted health rights awareness-raising campaigns in communities and encouraged community members to relay challenges they faced in accessing quality care. They reported identified problems on an SMS platform. These complaints were then mapped on Ushahidi, an open source monitoring platform that was initially developed to monitor election violence in Kenya (Figure 1).

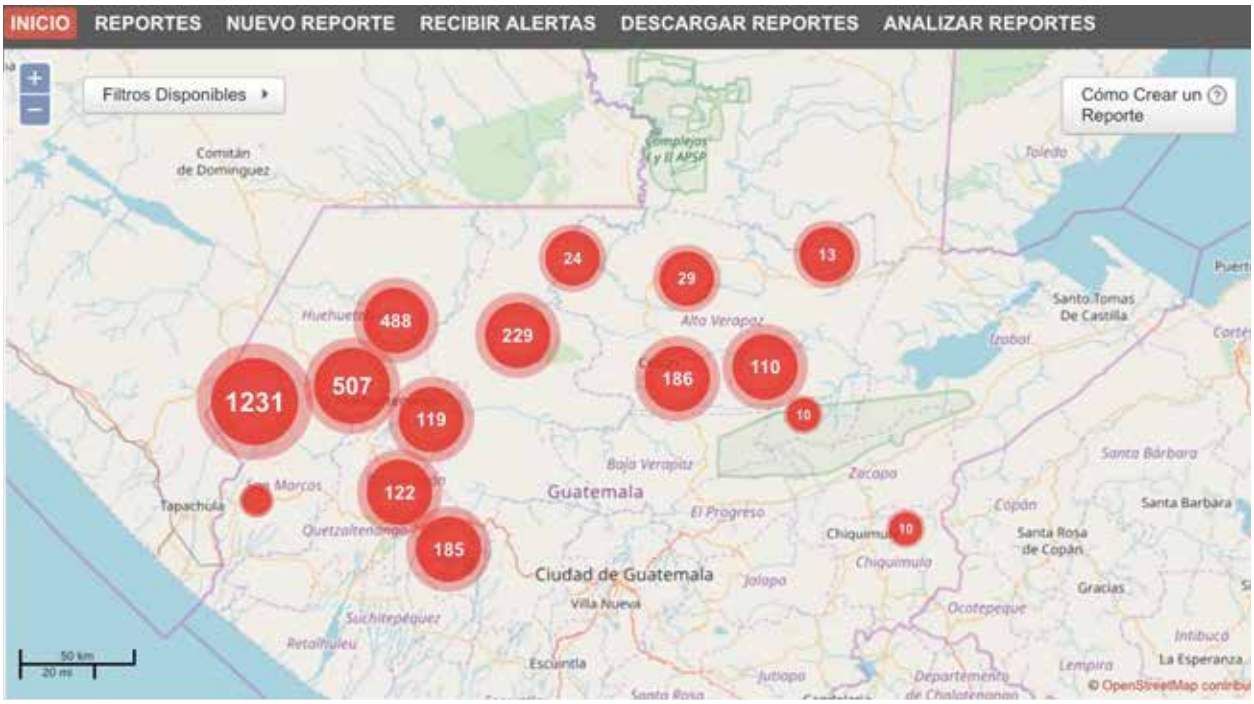
Nazdeek

Nazdeek, a legal empowerment organization, was formed in 2012. As part of their End Maternal Mortality (MM) Now Project, Adivasi (tribal) women volunteers identified and reported cases of maternal and infant health care violations occurring in tea plantation areas in Sonitpur District, Assam, India. Women could report violations via SMS, using numeric codes corresponding to specific locations and types of violations. Like the CEGSS project, the cases were mapped onto a publicly accessible Ushahidi platform (endmmnow.org). Locations included facilities run by tea plantation managers, which are legally required to provide basic health care to their workers; as well as public facilities, such as hospitals; Anganwadi centers (community centers providing health and food services to women and children); and ration shops. To implement the project, Nazdeek worked with a local organization and an international partner.

SAHAYOG

SAHAYOG, a women's health and rights organization based in Uttar Pradesh (UP), India, was established in 1992. SAHAYOG has a long-standing collaboration with community-based organizations (CBOs) throughout UP and with a grassroots women's forum (Mahila Swasthya Adhikar Manch or MSAM), that is comprised of approximately 12,000 poor, rural women leaders from Dalit, Muslim, and tribal communities. In 2011, the government initiated a scheme to ensure free

FIGURE 1. Screenshot of CEGSS CDRH reports of obstacles in health care provision, using Ushahidi platform



comprehensive maternity care, and the UP state government requested that civil society organizations monitor its implementation independently. In 2012, SAHAYOG launched a project to use interactive voice response to document health provider demands that women make informal payments for maternal health care services they were entitled to receive free of charge. A two-district pilot version of the project was evaluated in 2013, and then the project was refined and scaled up to four districts in 2014.[13] These reports were also mapped in real time via Ushahidi on a project website.

Each of these organizations conduct additional local and national level activities beyond the projects described here. While we do not discuss these other activities in this paper, it is important to acknowledge that the ICT projects are implemented in the context of ongoing engagement with the communities and the local and national governments addressed by the ICT efforts.

Research approach

We used a comparative qualitative case study approach to examine these three projects, which allowed us to consider the contextual particularities of each project, implementing organization, and site. While the extent of the current research was somewhat limited by budget, we sought to generate practical, action-oriented, context-dependent knowledge that is useful to practitioners.[15]

The research reported here represents an effort to go beyond routine monitoring and evaluation to facilitate our functioning as "learning organizations," to distill operational lessons about the use of ICT for the benefit of our own programs and beyond. We have worked on these issues for many years. We do not expect that there is a "magic bullet" project that can fix the problems we address. Instead, we try different strategies and assess whether or not these strategies—or elements of them—seem to work better than previous efforts.

Data collection

Table 1 summarizes the methods for each single case study. All three studies used semi-structured in-depth interview (IDI) and focus group discussion (FGD) guides for discussions with implementers. Researchers from all sites developed individualized research tools using a jointly agreed list of themes that were articulated based on a literature review, an initial in-person meeting regarding our programs and current knowledge, policy discussions on ICT and development, and priority questions and challenges we faced in implementing the ICT efforts. We were interested in factors related to program design, implementation, impact, and context, such as anonymity of the complainant, engagement from local level health providers, and health planner utilization of the data generated through the project. Our questions (and findings) relate primarily to the process of program implementation, with some insight regarding government responsiveness to the human rights claims. Comprehensively assessing changes in the right to health as a result of local level social accountability projects such as ours is difficult; we do not expect that aggregate health indicators will be affected given the fact that our projects are locally bound and implemented in a somewhat limited time frame.

In addition to the IDIs and FGDs with implementers, each project team developed project-specific data collection methods, such as review of project reports and interviews with additional stakeholders.

Data analysis

Two researchers at Columbia (SC and MS) read all the Nazdeek and SAHAYOG transcripts and an English language data synthesis from CEGSS and, using the initial list of themes that emerged from the literature review and in-person meeting, proposed a shortened list of relevant research themes. Themes included how the ICT mechanism compared with other governmental and non-governmental modes of filing complaints, differences in the design of the ICT tools (such as whether or not anonymity is offered and if the complaint is verified), usability of the ICT tool, ways in which various stakeholders perceive the ICT tool as being different (better or worse) than pen and paper approaches from both a process and an outcome perspective, and risk for those making complaints. These themes were

then entered into an Excel sheet, followed by data from each of the three cases. This sheet was shared with all authors for feedback, helping to ensure consistency in data analysis. Entering data into an Excel spreadsheet facilitated triangulation of data collected via different methods, and displayed discrepant data. Thus, we matched observed patterns in the data to our research themes, allowing us to "see" the data supporting various propositions. We found that all three projects made programmatic changes through the implementation. Since our data display gave a cross-sectional view of each project, we went back to the transcripts and wrote brief memos summarizing the program changes and the justification for each.

The Columbia researchers then drafted the paper and shared it with researchers from all sites for significant input through seven rounds of review.

Findings and discussion

We group our findings into four categories: 1) project implementation, 2) added operational value of ICT, 3) challenges and adaptive program changes, and 4) government responsiveness to right to health accountability demands made through ICT projects. While our research focused on ICT, we do not limit our discussion to ICT; offline activities were an integral part of the projects' theory of change.

1) Project implementation

Table 2 summarizes key descriptive findings related to project implementation. Please note that the offenses are all alleged; very few cases resulted

Table 1. Methods

	Study site and justification	Language and data analysis	Data collection methods
CEGSS	Study conducted in seven municipalities within Huehuetenango, Totonicapan, Alta Verapaz, Solola, and Quiche provinces	• IDIs and FGDs conducted using semi-structured guides • Data collected in Spanish • Analysis and synthesis done by CEGSS staff and written up in English	• Quantitative data analysis of 228 complaints sent to the platform between August 2014 and March 2015 • Review of monitoring and evaluation reports • Eighteen IDIs with community members and leaders
Nazdeek: End MM Now	Study conducted in two blocks of Sonitpur District in Assam: Balipara and Dhekiajuili	• Data collected using semi-structured guides • Conducted in local language, transcribed, and translated into English on site • Analysis done by researchers at Columbia University, with regular discussions and checks with the field-based team	• Data collected as part of routine monitoring and assessment of the End MM Now project, including quantitative assessment of 268 reports made by women volunteers from January 1, 2014 to September 30, 2015 • Review of internal reports • IDIs with block administrative officials (three) in governmental facilities and frontline staff (three) Accredited Social Health Activists • IDIs with one staff member from Nazdeek, one staff member from Pajhra (partner organization), two field coordinators (women volunteers) • One FGD with women volunteers in each of two blocks
SAHAYOG: My Health, My Voice	Two of the project's four districts, Azamgarh and Mirzapur, selected based on high rates of reporting over time, anecdotal reports of change, and the long-term presence of the women's collective Mahila Swasthya Adhikar Manch (MSAM) Relationship of MSAM with the government varied over the two districts, providing an opportunity for contrast	• IDIs and FGDs conducted in Hindi, voice recorded, transcribed, and translated to English • Analysis done by researchers from Columbia University, one of whom did much of the data collection in Hindi, with input and checking from SAHAYOG • Ethical approval from Columbia University and the Sigma IRB in UP	• Embedded in a larger research project • Key informant interviews with seven district officials and health providers, four MSAM members, four SAHAYOG personnel, and four CBO representatives • Eight FGDs with MSAM members in each of two districts, with a total of 52 participants; two FGDs with CBO partners with a total of seven participants • Nine days of non-participant observation in four facilities, including informal interviews with health care administrators and patients • Quantitative analysis of 1,876 calls made to the hotline between January 1, 2014 and September 30, 2015

in a formal legal process to eventually determine culpability.

Each project raises similar issues, though the relative frequency of each type of complaint varied. The projects included multiple "offline" activities to encourage community members to make reports or to raise concerns, and to spur governmental response to the data collected. These activities included

- strengthening grassroots associations,
- raising public awareness about health-related entitlements and about the project,
- NGO leadership meeting health facility leadership and staff,
- holding community assemblies or dialogue meetings with structured opportunities for citizens and health providers and decision-makers to interact, and
- engaging with authorities at multiple levels of the health system (for example, health facility, district, regional, national) to present the data and advocate for action.

When interviewed, organizational leaders and program implementers made two key points about project implementation, as related to ICT.

Laying the groundwork. As identified in other studies, realizing the potential operational efficien-

Table 2. Key descriptive findings

Organization	Who files the complaint	Complaint verification process	Degree of anonymity	Complaint trajectory	Issues raised
CEGSS	Trained community defenders for the right to health (CDRHs; volunteers).	CEGSS staff member calls CDRH to ensure that complaint was categorized properly.	Complainant name is recorded but not put on website. Complainant information is used in the event that CEGSS and complainant wish to pursue legal action. Offending provider is recorded but not displayed on website.	Complaints mapped on website are used for advocacy purposes. Complaints are aggregated by type and formally transmitted to the relevant governmental entity. CEGSS supports complainants who wish to also make a formal complaint to the relevant governmental entity.	• Informal payments • Disrespectful/rude treatment • Lack of supplies • Absenteeism • Denial of care • Undue referrals • Poor infrastructure.
Nazdeek	Trained Adivasi (indigenous) women volunteers or CBO members.	Nazdeek staff member calls complainant to verify details of incident.	Complainant name is recorded for verification purposes but not put on website. Offending provider name is not collected – however in the case of small facilities such as ration shops and Anganwadi centers, the provider is easily identifiable.	Complaints are mapped on the website, aggregated, and submitted to local authorities during Community Grievance Forums with women volunteers and local health officials, facilitated by Nazdeek. In many cases, Nazdeek works with volunteers to file administrative complaints through existing grievance mechanisms or Right to Information requests.	• Informal payments • Lack of supplies and equipment • Lack of health staff • Denial of care, abuse, and discrimination on grounds of gender, ethnicity, and religion • Undue referrals • Poor infrastructure and hygiene.
SAHAYOG	Trained CBO member or the complainant.	SAHAYOG verifies 10% of calls as a quality check.	Neither the complainant nor the offending provider are named or recorded.	All complaints are mapped online, and data regarding type of complaint and amount of money are posted on the website. This data is used in subsequent advocacy. Patients facing denial of care can call an emergency hotline that is always staffed.	• Informal payments, which at times result in denial of care if patients refuse to pay.

cies associated with ICT requires that the ICT is adopted and used correctly by as many people as possible.[16] Program implementers explained that prolonged, intensive engagement with the community, local organizations, and governmental actors was key to laying the groundwork for implementation. This preparatory engagement included educating stakeholders about the rights and entitlements in question, the intent of the program, what the data could reveal and how to use it, and program operations, including how to use the ICT tools. SAHAYOG's and Nazdeek's project relied on women from the community making reports, adding the imperative for the NGOs to learn about community member ability to use the required ICT tools and to build their capacity to do so.

Education and support were essential, as the women making reports were generally low-caste or tribal, and often illiterate. SAHAYOG's project included an explicit conscientization component, creating conditions for the women to learn about human rights in order to understand that these rights apply to them so that they were motivated to make reports.

Pre-existing relationships in the community and with the government. Existing relationships with concerned community members made ICT uptake easier and strengthened community support for the project. All of the organizations had pre-existing relationships established over the course of past work, and felt they had a base of trust in most of the communities addressed. This facilitated local NGO and community willingness and motivation to participate in the project as well as to use ICT, which was somewhat novel for many.

Moreover, in the case of all three organizations, the projects described here entailed introducing ICT to ongoing initiatives. To varying degrees, communities were already trained and engaged in health facility monitoring, and local health facilities were aware of these efforts.

Data from SAHAYOG demonstrates the importance of this prior engagement. In addition to working with CBOs and MSAM in communities where they had worked for many years, SAHAYOG entered some new communities for this project. The reports were much less frequent in the new SAHAYOG communities, suggesting the facilitative role played by a long-term presence.

2) Added operational value of ICT

Interviewees reported that ICT enhanced the projects in several ways. These included:

Efficiently collected contemporaneous data in easy-to-understand formats. Data recorded on ICT can be available immediately to the government, citizens, advocates, and the media. As described by CEGSS, this enables faster and more effective collaboration with the media. CEGSS representatives referred journalists to real-time online data, rather than waiting for CDRHs to gather and collate data over a number of months. For instance, professional investigative journalists confirmed the authenticity of complaints regarding demands for informal payments from patients requiring ambulance transport, and then published a report on corruption and the poor state of emergency care facing rural populations.[17]

Moreover, all three implementing NGOs suggested that the up-to-date data could inform governmental decision-making. Making extensive field visits in order to collect and aggregate data by hand is time consuming and resource intensive, such that the data available may not be current. In contrast, data collected and reported immediately by ICT can be considered almost real-time. In Guatemala, recent SMS complaints and photos of empty medical shelves at rural facilities were quickly presented to the Minister of Health as evidence that medicines had not yet reached rural areas. As a result, the minister ordered an investigation about why medicines were stored in regional warehouses and not distributed to rural facilities.

Accessible database of complaints and violations that allows easily identifying and visualizing gaps. The efficiency in data collection allowed the organizations to gather and easily manipulate larger amounts of data, which was then aggregated and mapped on the project websites. These presented

the data in a way that clearly indicated the scope of certain health sector problems, showed trends, and surfaced "hotspot" facilities with particular challenges.

Analysis of the data allowed the implementing organizations to capture a fuller picture of the health infrastructure in areas that are difficult to reach, such as especially remote tea gardens in Assam and, over time, to identify patterns of violations and systemic flaws (for example, scarcity of blood supplies or a flawed referral system) or recurring issues in a given facility (for example, cases of informal payments linked to health workers in a certain hospital). For example, the data in Uttar Pradesh showed that about one-fifth of the cases of informal payments were cases where patients were instructed to buy drugs or other supplies at a private pharmacy outside the health facility, even though patients were entitled to free supplies in the health facility. These types of data helped to guide the organizations' advocacy efforts, as they could prioritize certain issues and/or areas and make more informed demands to health authorities. In the SAHAYOG example above, as a result of the data collected, SAHAYOG decided to try to better understand the relationship between private pharmacies and health providers. They wanted to ascertain whether genuine drug and supply stock outs or corruption (or both) drive provider requests that patients purchase drugs from the outside, and how government might intervene to fix the problem.

This finding is in line with existing human rights and public health literature on the importance of data for illustrating systemic flaws, thus strengthening the value of ICT platforms in public policy debate.[18] Such data could be compiled and analyzed using paper, but the use of ICT makes such analysis easier to conduct and to communicate visually.

In the case of CEGSS and Nazdeek, the databases also served as a case management tool for individual case resolution. Nazdeek's internal database tracks the actions taken to address some of the cases (such as administrative complaints, requests under the Right to Information Act, and representations with authorities) and their outcome. In the case of CEGSS, the online platform is color coded to track how each complaint moves through the system from the time it is received (red), investigated by a government official (yellow), and resolved (green).

Accessible database of complaints and violations that allows easy identification and visualization of gaps. In the three project sites, the government also maintained its own health sector telephone complaint system, as well as an official system for written complaints for at least some of the period during which the ICT platforms were active. The organizations hoped that their ICT-based monitoring would be easier to use, less risky, and more comprehensive than the government systems in addressing complaints and improving health service delivery.

Community members and NGO staff explained that marginalized communities generally preferred making complaints to the civil society run ICT reporting systems rather than making official, in-person complaints. First, in most cases, the projects ensured anonymity of the complainants, protecting them from retaliation. Second, ICT allows users of services to make complaints without an interaction with an intimidating bureaucrat. Third, no travel is required. Travel can be a real obstacle for poor women or any other user with significant family and work responsibilities in areas that are poorly served by public transportation, such as Assam's tea gardens, and rural Guatemala and Uttar Pradesh.[19]

It is possible that in-person visits from discreet NGO staff would also meet client preferences for convenient, confidential reporting, but again, such a human resource-intense approach to reports seems infeasible in the long run, particularly on the scale of the SAHAYOG project. In fact, it would be difficult for Nazdeek and SAHAYOG to collect data themselves. In the case of Nazdeek, the tea plantations where the project took place were quite remote; tea plantation managers sought to limit civil society groups' access to the plantations; and, plantation residents seen talking to Nazdeek could be at risk for retaliation. Thus, complainants are far more likely to use a system managed by women living in plantation areas.

The situation was similar for SAHAYOG. While the use of ICT required significant support initially, it facilitated citizens making their own complaints, as opposed to NGO staff going to each site to collect reports. This likely lessened the risk of retaliation, since patients were not seen interacting with CBO staff. Moreover, the SAHAYOG project was implemented on a larger scale than the other two. Though the use of ICT required significant support to communities, it also facilitated scale, since most complaints could eventually be made without SAHAYOG or CBO involvement.

3) Challenges and adaptive program changes

Each project encountered multiple difficulties, some of which were similar across projects. Implementers altered the programs in response to some of these challenges. We summarize the commonalities and differences in challenges faced across programs. All of these challenges illustrate the fact that the gains in efficiency offered by ICT require significant financial resources, on the ground support, ICT expertise within the implementing organization, and concerted efforts to make ICT accessible to marginalized populations.

Limited technological literacy. As noted, the projects target poor and otherwise disenfranchised communities that may lack rights awareness and technological know-how and confidence to participate in the project. This problem was particularly acute for SAHAYOG, which relied on the aggrieved women, rather than trained advocates or volunteers, for reporting. SAHAYOG staff and partners reported that women required significantly more support to make reports via interactive voice response than initially anticipated. In response, SAHAYOG simplified the interactive voice response system, making it easier for women to select the category of informal payments demands that fit their situation.

Women in Uttar Pradesh also indicated that they faced problems posed by poor phone networks, lack of access to electricity (to charge the phone), and gender norms around phone use. In many households, the husband controlled the family mobile phone.

Still, the need for support decreased over time in Uttar Pradesh. Concern about support for the use of ICT is less relevant in contexts where trained volunteers make reports, but even so, they often require significant training and ongoing support. Nazdeek relied on women volunteers in tea garden areas, who, though trained on health entitlements and the use of the mobile phone, were not familiar with technology and had low literacy levels. Some volunteers reported orally to other volunteers or called the coordinator to make reports (a volunteer coordinator was assigned to each block). Nazdeek sought to address these challenges by increasing the number of in-person meetings with volunteers and later with the community at large.

CEGSS endeavored to minimize the problem posed by low tech literacy by giving communities a role in the design of the technology. Community leaders in Guatemala were involved in the entire process of designing the complaints platform—from the forms to the project website. The developer teams also field-tested the data collection forms in three different sites. However, CEGSS noted that, as found in many other human rights efforts, the poorest and most marginalized were often not present and/or able to take part in community participation fora, including those regarding the design of the project.[20]

ICT capacity required within implementing organization. ICT capacity was also required within the organization running the project. None of the organizations had implemented such ICT-dependent projects in the past; they were initially unaware of the extent of financial and human support required to keep the programs running smoothly. They sought unexpected technical help, which had financial implications. They all reported glitches in implementation and suggested that other organizations seeking to implement similar projects should carefully outline and consider the time and money required, as well as have realistic expectations about the role of technology in their theories of change.

Adequate technical and program training, support, and feedback to ensure high levels of

reporting. The volume of reporting ebbed and flowed. In addition to the challenges described above, all three projects encountered misunderstanding among project staff/volunteers, who would report problems of the same type only once. For example, a health defender in Guatemala would report one case of a medicine stock out at a facility, and then fail to report any subsequent instances of patients finding this medicine out of stock, since it had already been reported. This undercut a key objective of the projects, which was to show how many people were affected by health service problems, highlighting patterns of health entitlements failures. Additional training and support in all projects remedied this problem.

Empathy for the providers' plight, and the desire to prevent conflicts between frontline health providers and users arising from complaining, were other factors limiting reporting. For example, some community members in Uttar Pradesh explained that they were reluctant to report because they knew that health providers have few resources at their disposal. They felt that health facility infrastructure needed to be upgraded before complaining could be justified. To counter this concern, the three organizations emphasized that data were being collected to facilitate system-level changes, rather than to hold individuals in health facilities responsible, except in cases of egregious rights violations.

Community and volunteer misperceptions that the project was going to have an immediate impact also shaped reporting rates for both Nazdeek and SAHAYOG. Nazdeek struggled to maintain commitment among CBO volunteer reporters. In some cases, volunteers who did not see immediate, tangible changes in response to their work lost interest and slowed or stopped reporting. Women who initially committed to participating in the Nazdeek program did not feel motivated to continue participating after they had collected data. Yet, the next stage was an essential component of the program, where the data were being discussed with health authorities.

The three organizations tested different modes of communication and publicity to maintain community and volunteer engagement. SAHAYOG used stickers, pamphlets, graffiti (wall writing), and street theater, and, insofar as possible, engaged the local community health workers. In response to decreases in reporting, they also began to work with local CBOs to provide updates and feedback to communities on the progress of the project, explaining how the project reports and data were used to advocate for change.

CEGSS made radio announcements, distributed flyers, and organized meetings of community defenders at least once every three months to share their experiences, jointly troubleshoot problems, and encourage the defenders to educate their respective communities about the project.

Nazdeek held regular meetings with volunteers and conducted a participatory midterm evaluation of the project. As a result of volunteers' requests made during the evaluation, Nazdeek planned additional workshops and community meetings. They also sought to ensure that volunteers were recognized for their work by holding community meetings and providing volunteers with project identification cards. Over time, the number of volunteers participating in the project was reduced, but those who remained involved gained leadership in their communities and were increasingly keen to raise issues with respective authorities, even outside the grievance redressal forums.

While the need for technical support is unique to ICT, the challenge of providing feedback to community members and volunteers making reports as part of health system monitoring projects is not. However, the feedback challenge may be especially important to consider in ICT projects aiming to minimize program costs and operate at significant scale. While ICT seemingly decreases the need for human resources to implement the project, it does not obviate the need for feedback to communities. Implementers might consider using the ICT platform to provide feedback about how individual complaints are contributing to systems data, and how these systems data are being leveraged to demand answerability and remedy.

Risk. Women and CBO personnel in all three sites faced some level of risk for reporting or address-

ing shortcomings in the health system. CEGSS explained that some community members who have filed reports via official governmental channels experienced intimidation, assaults, and death threats against themselves and their families from public officials and employees. Representatives from Nazdeek and SAHAYOG explained that if an Accredited Social Health Activist, or ASHA (a cadre of community health worker in India), brings a patient to a health facility and the patient refuses to make an informal payment, the next patient the ASHA brings may be denied care. Nazdeek volunteers working in tea gardens were afraid of reporting about malpractices in tea garden hospitals due to risk of retaliation from their employer.

Because of these risks, the three projects offered anonymity to anyone making reports. Since the projects intended to produce aggregated data illustrating patterns of experiences with the healthcare system, patient names were not required. However, this anonymity may weaken some health system responsiveness and redress. For instance, when Nazdeek staff submitted data regarding a number of cases of informal payments in one of the Primary Health Centers, district authorities requested the names of the concerned women in order to intervene. Nazdeek instead disclosed the name of the doctor charging money and the amount paid in exchange for the services provided. In the case of SAHAYOG, several health facility managers interviewed in Uttar Pradesh claimed that they could not address informal payments unless they had the name of the complainant.

NGO staff explained that they needed to navigate these tensions among risk to the client, client desire for individual remedy, and governmental requirements for pursuing official complaints. All three organizations kept the names of complainants confidential (SAHAYOG did not even collect names) and emphasized the importance of producing data that could be used to secure policy changes and governmental guarantees of non-repetition. However, both CEGSS and Nazdeek had channels for individual clients to pursue cases to demand restitution, compensation, or rehabilitation.

4) Government responsiveness: progress toward fulfillment of the right to health

This study did not entail an exhaustive exploration of government responsiveness to the ICT for health accountability projects. However, improvements in government fulfillment of the right to health, as it related to ICT, were discussed in interviews and focus groups.

As noted, the SMS-based reporting allowed the three organizations to ascertain patterns in rights violations, to collect data on a large scale over a sustained period of time, to make that data available in real time, and to display the data in user-friendly formats. Between May 2014 and September 2017, 268 records of maternal rights violations were recorded and mapped on the End MM Now website. Between January 1, 2014 and September 30, 2015, there were 7,159 violations recorded through 1,876 calls to SAHAYOG's My Health, My Voice hotline. And between August 2014 and March 2015, 228 violations were reported to CEGSS.

The gathering and deployment of large-scale data likely resulted in a somewhat better response from the government. In the case of SAHAYOG, officials at all levels discussed the data with SAHAYOG and CBO partners, and some high-level officials committed to addressing the problems identified. The state government issued an order that hospital committees include a review of the complaints registered in the hotline in their regular meeting agenda; this order could be implemented because the committees could easily access the data online. Some hospitals made changes; for example, one primary health care facility responded to the evidence presented by establishing a mechanism in partnership with a private clinic to ensure the availability of drugs free of charge. Earlier research on the SAHAYOG project also found that the "elite cachet" associated with ICT seemingly bolstered officials' willingness to engage and believe the data.[21]

However, despite the SAHAYOG data showing patterns of service gaps, many within the government addressed the problems raised as being attributable to a few miscreant providers, rather than to systemic weaknesses in the health system.

They did not seem to integrate the data provided by the program into their decision-making routines; they generally consulted the data only when it was shown to them at meetings and dialogues. For the especially intransigent issue of informal payments, ICT data affected decision-makers in some contexts but not others. As described by SAHAYOG and CBO staff and health facility managers, the key factors seemed to be the professional commitment of the particular health facility manager, and the breadth and depth of the "corruption nexus" in the health facility at issue.

CEGSS had similar experiences with the aggregated data they presented to governmental agencies. Representatives of these agencies were willing to meet and discuss the data in open community dialogues. CEGSS was somewhat successful at instigating facility level changes, with reductions in absenteeism and apologies from providers following reporting. In isolated cases, partners and allies outside of CEGSS used the ICT-gathered data to successfully push for change. For example, in the Solola region, delegates of the San Pablo la Laguna Community Council presented evidence from the platform at Municipal Development Council meetings to describe the challenges people faced in accessing quality health care. In response, the council worked with health center staff to subsidize medicine for the poor, provide subsidies for maintenance of the ambulances and for patient transfers, and finance the improvement of surgical and medical equipment and the construction of a new health post. There were similar outcomes in other municipalities.

In the case of Nazdeek, local authorities demonstrated openness to receive the data. In interviews, they stated that they perceived the data to be reliable. There were anecdotal reports of resultant changes in health service delivery, such as decreases in informal payments, regular disbursement of cash entitlements, and improvements in the condition of the local district-level hospital. Nazdeek staff reported that the data collected through ICT also led to the opening of a space for engagement between women volunteers from the community and block and district-level officials – space that did not exist until then. Following the submission of a report with the findings of the first nine months of reporting, local authorities agreed to establish regular grievance redressal forums so that women volunteers could meet with block health authorities and discuss the issues that emerged through reporting. The data also fed into the filing of written complaints through the government's administrative system, which sought to address specific instances of rights violations, and, into the filing of right to information applications that sought to uncover bottlenecks in the disbursement of funding for health and nutrition services to lower-level facilities.

Conclusion

The larger accountability for economic, social, and cultural rights field offers lessons regarding how NGO or citizen-led engagement can foster accountability for the progressive realization of health care service delivery that is available, accessible, acceptable, and of adequate quality.[22] We contribute to that by focusing on operational questions arising among practitioners trying to leverage ICT for use in right to health projects among particularly marginalized populations.

Despite obvious challenges in using ICT tools, poorer and less technically savvy members of the community have been able to register a significant volume of complaints based on their experience of using public health services. With the anonymity provided through these NGO mechanisms, women users were protected from the risk of retaliation by the providers and avoided intimidating bureaucratic encounters. The NGOs in turn were able to collect and analyze reports to identify recurring patterns and systemic flaws, which would have been more difficult using pen and paper. The real-time data gathered through ICT could be easily shared with government officials and the media for greater impact; where relevant, databases could also function as case management tools.

However, several factors deterred reporting:

complaints did not usually lead to immediate improvement, some community members did not believe that their reports would lead to change, and some were reluctant to blame under-resourced frontline providers. The NGOs were hampered by technical challenges in these ICT-dependent projects and had not necessarily planned for the considerable financial and human support required to keep the projects running smoothly.

All three projects needed to conduct a number of offline activities in order to build trust with the health managers and providers, to foster rights and entitlement consciousness within the communities addressed by the project, and to convince community members of the importance of reporting. Uptake of the ICT tools was enhanced by these concerted efforts to engender government responsiveness while simultaneously building up an informed and empowered collective of users of public services.

These process findings have implications for the potential impact of ICT-enabled human rights accountability projects. The preliminary findings on impact were that while citizens overcame their fear and reluctance to report violations, many providers and managers did not respond adequately to address the systemic flaws that became apparent via the reporting. Health managers and policy actors remained constrained from providing a comprehensive system response or were unwilling to do so.

The standard bureaucratic approach of governments is to register individual complaints and seek to punish proven transgressions; this fails to transform the system or enhance answerability or enforceability for the users. The transformative potential of the projects more likely lies in the "micro-transgressions" of gender, caste, and other oppressive norms; the increased self and collective efficacy of those making reports; and the creation of opportunities for excluded people to interact meaningfully with government duty-bearers.[23] These changes may be a link in the causal chain that ends in increased responsiveness. If properly supported as a program component, ICT can facilitate linkages in the chain.

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Social Solidarity, Human Rights, and Collective Action: Considerations in the Implementation of the National Health Insurance in South Africa

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Abstract

Participation is recognized as an important contribution to implementing the right to health. It features as a key element of the global movement to achieve universal health coverage. The mobilization of groups into collective action is central in this. In South Africa, universal health coverage has become a feature of health policies, with the country's new National Health Insurance (NHI) scheme in the process of being established. The NHI is considered an experiment in social solidarity. This paper provides insights into civil society's experiences in the pursuit of universal health coverage via the implementation of the NHI. It explores the interplay of trust, reciprocity, and altruism and how these individual actions can advance toward solidarity and collective action. Our research shows that the road to universal health coverage via the rollout of the NHI will be complex. However, opportunities for collective action exist, including shared learning about human rights, as well as local initiatives within trusted circles. A collective health commitment is based on trust between the government and citizens. Thus, one of the first steps in implementing the NHI should focus on rebuilding trust, which could be developed by establishing platforms for citizen participation.

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Introduction

Participation is recognized as an important contribution to implementing the right to health and transforming health systems.[1] It features as a key element of the global movement to achieve universal health coverage, which has itself been framed as a practical expression of the right to health.[2] The Universal Declaration of Human Rights states that all human beings are born equal in dignity and rights and that everyone has the right to a standard of living adequate for the health and well-being of themselves and their families.[3] In addition, the International Covenant on Economic, Social and Cultural Rights and General Comment 14 on the right to health (which provides further interpretation of the covenant) recognize the importance of participation, stating that "the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, program or strategy developed to discharge governmental obligations."[4]

Key to achieving universal health care is a rights-based approach to health that integrates human rights norms in health policies and programs and that includes individual and collective action.[5] Such an approach embraces the principles of equity, equality, dignity, and non-discrimination and is applied to both the determinants of health and health care provision.[6] It means empowering society—particularly through awareness of citizens' right to voice their needs—to hold the government accountable for the provision of health care.[7] A rights-based approach to health acknowledges the voice of the most vulnerable individuals in society and provides them with the opportunity to address human rights violations in health care provision.[8]

An important component of this rights-based approach is the mobilization of groups for collective action to pressure governments to realize the right to health.[9] Such collective action is dependent on citizens being aware of their rights and being willing and able to hold duty bearers accountable.[10] A well-known example of collective action is the Treatment Action Campaign, whose campaigning, mobilization, and legal strategies ultimately led to the achievement of universal access to antiretroviral therapy for HIV/AIDS in South Africa. This campaign was driven by a strong civil society movement that aimed its collective action at national and international policies, demonstrating that collective action can thus contribute to shaping responsive state policies.[11] Civil society and community groups can pursue shared objectives for the realization of the right to health that provide a more powerful base than individual claims.[12] Although many view the right to health as individualistic in nature, Leslie London et al. (2014) argue that the right to health can actually be delivered to collectives, for public health policy interventions apply to communities and groups as well as individuals.[13] Rights claims that are framed collectively will therefore benefit society as a whole. In this way, solidarity emerges as a key concept.[14] Social solidarity emphasizes the interdependence between individuals in a society, which allows individuals to feel that they can enhance the lives of others.[15] It is a core principle of collective action and is founded on shared values and beliefs among different groups in society.[16] Social solidarity has been deemed essential to the realization of rights.[17]

South Africa is a country where evolving social policy demonstrates the importance of social solidarity to human rights approaches. Following decades of colonial rule and apartheid characterized by systematic human rights violations, a new bill of rights was adopted in 1996 as part of the country's new constitution. Section 27 of the Constitution notes that "[e]veryone has the right to have access to health care services, including reproductive health care, sufficient food and water, and social security, including, if they are unable to support themselves and their dependents, appropriate social assistance."[18] However, despite the promise of the Constitution and the passing of many years of democracy, widespread knowledge of the right to health remains lacking, inequalities in health status and the distribution of resources persist, and the practical realization of the right to health remains a challenge.[19]

In South Africa, reforming the health system has been a priority.[20] The pursuance of universal

health care has become a feature of recent health policies, particularly in arguments for the introduction of a National Health Insurance (NHI) scheme, which is currently in the process of being established.[21] With the implementation of the NHI, the South African government aims to move toward universal health coverage via improved access to and provision of quality and equitable health services, which can be seen as a step forward in achieving the right to health.[22] Although the right to health has been part of the Constitution for over 20 years, and transformation of the country's health system to achieve equity in health was first mooted in a 1997 white paper, the practical implementation of steps to achieve equity and universal access has been uneven and incomplete. Seeking to fill this gap, a series of NHI green and white papers have been issued in recent years to accelerate policy intent.[23]

To achieve universal health coverage, the NHI must rely in some measure on people's willingness to accept risk- and income-related cross-subsidies, which renders its implementation an experiment in social solidarity.[24] Social solidarity is an important foundation of equitable health care systems whereby everyone is willing to pay for health care according to their means and everyone benefits according to their needs.[25] The success of the NHI depends largely on the willingness of South Africans to see health care within the framework of social solidarity, in which health care is treated as a collective construction rather than an individualist one.[26] Hence, collective progressive payments into a NHI fund can be seen as a form of solidarity and the collective understanding of health en route toward universal health care. Francesco Paolucci suggests that health care may be more likely to attract actions of social solidarity because people would, for a range of reasons, be willing to pay for the consumption by others of goods and services related to health and health care.[27]

This paper explores the views and experiences of members of health civil society groups in relation to social solidarity and collective action. Concepts closely related to social solidarity are trust, reciprocity, and altruism.[28] Although these concepts are instituted as individual acts, the outcomes can contribute to enhancing social solidarity and collective action. Our research aim was to explore the interplay of trust, reciprocity, and altruism and how these individual actions can advance solidarity and collective action within a rights-based framework. The experiences of civil society participants may provide insight regarding how to apply the concepts of solidarity and associated individual acts for collective action to the implementation of the NHI, so as to advance universal health care as an expression of the right to health.

Social solidarity and collective action

We adopted a conceptual framework (see Figure 1) based on Robert Campbell et al. to explore social solidarity and collective action needed for the implementation of the NHI.[29] The framework is divided into individual actions (concerning actions related to trust, altruism, and reciprocity) and collective actions (concerning actions such as social solidarity). The framework was used as a tool for the exploration of individual acts in order to reflect on or predict what could happen in a collective situation, such as social solidarity in support of the NHI.

Collective action

For the purposes of this paper, collective action is defined as the behavior and actions of a group working toward a common goal, which, in this case, is the achievement of collective health as the practical utilization of universal health care through the implementation of the NHI.[30]

Social solidarity

Solidarity is an element of human association that emphasizes the cohesive social bond that holds a group together, which is valued and understood by all group members.[31] There are different motives for solidarity. For some, affection and shared norms and beliefs are motives, while for others, rational choice and self-interest are drivers.[32]

Individual actions

The concepts of trust, altruism, and reciprocity are

grouped under individual acts, as they are instituted from an individual standpoint.

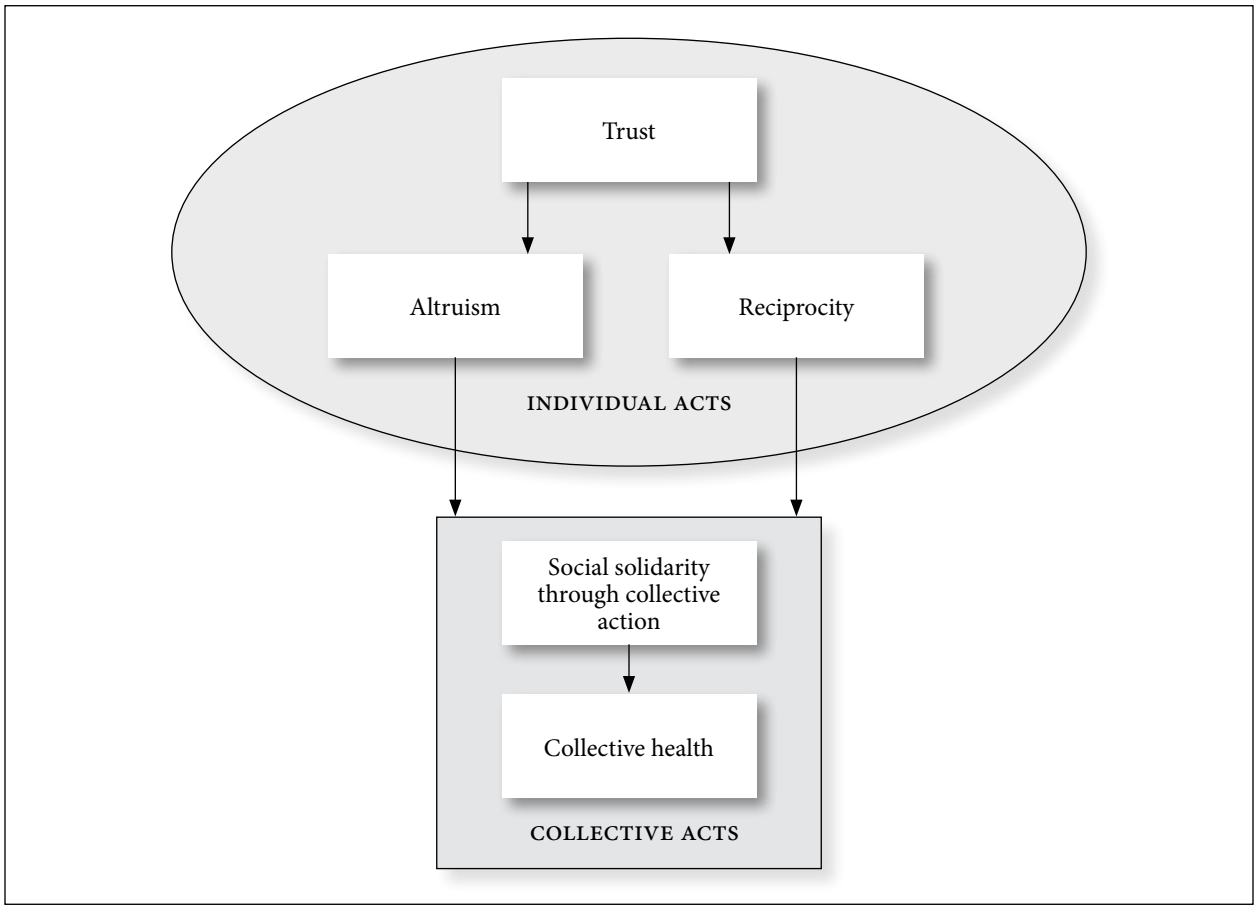
Trust

Trust is a relational concept that can be instituted between two individuals or between an individual and an organization.[33] A common understanding of trust is "voluntary action based on expectations of how others will behave in the future in relation to yourself."[34] This concept has been widely recognized as enhancing cooperation between individuals and groups and ensuring that economies and nations thrive.[35] Trust and shared values can increase feelings of self-esteem and security within and between communities, and they can provide a basis for achieving collective goals.[36] Trust is important to a strong health care system, since such a system requires cooperation and shared values within society.[37] Trust in someone is based on reputation, former experiences, background, culture, and social class.[38] Trust becomes weaker when social distance increases, as the expectations of strangers are unknown.[39] Trust is higher among friends than strangers.[40]

Altruism

Altruism refers to behavior that reflects an unselfish desire to live for others.[41] Altruism is considered to be the opposite of selfishness and involves placing what is good for others above what is good for oneself. It comprises a moral obligation to sacrifice oneself—or time, energy, or possessions—for the collective good.[42] Pure altruism contains no expectation of receiving something in return.[43] Altruistic behavior is voluntarily and intentionally performed.[44] Émile Durkheim argued that altruism and shared values should lie at the base of social solidarity to avoid selfish behavior; he argued that individuals should

FIGURE 1. Conceptual framework



consider not only their own interests but also their duties to the community.[45] Altruism needs a base of trust before being instituted.[46]

Reciprocity

Reciprocity is assistance to an individual or a group provided by another individual or group under the assumption that the favor may be returned in the future.[47] The concept differs from altruism in that reciprocal action comprises expectations of future rewards, whereas altruism does not have these expectations.[48] Reciprocity is a strong determinant of behavior and contributes to equal relationships.[49] It can produce an obligation to return the favor in the future, which enhances continued relationship. An act of an individual in a reciprocal system is a combination of "short-term altruism" and "long-term self-interest."[50] Reciprocal behavior comprises a willingness to contribute to the collective good and to reprimand those who refrain from contributing.[51] Reciprocity promotes solidarity and shared interests by fostering repeated interactions among community members—hence, a two-way arrow is placed in the framework in Figure 1.[52] Reciprocity has been used to explain the continuation of collective action in situations where instant incentives are absent.[53]

Methods

We conducted our research in the Western Cape Province of South Africa from March to July 2012. This province is characterized by substantial inequalities in income, housing, education, and access to health services.[54] Our research was undertaken as part of the Learning Network for Health and Human Rights, a collaborative program that, at the time, involved six civil society organizations (CSOs) and three universities working toward good practice in realizing the right to health.[55] The Learning Network uses reflective activities to explore how collective action can identify good practice with regard to using human rights to advance health.[56] Member organizations include constituency-based CSOs and service- and advocacy-oriented nongovernmental organizations addressing both health and the social determinants of health.

We undertook a qualitative mixed-method exploratory study that relied on five focus groups, one semi-structured interview, and observations (see Table 1). Purposive sampling was used to identify members of the CSOs in the Learning Network. Through CSO contacts, we arranged focus groups comprising mixed-gender groups of 5–12 adults (over 18 years old) per group. The participants came from historically disadvantaged socioeconomic backgrounds. Participants' informed consent was obtained. The focus groups were conducted in English, with Afrikaans translation into English provided during the sessions by a trained interpreter. All focus groups and interviews were voice recorded. Transcripts were anonymized, and pseudonyms are used in this paper. Approval was obtained from the Human Subjects Research Ethics Committee in the Health Sciences Faculty, University of Cape Town (HERC REF:146/2012).

To start each focus group discussion, we used a vignette from a DVD entitled *Law and Freedom*

TABLE 1. Overview of methods

Type	Number of participants	Sex of participants
Focus group discussion 1	11	All female
Focus group discussion 2	5	3 female, 2 male
Focus group discussion 3	5	All female
Focus group discussion 4	8	6 female, 2 male
Semi-structured interview	1	Male
Observations	N/A	Mix

concerning post-apartheid South Africa. In the excerpt, pensioners who had been denied access to social security in 1998 by the Eastern Cape government in an attempt to root out corruption in pension claims went to court to seek restoration of their benefits.[57] One pensioner, Ms. Meltafa, was the first litigant in this class action against the government. She was offered a direct settlement by government officials. Despite her financial distress, she decided to persist with the claim, reasoning that others could benefit if the case was successful. Her rights claim can be understood from a more collective notion than can most court actions. Participants of the focus group were asked to reflect on the ideas generated by the vignette and to share their ideas on the elements necessary for collective action. The concepts of trust, reciprocity, and altruism were discussed separately, and participants were asked to give examples of these concepts as they relate to health or collective action.

We undertook a thematic analysis using inductive and deductive reasoning to identify broad themes.[58] We used the conceptual framework outlined in Figure 1 as a tool for reflection.[59] After first-order coding, we performed advanced coding, which facilitated a higher level of abstraction and a categorization of the data. We summarized the codes into matrices that clearly displayed the data.

Results and discussion

Individual acts

We analyzed the results in terms of the concepts of trust, altruism, and reciprocity and how these concepts evolve from individual approaches to collective actions.

Trust

We explored the notion of trust by asking whether people can rely on one another. Participants said that different communities cannot rely on one another because "people are coming from different backgrounds" (FDG2, woman 1). Participants defined the notion of community as "the people you live within a particular area, with its own structures and group norms" (interview, man L). The main reason put forward for this lack of trust was the fact that, nowadays, everyone looks out only for themselves. One of the participants (interview, man L) referred to the fact that strong ties in society used to come from the action of Ubuntu (a traditional African worldview in which a person exists because of and through relationships with other people).[60] However, this feeling has been eroded by modern urban culture, which encourages individuals to act for themselves. This lack of trust in others could pose a threat to cohesive bonds, as, according to Mark Smith, nations thrive when trust and social networks are strong.[61]

A feeling of mistrust in others was a recurrent theme: "So there is no trust or whatever, you can't trust nobody; you can't trust your husband, you can't trust anyone these days … even me, you can't trust your problem to me" (FGD1, woman 8). Additionally, a woman mentioned, "I think that many people in South Africa, and especially now, think that people are taking advantage of them." Moreover, participants did not believe that others keep their promises: "They don't keep promises, they just speak," and "it is all half-truths." These quotations show that there is a strong feeling of social distance within communities that is affecting the solidarity expressed toward others. Social distance is increased by the memories of apartheid and by differences in power, status, and wealth. This feeling was underlined by a female participant (FGD4, woman C) who stated, "Even though Apartheid is gone, there is [a sense of] I am better than you, I am living in a better community, so why should I help you?"

Similar to Christine Binzel and Dietmar Fehr's findings, we found that trust was lower among strangers: "The time when not anyone could come this way, to this country, there is no drugs. With only South Africans, we have no idea for the drugs. The time when we had freedom, every people could come here, and now there is so many drugs" (FGD1, woman 8).[62] These comments imply that illicit drug use is the fault of foreign nationals entering post-apartheid South Africa in an uncontrolled manner, a sentiment not uncommon among

socioeconomically disadvantaged communities in South Africa.[63]

The government in particular—including state institutions and political spaces in general—was seen as untrustworthy: "People lost hope, people haven't got confidence in the government anymore. Our people say no to politics, our people don't want politics" (FGD1, woman 3). According to participants, promises of jobs, a good health system, and education are not delivered. Corruption was mentioned as an important factor for this lack of trust. Furthermore, trust inspired by the installation of a democratic post-apartheid government has faded away "because we fought for this freedom. And we used to trust them. I think the main problem is also [that] the system is very much [home] to the criminals now" (FGD1, woman 6).

Individuals' lack of trust in one another, in strangers, and in the government may reduce their willingness to unite in collective action, as people may not feel empowered enough to assert their rights or trust that their claims will be taken seriously. Furthermore, it may affect individuals' willingness to go beyond their small group of kin and act on behalf of the greater good. Applying this panorama to the implementation of the NHI, it can be argued that a solid base is missing, for trust is the first step toward social solidarity and collective action. If people do not trust that their contribution to the NHI will benefit themselves and others, it may be hard to foster a willingness to pay.

Altruism

We explored the concept of altruism by asking participants if they would help someone without expecting a favor in return. Some said that doing favors arises from care for others: "You must do it out of your heart, not to expect anything back from that person" (FGD4, man E). The participants provided an example of altruism in which a community helped a woman whose house burned down by providing her with clothes and food. This example prompted several reactions: "My opinion is that it does not always happen like that in our communities. But if our community or our people could do the same thing … it would help a lot for people who are being treated out of their rights" (FGD2, woman 1). The respondent thus both dismissed the example as representing what happens in reality but also acknowledged that it should happen because solidarity is important for realizing human rights.

Although participants shared a positive view on altruism, they agreed that this was not the norm and that most people just look out for themselves. One example they offered was that of elected local ward counselors who use their political power to provide favors to family members instead of helping the community. As one participant explained, only a small number of people do things to benefit the whole community: "It would be people that are passionate about the community, that are passionate about whichever group or community they are helping … but very few [are]" (FGD2, woman 5). A similar opinion was voiced by another participant: "There are people that [do things for the community]. But there are others that will do something for you, but then you are on the owe-list" (FGD3, woman C). An "owe-list" implies that the person performing the favor will eventually ask for a settlement of the "debts" when convenient, which is similar to reciprocity.

Participants' comments showed that they felt they owed something to the community but did not have enough resources or power to make a difference. They recognized the importance of enabling others to claim their rights, as in the video vignette. After watching the video, one woman said, "You can stand up for other people. Because they don't know what is going on" (FGD1, woman 6). Sharing knowledge about human rights, health claims, and institutions was mentioned by participants as a simple option that does not require many resources. This represents an opportunity in which altruism can lead toward social solidarity, as shared learning is often a first step toward collective action.[64] However, participants believed that people are generally unwilling to sacrifice money for others since most people have their own financial problems to worry about. Instead, people want to receive something in return, as this quotation illustrates: "Maybe if they give money away for the sake of giving, there must always be what is the purpose of this money,

what am I getting out of this at the end of the day" (FGD3, woman C).

The evidence gathered through our research confirms the relationship between trust and altruism in the framework outlined in Figure 1. Similar to the concept of trust, altruism is unlikely to be established between strangers or with individuals outside one's community. Community members are more likely to be altruistic when it comes to their fellow members: "In a big society, people are more likely to look out for themselves but within family circles they tend to look after each other" (interview, man L). It can be argued that there is a small possibility that solidarity will arise from altruism. However, this will occur only within small communities where a strong base of trust is present. This collective action is unlikely to involve material or financial goods but rather intangible goods such as advice or shared learning.

Reciprocity

We explored the concept of reciprocity by examining participants' willingness to return favors, as well as their reasons for this willingness or lack thereof. Participants described exchanging favors as "a way of getting in another one's good book" (FGD3, woman C) and as a means "to be favored yourself" (FGD3, woman N). Their responses suggested that self-interest is an important driver for favors: "You might have something extra that you might not need now and you can translate it into something that you might benefit from later" (interview, man L). Another participant mentioned that doing good is easier when one knows that the result is positive: "It's almost like the effort equals the benefit" (FDG2, woman 3).

Although Aafke Komter has suggested that self-interest can be a motive for solidarity, it became clear from our research that self-interest must be accompanied by feelings of affection and trust in order for this to be true.[65] Self-interest alone may not persuade more advantaged individuals to contribute to an NHI scheme knowing that the needs of the less advantaged are larger than their own benefits. Jane Goudge et al. argue that in cases such as this, solidarity becomes less of a motivation for decisions than self-interest.[66] However, if self-interest is combined with feelings of trust or altruism, it may become a driver toward collective action.

Receiving a favor leaves one feeling obliged to return it, which enhances a bond between individuals and provides a feeling of a collective goal: "What you benefit at the end of the day, you have to make sure that you are ploughing back for other people who are poor … more than you … Even [if] you do not pay back by money, then you do some other things in the other community" (FGD2, man 4). One of the participants added that time plays a role: "You might help somebody now, but you might need to wait for a long time to get the benefits" (interview, man L). An example illustrating this is when families save money to send their children to university, expecting that these children, after graduating, will be able to support the whole family. Contributions to the NHI could be framed on a similar note: you might not need benefits today, but you might need them later in case of sickness.

Participants revealed a strong distinction between a willingness to reciprocate within trusted circles and a willingness to reciprocate with strangers outside one's community. Reciprocal acts or bonds were found to be more established within families and groups of close friends. Marshall Sahlins distinguishes generalized from balanced reciprocity by describing generalized reciprocity as instituted between individuals who are kin and who feel a weak obligation to reciprocate in a short time frame.[67] Meanwhile, balanced reciprocity requires the direct and immediate exchange of a favor of the same value. The results from our focus groups suggest that relationships based on balanced reciprocity are present. However, for such reciprocity to be established, a base of trust is needed.[68] If trust is missing, the willingness to reciprocate favors diminishes, as can be seen in this quotation: "I'm sorry to say to you, if it is somebody who was in the government. I can't make any favor for him, because they did not make any favor for us" (FGD1, woman 11).

Collective action and social solidarity

According to Durkheim, interdependence between individuals forms the basis of social solidarity.[69] Along these lines, our focus groups aimed to identify examples of social bonds and shared values. Participants acknowledged the importance of collective action: "If we can work together, all of us, South Africa would be beautiful. Nobody gets crime, nobody can sleep in the street, nobody can smoke the Dagga [marijuana] and taking the tik [methamphetamine]" (FGD1, woman 1). One example of social solidarity recounted by participants was a case of patients' rights violations in which a health clinic had different queues for HIV and tuberculosis patients, which exposed HIV/AIDS patients to stigma. Community members took the issue to the clinic manager, after which the queues were merged and the signs removed. Relating the case of Ms. Meltafa to contributions to the NHI, one could argue that the aspect of solidarity lies in the contribution to the collective, as can be seen in the health clinic case, and the benefit from added protection via the NHI. In Ms. Meltafa's case, she contributed her time and resources, and she risked losing the government grant. A contribution to the NHI could be seen as a similar act for the larger society. However, participants lamented that examples of solidarity actions are not common in practice: "Solidarity is lacking very, very much" (FGD2, woman 2).

Participants described collective action as a commitment to society as a whole, like that of Ms. Meltafa, who did not accept the settlement and instead continued to fight so that everyone could benefit. They considered collective action important but difficult to achieve, as noted by one participant: "It is about collective action at the end of the day, but how do you get people to realize that collective action would work?" (FGD2, woman 2). Participants argued that collective action can be undermined by individualism: "There are people that do things to help the community as a whole. But that is also a struggle, because … there is always one that is turning away" (FGD3, woman C). Another participant stated, "It depends on how bad they want the situation to change. So people will stay united for a special purpose, and then when it is fulfilled, they disperse" (FGD2, woman 3). Given that contributions to the NHI will be continuous, this lack of long-term commitment may be problematic.

Solidarity is a shared recognition of a common good that holds a group together.[70] Nevertheless, participants saw South African society not as a group with common goals and shared values but rather as a divided society: "We've got a divided community that is a fact and that is the truth" (FGD4, woman M). South Africa needs a new feeling of "mutual compassion" that will bring people together.[71] Chuma Himonga extends this by noting that the concept of Ubuntu could serve this role, as its attributes such as interdependence and community orientation possess the ability to advance the right to health.[72]

An opportunity for collective action could be thought to be represented by voting in elections for local political leaders. However, participants dismissed this form of representative democracy as a meaningful channel for realizing rights claims, feeling that their vote was unlikely to make a difference. Moreover, they expressed being afraid of claiming their rights in government institutions since they feared they might be shouted at or sent away. One participant who is a social worker indicated that people are aware of their rights and empowered to claim them but are discouraged from doing so: "They don't see any action so they just see that as something that's put on the wall to look pretty" (FGD2, woman 5). Furthermore, participants suggested that people are passive about claiming their rights: "So it's almost like they are sitting back, thinking, I have my rights. So one day it will come to me" (FGD2, woman 2). Additionally, it was mentioned that "civil society is not an accepted place to be in nowadays as collectively organized meetings are seen as trouble making" (interview, man L). Maria Stuttaford et al. outline the importance of ensuring that spaces where people can go to claim their rights are acceptable and appropriate.[73] If this is not the case, people may

shy away from expressing their needs. Ways for communities to influence decision making in the NHI will be critical if collective action is expected to help generate social solidarity for the NHI.

Participants mentioned various ideas regarding the necessary elements for engaging in collective action. One idea was that community members should engage in government institutions and serve on boards responsible for decision making. Another idea was that shared learning was important for the collective, since communities experience similar issues: "We need to network with others, we need to invite them to come and maybe strengthen us, to empower us" (FGD4, woman M).

We recognize that this study did not include the voices of the economically wealthier. For future research efforts, it would be important to explore the social solidarity and collective action framework with diverse populations in order to offer broader insights into how health goals related to universal health care can be reconciled with rights claims to health in a future NHI in South Africa.

Conclusion

Our research findings suggest that the road to achieving the right to health and universal health care via the implementation of the NHI will be complex. We applied a framework linking social solidarity and collective action to participants' views in order to predict if and how social solidarity could both contribute to and be generated in the establishment and implementation of the NHI. Our findings suggest that collective action and solidarity are valued but are considered to function only in the context of small-scale trusted circles. The key question remains how this solidarity and collective action can be expanded for NHI implementation. Experiences from the Learning Network for Health and Human Rights provide insights regarding opportunities for collective action by showing that small-scale individual acts such as shared learning about health and human rights or local initiatives can work toward the collective good.

The exploration of reciprocity showed a key opportunity for collective action by acknowledging self-interest as a driver. User payments to the NHI can be framed as individual acts toward collective health, and the expectation of benefits for oneself can form a basis for collective action if combined with the existence of altruism and certainty of future rewards. This relates to the willingness to cross-subsidize those who are worse off or sicker than oneself.[74] For such willingness to exist, trust in the return on "investment," in case one falls ill, needs to be present.

Our findings also point to certain areas that require strengthening in order for the NHI to succeed. A basis of trust should be established between the government and South African society. Given our findings and those of other studies showing that the public's trust in the South African government is low, a first step in the implementation of the NHI should focus on rebuilding trust.[75] Part of this effort could include the establishment of platforms for collective action and citizen participation.[76] There should be a shared recognition and acceptance of the importance of civil society action and collective action between the government and communities. However, there are concerns about the exclusion of civil society in the establishment of the NHI.[77] The NHI could be an opportunity to strengthen bonds between the state and citizens given that it builds on the willingness of citizens to pay for the worse off.[78] However, the creation of a progressive financing system in and of itself does not guarantee this willingness. If the government can reestablish a basis of trust and acceptance among civil society, there might be an opportunity for South Africans to benefit from the solidarity and collective health that the NHI envisages.

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Gendered Power Relations and Informed Consent: The *I.V. v. Bolivia* Case

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Abstract

In a landmark decision handed down on November 30, 2016, the Inter-American Court of Human Rights analyzed the foundations of the right to informed consent. The court held Bolivia responsible for the forced sterilization of I.V., an immigrant woman from Peru, and recognized the importance of personal autonomy as a constitutive element of personality. This paper discusses the ethical foundations of the decision and explains the relevance of this judgment in furthering women's rights in Latin America.

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Introduction

The right to health, a fundamental human right, requires respect for the will of the individual person with regard to his or her own well-being and personal health. This is closely linked to the right to autonomy and the right to free development of the individual. Patients' right to informed consent—that is, their right to make informed choices about their bodies according to their values—is essential to the right to health.[1]

In a landmark decision handed down on November 30, 2016, for the very first time in the inter-American human rights system, the Inter-American Court of Human Rights analyzed the foundations of the right to informed consent. In its ruling, the court held Bolivia responsible for the forced sterilization of I.V., an immigrant woman from Peru, and recognized the importance of personal autonomy as a constitutive element of personality.

This article examines the grounds of the *I.V. v. Bolivia* case. In the first section, we offer a brief description of the background of the case. The second section examines the power relations, the ethical foundations of informed consent, and the concept of equal dignity present in the case by exploring the links between human rights, dignity, and health. Lastly, the third section remarks why the decision of the Inter-American Court of Human Rights is groundbreaking and sets out our thoughts about the relevance of this judgment in furthering women's rights in Latin America.

Facts of the case

I.V. was born in Peru in 1964. When she was 17 years old, she became pregnant; several months later, while still pregnant, she was accused of "apology for terrorism" and was detained by the Counter-Terrorist Directorate, a branch of the National Police of Peru. While in custody, she was physically, psychologically, and sexually assaulted. She was later imprisoned in a penitentiary in El Callao, which she left only to give birth to her daughter in a hospital. After 10 months, I.V. was released from prison and reunited with her seven-month-old daughter, whose upbringing had been left in charge of I.V.'s mother. A year and a half later, I.V. was arrested again and tortured by the Counter-Terrorist Directorate. She was then sentenced to three years in prison.

In 1993, in the context of Fujimori's dictatorship, I.V. fled to Bolivia, where she was granted asylum based on the physical, sexual, and psychological mistreatment at the hands of the Peruvian anti-terrorism agency. In Bolivia, she was able to rebuild her and her family's lives and began working at a hotel. In 1999, she got pregnant again and stopped working.

On July 1, 2000, I.V. went to the emergency room of the Women's Hospital in La Paz after her water broke, and she received a caesarean section. During the procedure, complications arose due to multiple adhesions in the lower segment of her uterus. The following morning, the doctor informed I.V. that her Fallopian tubes had been tied and that she would not be able to have children again. The tubal ligation had taken place without her prior and informed consent.

Later that year, she submitted a series of complaints before the relevant medical regulatory bodies, which resulted in administrative proceedings against the doctor who had tied her tubes. During the course of those proceedings, the doctor argued that he had obtained I.V.'s verbal consent during the trans-operative period, while I.V. was under epidural anesthesia. However, the medical audit conducted by the Ministry of Health concluded that there was no written preoperative consent for the tubal ligation surgery and that it is not acceptable to seek a patient's consent during the surgical or trans-operative act, since the patient is under surgical stress and under anesthesia, even if it is regional anesthesia.

By that time, Peruvian authorities had initiated a criminal procedure against the doctor, which I.V. joined as a civil party. This proceeding concluded four years later, when the Bolivian courts declared the claim time-barred. In March 2007, through the Bolivian Public Defender's Office, I.V. then referred her petition to the Inter-American Commission on Human Rights, which declared it admissible a year later.[2]

In its merits report, the commission found that Bolivia violated, to the detriment of I.V., articles 5(1) (right to humane treatment), 8(1) (right to a fair trial), 11(2) (right to privacy), 13 (freedom of thought and expression), 17 (rights of the family), and 25 (right to judicial protection) of the American Convention on Human Rights and article 7 (duty of the states to prevent, punish, and eradicate violence against women) of the Convention of Belém do Pará.[3] In 2015, the commission referred the case to the Inter-American Court of Human Rights after concluding that Bolivia had not complied with the commission's recommendations.

In its ruling on the case, the Inter-American Court stated that "the informed consent of the patient is a *sine qua non* condition for the medical intervention, which is based on respect for the patient's personal autonomy and freedom to choose her life plans without interference."[4] In other words, the court acknowledged that informed consent ensures the effectiveness of the rule that recognizes autonomy as an inalienable element of the dignity of the person.

Remarkably, the court made a reference to gendered power relations and their impact on dignity, suffering, and health.[5] This marks the first time in which the Inter-American Court has connected gender stereotypes to forced sterilization and has recognized the role that gendered power relations play in reinforcing gender stereotypes and social practices that position women as dependents and subordinates. Moreover, the court pointed to the impact that this type of power relationship can have on excluding, restricting, and nullifying the recognition, enjoyment, and full realization of women's sexual and reproductive rights. Thus, the ruling is important not only because of its focus on informed consent but because of its emphasis on women's sexual and reproductive rights under both the American Convention on Human Rights and the Convention of Belém do Pará—in fact, it may be seen as the second decision of the Inter-American Court of Human Rights on reproductive rights (the first one being *Artavia Murillo v. Costa Rica*).[6] The court emphasized that women's freedom to decide freely on their bodies and their reproductive health, especially in cases of sterilization, may be undermined by discrimination in access to health; by power relations with respect to a woman's husband, her family, her community, and relevant medical personnel; by additional vulnerability factors; and by gender stereotypes in health care services. As a result, the court noted that "factors such as race, disability, socioeconomic status, cannot be a basis for limiting the patient's free choice … or obviate obtaining her consent."[7]

What lies beneath

The concept of informed consent imposes on medical professionals the duty to refrain from exercising paternalistic control and instead provide women with the information necessary for them to decide which course of action to adopt. In other words, "no physician, in so far as he is a physician, [should] consider his own good in what he prescribes, but the good of his patient."[8] However, the physician-woman relationship is usually full of gender prejudices and stereotypes. That is, the relationship between a physician and a woman patient is per se an asymmetrical power relationship that has the potential to endanger women's reproductive autonomy and dignity.[9] Paternalism in health care was widespread for many years under the belief that physicians were in the best position to make appropriate decisions concerning the health of their patients.[10] According to Thérèse Murphy, even today, interactions between health professionals and their patients are often driven by "expert" professional discourses where the patient's voice may be lost.[11]

In the words of Rebecca Cook, "the role of health professionals is to give the individual decision-maker medical and other health-related information that contributes to the individual's power of choice and does not distort or unbalance that power."[12]

In this sense, the Inter-American Court's decision analyzed, for the first time in the court's history, women's freedom of autonomy in sexual and reproductive health under the lens of *social determinism*—the idea that people's actions are determined by factors such as their belonging to a

certain social class, by the way in which they participate in productive structures, by their educational background, and by the cultural traditions and social habits of their environments, among others.[13] The court recognized that throughout history, sexual and reproductive health has been limited or annulled based on negative and harmful gender stereotypes according to which women's primary role is the fulfilment of a reproductive function and men are seen as decision makers over women's bodies. The court determined that such stereotypes, coupled with gendered power relations, may end up leading "to a situation in which a decision is made to sterilize women and not men, based on the stereotype that women are the ones who hold the primary role of procreation and should be responsible for contraception."[14] Accordingly, the court concluded that the doctor's failure to request I.V.'s consent to the sterilization procedure was a reflection of this historically unequal relationship.[15]

Thereby, having stressed women's particular vulnerability to forced sterilization, the Inter-American Court found a violation of the right to non-discrimination. Indeed, the court noted how the process of informed decision making in this case operated under the negative and harmful stereotype that I.V., as a woman, was unable to make such decisions, leading to "an unjustified paternalistic medical intervention" restricting her autonomy and freedom.

The court's reasoning took the "social determinism" argument and linked it with personal autonomy and the idea of human dignity in order to find Bolivia responsible for creating—or at least maintaining—unequal power relationships and gender stereotypes. The court recognized that the obligation to eliminate all forms of discrimination against women carries the obligation to eliminate discrimination based on gender stereotypes that are socially dominant and persistent and that consciously or unconsciously constitute the basis of practices that reinforce women's position as dependents and subordinates.[16] The court based its reasoning on the Ethical Framework for Gynecologic and Obstetric Care from the International Federation of Gynecology and Obstetrics, which acknowledges that women tend to be vulnerable "because of social, cultural and economic circumstances."[17]

Human dignity has been defined in many different ways, but the central premise of these definitions is that human beings should not be treated as a mere means to an end. Dignity implies having agency. The decisions that may affect us must be made in a context were no one is dominating or controlling us. In order to be able to make our own decisions for ourselves, we must have the relevant information that allows us to make an informed choice. As Alicia Ely Yamin puts it, "dignity requires the conditions that enable one to govern one's self and exercise ethical as well as physical independence within a specific social context; it also requires us to respect the humanity in others."[18]

According to the International Federation of Gynecology and Obstetrics, within the doctor-patient relationship, "women's care has often been dominated by the paternalism of their advisors."[19] This paternalism is inconsistent with women's fundamental human rights and dignity, which require obtaining a woman's informed consent before any medical intervention.[20]

From a deontological approach, human beings are, in and of themselves, the end.[21] Under this perspective, the reason behind the protection of human dignity is the notion of personal autonomy, or the idea that people are capable of developing their own conception of the good life and that neither the state nor third parties may interfere with that choice (provided that it is not harmful to others). Instead, the state should design institutions that facilitate the pursuit of individual or collective plans. This point has often been made within the inter-American human rights system.[22] Furthermore, under this deontological view, personal autonomy is the companion to the principle of inviolability of the person: as a rule, a person and her personal plans may not be sacrificed in the name of others or of a collective entity. According to this deontological account, persons cannot be used as a mere means for the purpose of values that they do not share.[23] Thus, doctors cannot impose their views on how women should fulfill their sexuality and should not act on

women's bodies without their consent. These ideas are clearly reflected in the Inter-American Court's reasoning in *I.V. v. Bolivia*, for the court considered that informed consent ensures the effectiveness of the rule that recognizes autonomy as an inalienable element of the dignity of the person.[24] Accordingly, the court considered that health

> *not only covers access to health care services ... but also the freedom of each individual to control their health and their bodies and the right not to be subjected to interference ... In this way, the existence of a connection between physical and psychological integrity with personal autonomy and the freedom to make decisions about one's body and health requires, on the one hand, that the State ensure and respect decisions and choices freely and responsibly made and, on the other hand, that access to relevant information is guaranteed so that people are able to make informed decisions about the course of action regarding their body and health according to their own plan of existence.*[25]

In other words, to recognize human beings as such, we need to ensure that they enjoy the agency to make their own decisions. The state has a duty to ensure and respect the exercise of our autonomy—of our agency—when we make free and responsible decisions.

Another remarkable step in the court's reasoning was its decision to rely on the definition of violence against women enshrined in the Convention of Belém do Pará and to frame a violation of women's reproductive rights as a result of gender-based discrimination. The court concluded:

> *[T]he doctor should have foreseen that the intentional alteration of I.V.'s physical capacity of biological reproduction in total disregard for her autonomy and reproductive freedom was going to provoke an intense emotional suffering and, in spite of it, he did not modify his behavior under the belief that he was the one in the best position to make the decision that he considered most beneficial for I.V.*[26]

The court considered that an intrusion of such magnitude on the body and personal integrity of I.V. without her consent foreseeably caused significant suffering for the victim, since the doctor made himself what should have been a personal decision for I.V.

Conclusion: Significance of the *I.V. v. Bolivia* decision for Latin America

It is important to emphasize that, in its ruling, the Inter-American Court sought to stress the fact that I.V.'s suffering was not an isolated case. Rather, for the court, I.V. was but one example of widespread structural discrimination against and paternalistic treatment of women in Latin America. Although the court was deciding on the specific claim brought by I.V., it also sent a clear message to all states parties to the American Convention on Human Rights and the Convention of Belém do Pará. Under human rights law, states have the obligation to respect and guarantee human rights for everyone without discrimination. States such as Bolivia that fail to develop a gender-sensitive approach to health care are in violation of their international duties to respect, protect, and fulfill the human right to health. By recognizing that women have historically been subject to various forms of discrimination, the court made it clear that states have an obligation to remedy that discrimination and integrate a gender perspective in the design and implementation of laws and public policies affecting women. This is all the more important since states parties to the American Convention on Human Rights have also either ratified or acceded to the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). In that line, the CEDAW Committee has noted that states parties are obliged to take steps to prevent, prohibit, and punish violations of human rights guaranteed by CEDAW, regardless of whether such violations are committed by the state or by third parties (such as doctors).[27] In this light, doctors have a duty to refrain from exercising paternalistic control over women's bodies and must provide women patients with the necessary information for them to decide on the course of action to be taken.

By incorporating a gender perspective into its analysis and reasoning, the Inter-American Court was able to offer an overall picture of the structural

context in which violations to women's sexual and reproductive rights occur and provided fertile ground for further discussions on the ways in which discrimination and human rights intersect. In this way, it removed from women the burden of proof for a specific rights violation by placing the issue within a historical, cultural, and structural context.

Latin American countries that fail to ensure and protect the right to informed consent contravene their obligations under international and regional human rights law and violate women's right to health, dignity, and, ultimately, their autonomy. But legal change on its own will not achieve the desired end. National gynecologic and obstetric associations, together with civil society organizations, play an important role in raising awareness within the medical profession and society about women's human rights and ensuring both the implementation and oversight of states' actions. In this way, informed consent will not be just written law but a reality.

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Intersex Variations, Human Rights, and the International Classification of Diseases

MORGAN CARPENTER

Abstract

Over time, the World Health Organization (WHO) has reviewed and removed pathologizing classifications and codes associated with sexual and gender minorities from the International Classification of Diseases (ICD). However, classifications associated with intersex variations, congenital variations in sex characteristics or differences of sex development, remain pathologized. The ICD-11 introduces additional and pathologizing normative language to describe these as "disorders of sex development." Current materials in the ICD-11 Foundation also specify, or are associated with, unnecessary medical procedures that fail to meet human rights norms documented by the WHO itself and Treaty Monitoring Bodies. This includes codes that require genitoplasties and gonadectomies associated with gender assignment, where either masculinizing or feminizing surgery is specified depending upon technical and heteronormative expectations for surgical outcomes. Such interventions lack evidence. Human rights defenders and institutions regard these interventions as harmful practices and violations of rights to bodily integrity, non-discrimination, equality before the law, privacy, and freedom from torture, ill-treatment, and experimentation. WHO should modify ICD-11 codes by introducing neutral terminology and by ensuring that all relevant codes do not specify practices that violate human rights.

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Introduction

In 2015, the World Health Organization (WHO) published a paper on sexual health, human rights, and the law. This paper described sexual health as "a state of physical, emotional, mental and social well-being in relation to sexuality" where "achievement of the highest attainable standard of sexual health" is linked to enjoyment of the rights to non-discrimination, privacy, freedom from violence and coercion, and rights to education, information, and access to health services.[1] WHO described how harmonizing laws and regulations with human rights standards can "foster the promotion of sexual health" while laws that contradict human rights principles have a negative impact.[2] It concluded by advising that "States have obligations to bring their laws and regulations that affect sexual health into alignment with human rights laws and standards."[3] In this paper, I argue that these same principles apply to WHO's International Classification of Diseases (ICD) in relation to the impact of ICD codes on the health and well-being of people born with intersex variations. I conclude that WHO should bring ICD classifications and standards into line with existing WHO and UN human rights standards and agreements applicable to the situation of intersex people.

Background

In recent years, Topic Advisory Groups established and administered by WHO on genito-urinary reproductive medicine, and on other matters, have engaged in a re-evaluation of classifications and codes associated with sexual and reproductive health, including the sexual health of both sexual and gender minorities. The trend has been to depathologize codes associated with sexual minorities, reflecting both human rights norms, and the poor-quality evidence and social rationales that justified their existence.[4] Thus, though a code for egodystonic sexual orientation was retained in the ICD with endorsement of the ICD-10 in 1990, homosexuality, *per se*, was removed.

The ICD-11 was formally introduced on June 18, 2018, drawing a structure and a subset of material from an ICD-11 Foundation Component into a first release of the ICD-11 for Mortality and Morbidity Statistics (ICD-11-MMS).[5] The World Health Assembly is expected to approve the ICD-11 in May 2019, and further changes are likely to occur prior to this approval.

The ICD-11 has reconceptualized or deleted codes relating to sexual and gender minorities. Remaining diagnostic classifications related to sexual orientation have been deleted entirely. In relation to gender minorities, Chou and others stated in 2015:

> *The ICD-10 categories 'Transsexualism' and 'Gender Identity Disorder of Childhood' have been proposed to be re-conceptualized in ICD-11 as 'Gender Incongruence of Adolescence and Adulthood' and 'Gender Incongruence of Childhood', respectively.*[6]

Chou notes that broader changes have also been introduced, including a new chapter on sexual health.[7] The new chapter brings together a range of sexual health issues, including codes enabling the classification of female genital mutilation, unwanted pregnancy, sexually transmitted infections, and violence against women.

This reconceptualization of the ways in which concepts relating to the health of sexual and gender minorities are classified has not, however, extended to concepts relating to intersex persons, that is, persons with congenital variations in sex characteristics/differences of sex development. This population is sometimes aggregated with other sexual and gender minorities to comprise an "LGBTI" community, including in publications by WHO and other international institutions.[8] Rather than ending the unnecessary pathologization of all LGBTI populations, the ICD-11 layers pathologizing new language describing such variations as "disorders of sex development" (DSD) onto existing language such as "pseudo-hermaphrodite" that has often been critiqued as pejorative.[9] As I will later show, current ICD Foundation codes specify and are associated with unnecessary medical procedures that fail to meet human rights norms detailed by WHO and other UN organizations, and recommendations of UN Treaty Monitoring

Bodies, and are not underpinned by an appropriate evidence base.

Umbrella terms

Objections to the language of "disorders of sex development" began immediately after it was clinically adopted in 2006 and have continued to the present time.[10]

Populations described by the term "disorders of sex development" (DSD) find this language pejorative and inappropriate, a finding borne out consistently in research by clinical teams and peer support bodies. This language unnecessarily pathologizes often benign characteristics. Amongst persons seeking healthcare, whether due to innate or iatrogenic causes, a 2017 study found that DSD nomenclature may "negatively affect access to healthcare and research": "the use of DSD and related terms is causing distress and avoidance of medical care among some affected individuals and caregivers."[11]

The research team found these findings "consistent with previous studies that demonstrated negative perceptions of DSD nomenclature."[12] Among those, a CARES Foundation survey on issues relating to congenital adrenal hyperplasia in the US found that "more than half of those surveyed said they would not choose to receive care from centers or participate in research studies that use the term DSD."[13] US youth and advocacy organization interACT and Australian and New Zealand advocates have taken similar positions.[14]

Australian research based on a survey of 272 people born with atypical sex characteristics found that participants engaged in code-switching: 3% used the term "disorders of sex development" to describe themselves, while 21% used the term to access medical services.[15] This shows not only that such individuals feel it necessary to disorder themselves in order to access appropriate care, but also that clinicians may not be aware of or exposed to the terms that individuals prefer to use.

Human rights institutions have linked the terminology used to describe innate variations of sex characteristics with human rights violations. The Office of the High Commissioner for Human Rights, the Inter-American Commission on Human Rights, the Human Rights Commissioner of the Council of Europe and other human rights experts have recommended that medical codes that pathologize all variations of sex characteristics should be reviewed and modified, to "ensure that intersex persons can effectively enjoy the highest attainable standard of health and other human rights."[16] These echo recommendations to WHO from intersex human rights defenders.[17]

In a 2016 joint statement, multiple UN Treaty Monitoring Bodies, Special Rapporteurs, the Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe, Office of the Commissioner for Human Rights, and the Inter-American Commission on Human Rights called for the combatting of root causes of human rights "violations such as harmful stereotypes, stigma and pathologization," and so, "it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies."[18] Changing nomenclature from "disorders of sex development" to neutral terminology is necessary to achieve this goal.

An umbrella term is necessary. Variations of sex characteristics are known to be heterogeneous, with at least 40 different known variations; there is also wide agreement that a significant proportion of people born with variations of sex characteristics do not have a specific or clear diagnosis.[19] Aggregation facilitates the provision of services for people with otherwise disparate variations of sex characteristics.[20] Individuals have frequently also received multiple different diagnostic labels, not only due to change in nomenclature over time, but also due to diagnostic error and the availability of new genetic tests. Umbrella terms help to establish continuity.

An umbrella term can also help individuals without a clear genetic diagnosis find peers and persons with shared lived experience. In situations where individual variations of sex characteristics are statistically rare or uncommon, umbrella terms provide a vital connection with other individuals with related or common experience. By helping in-

dividuals to find common ground, umbrella terms also help facilitate collective action, for example, to tackle shame, stigma, and discrimination.

Indeed, in recent decades, it is the term "intersex," along with specific diagnostic codes, that have facilitated peer connection and collective action, in contrast with the term "disorders of sex development." The term "intersex" is increasingly popular, with intersex communities, advocacy groups, and peer support groups now developing across the globe, and this can be expected to continue. Such peer support, advocacy, and other community groups undertake critical work to support individuals, tackle stigma associated with being born with variations of sex characteristics, tackle misconceptions, combat human rights violations, and hold policy makers and practitioners to account. A proportion of these groups are identified in a 2016 clinical update noting that peer support "is a key component of the 2013–2020 WHO Mental Health Action Plan," and that routine inclusion of peer support is necessary in "clinical care at the earliest possible time."[21]

Nevertheless, using the term "intersex" in clinical settings repathologizes a term increasingly used in social, advocacy, and human rights settings. It has become an affirmative term, available irrespective of diagnostic code, gender identity, or legal sex; despite this, and like all stigmatized populations, language is contested, and misunderstandings and instrumentalization affect its acceptance.[22]

A term other than "intersex" may recognize contention regarding terminology, while also acknowledging that persons can acceptably use different terms in clinical and social settings. Well chosen, a change in clinical terminology can help narrow the distance between community and clinical organizations. In line with a community submission to WHO, I propose that umbrella nomenclature in the ICD-11 be modified from "disorders of sex development" to neutral terminology, such as "congenital variations of sex characteristics" or, failing that, "differences of sex development," a term already used by some intersex people and organizations, clinicians, and rights institutions.[23]

Specific ICD codes

Individual codes in the ICD-11-MMS and ICD-11 Foundation typically contain both a title and description. In some cases, additional information is provided. In relation to a range of codes relating to intersex variations, these details in the ICD 11 Foundation provide the preconditions for medically unnecessary and often irreversible interventions. Further, for some ICD codes, additional information attached to those codes explicitly specifies such interventions. Consequently, adoption of a neutral umbrella term alone is not sufficient; changes to specific codes are also necessary.

Forced and coercive medically unnecessary interventions on the bodies of intersex children may sometimes be described critically or euphemistically as "normalization" surgeries, but also as "corrections," treatment for "malformations," genital "enhancement," "genital reconstruction," "sex assignment" or "gender assignment," or "gender reassignment."[24] The procedures involved may include labiaplasties, vaginoplasties, clitoral "recession" and other forms of clitoral cutting or removal, gonadectomies, hypospadias "repairs," phalloplasties and other forms of penile augmentation surgeries, other forms of urogenital surgeries, and prenatal and postnatal hormone treatment.[25] Associated practices may include dilation, repeated genital examinations, post-surgical sensitivity testing, and medical photography.[26] Many of these procedures have been found to be direct violations of a right to bodily integrity and, when conducted without informed consent by the person concerned, may be regarded as torture or ill treatment.[27]

The World Health Organization paper on sexual health summarizes concerns regarding the sexual health and rights of intersex persons, distinguishing between "medically unnecessary, often irreversible, interventions" resulting from "so-called sex normalizing procedures" to ensure that children's bodies "conform to gendered physical norms" and procedures that "may sometimes be justified in cases of conditions that pose a health risk or are considered life-threatening," noting that some of these may be poorly justified.[28]

Multiple intersex variations may be associated with specific genital characteristics at birth. In each case, genital appearance may be atypical but benign, with that appearance having no consequences for physical health.[29] Nevertheless, descriptions for ICD-11 Foundation codes may promote or specify surgical intervention to modify those sex characteristics. Among these, the ICD-11 Foundation codes for congenital adrenal hyperplasia, 5-alpha-reductase 2 deficiency (5a-RD2), and 17-beta-hydroxysteroid dehydrogenase 3 deficiency (17ß-HSD3) are notable. Each of these variations are associated with specific genital characteristics at birth, and each ICD-11 classification contains supporting descriptions that promote or explicitly require surgical interventions.

The ICD-11-MMS code for congenital adrenal hyperplasia notes that: "Genital anomalies may be noted at birth in affected females," while ICD-11 Foundation code information remarks that genital surgery may be required without specifying why or under what conditions, stating: "Genital anomalies in females may require surgical intervention(s)."[30]

The ICD-11 Foundation code information for 5a-RD2 deficiency remarks that surgery is necessary, with the type of surgeries dependent on sex assignment and the likely outcomes of masculinizing surgery:

> *Gender assignment is still debated and must be carefully discussed for each patient, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy should be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized.*[31]

The ICD-11 Foundation code information for 17ß-HSD3 makes similar assertions:

> *If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized.* [32]

The statements in codes for both 5a-RD2 and 17ß-HSD3 favoring genitoplasties share a heritage evident in a 1993 paper on clinical practices by Hendricks that shared the idea that: "You can make a hole but you can't build a pole."[33] This rationale is based upon the technical possibilities of surgery, but it also reflects heteronormative norms about physical function: the idea that someone cannot be a man if they cannot penetrate a woman, and that someone cannot be a woman without being penetrated by a man. The same attitudes are also evident in narrow expectations for male and female bodies expressed in the idea that "real men" have to be able to stand to urinate.[34]

Human rights defenders question those attitudes as surgical intervention is dictated by social and cultural factors. Indeed, no potential quality of life issues are indicated in the ICD-11 information, other than those that might be derived from an associated minority status and, in the case of 17ß-HSD3, infertility. In the cases of both 5a-RD2 and 17ß-HSD3, genetic deselection is described as an option. This suggests the possibility of a pre-emptive elimination of bodies with intersex variations in place of surgical intervention, but neither surgery nor prenatal deselection are adequately justified.

A series of clinical papers has outlined risks of gonadal tumors as rationales for monitoring gonads in children with 5a-RD2 and 17ß-HSD3. For example, a 2006 clinical statement calls for the monitoring of gonads in children with 17ß-HSD3 due to a "medium" risk of gonadal tumors.[35] A later clinical review reduced the associated risk level.[36] However, the mention of gonadectomies in ICD-11 clinical descriptions for both 17ß-HSD3 and 5a-RD2 is dependent not on tumor risk but instead on gender assignment. This gendering of gonadectomies contradicts assertions made about tumor risk management and highlights the role of gender stereotypes in determining clinical practices. This gendering of gonadectomies also constrains children's future possibilities and choices, including those associated with gender identification, and for hormone production, and access to novel reproduc-

tive technologies.

A 2016 Australian legal case provides a specific example to illustrate the rationales and gender stereotyping that underpin the content of these ICD-11 codes. The case was taken before the Family Court of Australia to approve the gonadectomy of a 5-year-old child with 17ß-HSD3, described as having a "sexual development disorder" (that is, a "disorder of sex development"). The case documented the judge's view that a prior clitoral "recession" (a form of clitorectomy) and labioplasty had "enhanced the appearance of her female genitalia."[37] The judgment also disregarded evidence recommending monitoring of gonads, and made no reference to new evidence on reduced risks.

The rationale for the child's gonadectomy was substantively comprised of gender stereotypes, observed by a treating doctor in her multidisciplinary team and recounted by the judge:

> a. *Her parents were able to describe a clear, consistent development of a female gender identity;*
> b. *Her parents supplied photos and other evidence that demonstrated that Carla [a pseudonym] identifies as a female;*
> c. *She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and 'fairy stations';*
> d. *She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and*
> e. *Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys.*[38]

This evidence describes parental descriptions, and culturally specific, socially constructed ideas of femininity associated with a child too young to freely articulate a gender identity, for an irreversible medical intervention. Given that the surgeries in this case were each predicated on the initial gender assignment, the timing of the gonadectomy was deliberate: "it will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure."[39] Yet, at the same time, the heteronormative nature of the gender stereotypes involved in clinical and judicial decision-making led the judge to comment: "Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse."[40]

The evidence in support of these medical interventions is lacking. A 2006 clinical statement cited clinician feelings, and a "belief" that early surgery "relieves parental distress and improves attachment between parents and child."[41] In the decade since, the quality of available evidence has not improved. A 2016 clinical review found that there is no consensus on surgery timing, indications, procedures, or outcome evaluation, and no evidence on the impact of intervention or non-intervention during childhood for the affected person, their family, or society.[42] A 2017 Council of Europe bioethics committee report summarized key research to state that:

> *(1) "quality of life" studies on patients into adulthood are lacking and are "poorly researched", (2) the overall impact on the sexual function on children surgically altered is "impaired" and (3) the claim that gender development requires surgery is a "belief" unsubstantiated by data.*[43]

The same paper makes a point, directly relevant to the Family Court case *Re: Carla*, that there is no guarantee that "infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance" or function.[44]

Clinicians have argued that the practices documented in Carla's case and described in the ICD-11 no longer take place routinely, but such claims lack evidence, and so lack merit.[45] Governments have similarly attributed change to clinical practices. For example, the state where Carla lived had previously, in 2012, offered a reassurance that:

> *Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention … Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health.*[46]

Similarly, a local clinical organization has suggested "a trend toward consideration of less genital and gonadal surgery" without providing supporting evidence.[47] The recent nature of the medical history detailed in Carla's case does not support such assurances, and nor does the ICD-11 Foundation code for 17ß-HSD3.

Human rights standards

In recent years, UN Treaty Monitoring Bodies have responded to testimonies by survivors of such practices provided by institutions and individuals in countries around the world. They have cited Treaty Articles on non-discrimination and protection from torture and experimentation, and on liberty and security, privacy, and equality before the law, issuing multiple recommendations in relation to such interventions.[48] These include the observations listed below.

- States must guarantee bodily integrity, autonomy, and self-determination to intersex children, and ensure that no one is subjected to unnecessary medical treatment during infancy or childhood.[49]
- States must protect intersex persons from violence, and harmful practices such as intersex genital mutilation.[50]
- States must adopt legislation to prohibit the performance of surgical or other medical treatment on intersex children unless such procedures constitute an absolute medical necessity, and until they reach an age at which they can provide their free, prior and informed consent.[51]
- States must repeal all types of legislation, regulations, and practices allowing any form of forced intervention or surgery, and ensure that the right to free, prior, and informed consent to treatment is upheld and that supported decision-making mechanisms and strengthened safeguards are provided.[52]
- States must ensure that no one is subjected to undocumented medical or surgical treatment during infancy or childhood.[53]
- States must ensure that intersex people's personal integrity and sexual and reproductive health rights are respected.[54]

These examples indicate a growing consensus by international human rights institutions in opposition to unnecessary irreversible surgeries on infants and children with intersex variations. At present, the ICD-11 Foundation code materials specify or otherwise facilitate such practices.

Reframing intersex-related codes and classifications

Given demands to review diagnostic terminology to avoid unnecessary medicalization, terminology in diagnostic codes should be changed to ensure that it does not predicate surgical interventions. At the same time, individuals able to provide consent need to able to access medical interventions. A more neutral language is needed in order to balance these needs. For example, the ICD-11 classification of "malformative disorders of sex development" could be replaced with "structural congenital variations of sex characteristics" or "structural differences of sex development." Descriptions facilitating medical interventions based on gender stereotypes or social norms should be deleted, including requirements, specifications, or suggestions for surgical intervention or genetic deselection.

Individuals subjected to unwanted medical interventions to modify their genitals may suffer consequences including impaired sexual function and sensation, incontinence, scarring, a need for further surgery, and lifelong hormone treatment.[55] For such persons, the introduction of a new ICD-11 code for "intersex genital mutilation" analogous to

an existing code on female genital mutilation may, like the code on female genital mutilation, facilitate access to consequential and reparative treatments.

Conclusion

Over time, WHO has consistently reviewed and removed pathologizing classifications and codes associated with sexual and gender minorities from the International Classification of Diseases (ICD). However, classifications associated with intersex variations, or differences of sex development, remain pathologized. As a result, the ICD-11 facilitates, and specifies, procedures that are regarded by UN and other institutions as violating human rights. Intersex advocates have made multiple collaborative submissions to WHO on these issues.[56]

WHO should reconsider the introduction of unnecessarily pathologizing language of "disorders of sex development" into the ICD. It should instead adopt alternative language such as "congenital variations of sex characteristics" or, failing that, "differences of sex development."

Codes and clinical information relating to all individual variations in sex characteristics should be reviewed to ensure that they do not specify or facilitate interventions that fail to meet human rights norms and that lack adequate supporting evidence. Terminology predicating unnecessary medical interventions without the consent of the recipient should be replaced.

To assist persons subjected to irreversible medical interventions, the addition of a new code for "intersex genital mutilation" may facilitate access to reparative treatments.

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Transsexuals' Right to Health? A Cuban Case Study

EMILY J. KIRK AND ROBERT HUISH

Abstract

In 2008, Cuba's minister of public health signed Resolution 126, an act that assured complete coverage for Cubans seeking sexual reassignment surgeries (also known as gender confirmation surgeries), the first of any country in Latin America to do so. Ten years later, Cuba is celebrated as having one of the most open and inclusive LGBTQ public health and education programs in the Americas. As illustrated throughout this article, the Cuban state approaches sexuality and sexual identity not as rights-based issues but rather as health-based challenges. Through the case study of Cuba's understanding of transsexuals' right to health, we argue that Cuba has provided an example of how the right to health for all moves toward breaking down the barriers of stigma by improving health outcomes for those with transsexual health needs.

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Introduction

In 2008, Cuba's minister of public health, José Ramón Balaguer Cabrera, signed Resolution 126, an act that assured complete coverage for Cubans seeking sexual reassignment surgery, also known as gender confirmation surgery. Ten years later, Cuba is celebrated as having one of the most open and inclusive LGBTQ—known in Cuba as sexual diversity—public health and education programs in the Americas. This is important for two reasons. First, the resolution guaranteed publicly funded sexual reassignment surgery and complete medical care to all trans Cuban citizens under the National Public Health System, the first of any country in Latin America to do so. Second, Cuba has a history of anti-gay policies that systematically discriminated against and criminalized sexual diversity. Why would a country with a proven track record of discrimination become a leader in the Americas for gender and sexual diversity rights? This is because, as we argue here, the Cuban state does not view gender and sexuality as rights-based issues. It approaches them as health-based challenges. For what some may see as a small distinction in terminology, Cuba's "health-based approach" to sexuality and sexual diversity more broadly is in fact noteworthy in terms of both the approach and the outcomes. Cuba's public insurance for sexual reassignment surgery is the result of a broader social commitment to health as an intrinsic right and health care as an integral aspect of this right. Such a commitment to a rights-based approach to health is, as we argue, powerful enough to overrule historically entrenched discrimination within society.

It is worth noting that, as a result of Cuba's complex history regarding sexual diversity rights, some insightful studies have sought to illuminate the island's discriminatory past and the significant changes that have followed, particularly in post-1959 Cuba. Most notably, these include the works of Emilio Bejel, which explores the incorporation of sexual diversity into Cuba's national identity, and the work of Noelle M. Stout, which analyzes "queer intimacy" in post-Soviet Cuba. Similarly, Marvin Leiner's work explores sexual politics, focusing primarily on homosexual men, while Lois M. Smith and Alfred Padula's study assesses the role of women in the evolution of sexuality and sexual diversity in revolutionary Cuba. However the topic of transsexuals is vastly under-researched. This article thus offers an assessment of transsexuals in Cuba, focusing specifically on their right to health.

The health-based approach

Globally, while impressive gains have been won by sexual diversity activists striving for equal recognition of identity and same-sex civil unions under the law, struggles to achieve equity are ongoing. Rights-based activism, which is the pursuit of civil equity under the law through both official and unofficial channels, tends to be a work in progress. Movements often achieve a set of rights through political compromise, tireless activism, and changing political demeanors on certain issues. As a result, it can take generations for equity to emerge within society, leaving the marginalized without access to the rights that future generations may one day enjoy. Even civil rights activists in the United States faced this challenge in winning small, incremental victories rather than broad, sweeping changes. First Nations communities in Canada continue to struggle for equity after generations of activism, advocacy, and civil disobedience.

But what if a country lacks civil society mechanisms for such protest and challenges to authority? In most cases, authoritarian governments are quick to quell dissent, persecute disruptors, and reinforce their own authority. Some observers view Cuba as a place where the government uses a heavy hand in the lives of individuals, often quashing civil disobedience. Others focus on how, despite allowing for political civil liberties, the Cuban government has had a longstanding history of collaborating directly with communities to identify needs and challenges, engaging in both a top-down and bottom-up approach. This invites some reflection on epistemic and political freedoms. Susan Babbitt notes that the nature of ideas—for example, the idea of including "others" within a rights discourse—requires more than reason; it requires moral and social action. She argues that beliefs about people who hold a

normative place within society, and those who are viewed as outsiders, can be "deep-seated and insensitive to evidence." Furthermore, ideas for societal change and deeper inclusion can come from within rather than being imposed. In this sense, Cuba has a unique history of epistemic freedoms stretching back to the 19th century and even reflected in the 1895 independence declaration titled the Manifesto of Montecristi, which prioritizes "the nature of ideas." In this sense, the pursuit of rights can be understood as a process of engagement rather than a gift from government.

We raise this point as Cuba's sexual diversity community demanded equity and acceptance from the Cuban government through the epistemic freedom of social activism as well as political engagement through the National Center for Sexual Education (known by its Spanish acronym, CENESEX). In response, policy changes within the National Assembly, several government ministries, and popular organizations have been ongoing—each focusing on health as the main determining factor.

Resolution 126 notes that, in accordance with the National Assembly's Law No. 41 of 1983, titled "Of Public Health," which states that the Ministry of Public Health "guarantees the right of the population to have their health protected," comprehensive health care in Cuba should extend to transsexual persons. How did trans identity come to be approached as a health issue rather than one of equity? Cuba's socialist government prides itself on its ability to ensure social equity for all Cubans, so why not approach the needs of sexually diverse persons as an extension of such equity?

The significance of this resolution is noteworthy, as the minister himself was known as a staunch and dogmatic revolutionary, and throughout the earlier decades of the Revolution was a vociferous opponent of sexual diversity rights. In effect, a man who had earlier opposed all forms of sexual diversity signed a resolution providing comprehensive medical care for transsexuals. Indeed, particularly in the 1960s, the revolutionary narrative emphasized the creation of a "new man," a common discourse in many socialist countries in the 20th century. The "new man" was characterized by strength, integrity, and morality, and strongly rejected any form of sexual diversity. Homosexuality was thus seen as misguided and criminal and was understood as something that could be corrected through deeper, albeit forced, commitments to revolutionary practices of work, duty, and service. How did the Cuban government change from openly targeting sexually diverse persons to supporting complete medical coverage for sexual reassignment surgery?

The right to health

The use of human rights language in Cuba is touchy at best. Government ministries shy away from the use of "human rights," and occasionally the Cuban Communist Party outright scorns the terminology, citing US imperialism as the real crime against humanity. That said, Cuba comfortably embraces the concept of the right to health for all, a policy adopted from the 1978 International Conference on Primary Health Care. In Cuba, health is perceived as an intrinsic right, meaning that it is inherently tied to the essence of one's being. From there, health care is an integral right of all Cubans, meaning that the state has a direct role in ensuring that individuals' intrinsic right to health is maintained and protected. For health care to be an integral right, society must guarantee that all citizens receive care in a way that is inclusive and that leads to the achievement of the intrinsic right.

While most countries might hesitate to describe health as an intrinsic right and prefer to characterize health care as more of an instrumental service, Cuba's Constitution is explicit in stating that health care is provided for the benefit of both individuals and the broader population. However, up until 2008, sexual reassignment surgery was not explicitly included in the National Public Health System. Beyond the harm caused to Cubans seeking this therapy and care, a broader epistemological fracture emerges: if Cuba systematically denies a health procedure on the grounds of sexuality, then the health care system is no longer fully integral. It then becomes instrumental, which could open the door for other denials of coverage for services that are viewed as unrelated to health and are seen

merely as lifestyle choices. This becomes a challenge in Cuba, where the very concept of health is viewed broadly, and upstream determinants are taken seriously. To deny sexual reassignment surgery while expanding coverage for other forms of health care presents an uneasy moral dichotomy.

Cuba's ultimate decision to include sexual reassignment surgery under an integral right approach extends from a deep tradition of best practices in public health and health provision. In many areas of Cuba's health care system, from prenatal care to vaccination, Cuba follows international standards of care and service provision. This is to say that many of the foundations of Cuba's health care system, from the establishment of community-level polyclinics to the incorporation of universal health care, are designed based on international standards and protocols of best practices. For sexual reassignment surgery and other sexual health protocols in Cuba, many of the designs and recommendations are adapted from broader literatures. In sum, the value of such surgery in Cuba is less about a truly revolutionary breakthrough and more about a professional recognition of best practices in maintaining an integral health care system.

From camps to communities

Under Fidel Castro's leadership, homosexuality in particular was viewed as anathema to revolutionary values. Re-education programs—including internment at work camps with the aim of teaching effeminate males to be more "masculine"—were commonplace. For example, between 1965 and 1968, the Military Units to Aid Production camps housed thousands of perceived homosexual men, among other groups, in an effort to re-educate them to follow revolutionary norms. Programs also existed for effeminate boys, who were sent to specialized boarding schools that sought to teach them to be more manly by encouraging them to play with guns, play sports, and spend more time with men. Sexual education, too, focused on the importance of heteronormativity. In 1969, for example, the deputy minister of education, Abel Prieto Morales, wrote an article in the popular *Bohemia* magazine that explained in detail why sexual diversity was unacceptable and must be considered an illness. This view is not surprising, as it was orthodoxy in Western medicine at the time; nonetheless, it is illustrative of Cuba's notably discriminatory history. From the onset, the government looked at sexual diversity through a medicalized lens.

A major shift from medicalizing sexual diversity toward a health-based approach came in 1972 with the establishment of the National Group for Work on Sexual Education (know by its Spanish acronym, GNTES). Directed by Vilma Espín, a guerrilla fighter during the Cuban rebellion (1953–1958), political leader in post-1959 Cuba, and wife of former president Raúl Castro, GNTES would become a driving force behind transsexuals' health rights. The other key GNTES figure was Celestino Álvarez Lajonchere, a respected obstetrician and gynecologist in Cuba. The group's main objective was to research sexual education and to develop a national program in order to improve health care indicators associated with reproductive health and sexuality. Amid this dark period of conformity, GNTES gradually began broadening its research interests to include sexually diverse groups. It conducted research on other countries' sexual education programs and published several widely read popular-science books, which included information on sexual diversity. In addition, it carried out research projects aimed at gaining a better understanding of how to improve Cuba's national sexual education program, as well as how to include themes of sexual diversity in the education system.

Of particular importance, in 1979, under the auspices of the Ministry of Public Health (MINSAP), GNTES established the Multidisciplinary Commission for Attention to Transsexuals. The commission's aim was to provide the necessary care for transsexual citizens, including medical and social services. As described by Mariela Castro Espín, this commission comprised "specialists in the care of transsexual persons, and … adopted internationally approved diagnostic and therapeutic procedures, which were incorporated as services offered free of charge by the [National Public Health System], along with courses to train sex therapists."

In this way, MINSAP transitioned from viewing sexual diversity as a medical issue that required cure through socialist doctrine to seeing it as an identity that presented unique health and public health needs.

While the commission's work initially focused on health-related support (such as therapy and the provision of hormones), as research on the needs of the transsexual community increased, it evolved to incorporate additional services; this occurred around the same time that other areas of the health system were adopting international best practices. In addition, the commission considered social assistance to be an integral component of health care for transsexual individuals and the trans community more broadly. Such assistance consisted mainly of counseling services involving patients, family members, and friends; recommendations on procedures to change names on official documents; and support groups where participants could feel comfortable asking questions that ranged from clothes to relationships.

The first sexual reassignment surgery in Cuba occurred in 1988. Although the operation (male to female) was considered successful and was reported in the national press, it was not celebrated by the general population. Indeed, the news was "met with widespread rejection as a result of enduring transphobia." There was considerable discrimination against Cuba's trans community at the time, as many felt that costly and advanced medical resources were being wasted on individuals' "lifestyle choices." In addition, it is also worth noting that as a result of the HIV/AIDS crisis of the late 1980s and early 1990s, discrimination against sexual diversity resurged, as it was believed that these groups were largely responsible for infecting others.

Despite the success of the initial operation, sexual reassignment surgeries were suspended for almost 20 years. Although some observers have argued that this decision was grounded in transphobia, there is little evidence to suggest so. In the 1990s, amid the catastrophic economic crisis of the Special Period (beginning officially in 1990 with a proclamation by then president Fidel Castro, the Special Period refers to the economic crisis following the significant deterioration of Soviet Union-Cuba trade relations in the late 1980s and the implosion of the Soviet Union in 1991), the lack of medical knowledge and equipment were the primary reasons for discontinuing the procedures. In addition to involving the first sexual reassignment surgery, 1988 was also an important year, as it was when MINSAP determined that the efforts of GNTES in sexual education needed to be increased. The following year, the small research group was reestablished as the National Center for Sexual Education, an official center of MINSAP.

The establishment of this national center led to two major shifts. First, Mariela Castro Espín—daughter of Vilma Espín and Raúl Castro—joined the center in the early 1990s and became its director in the early 2000s. She took an interest in improving health outcomes for the trans community, which became central to the center's aims. Second, the center determined in 2004 that the Multidisciplinary Commission for Attention to Transsexuals required a broader mandate, which resulted in the creation of the National Commission for the Comprehensive Care of Transsexuals.

Building on some 20 years of research on transgender health and on technological advancements in sexual reassignment surgery, the new commission specifically sought to assist Cuba's trans community in improving overall health and achieving the "highest level of dignity." Each of the commission's central goals focused on the provision of health care. For example, one goal was to provide the necessary specialized medical care for the health of all trans Cubans. Another goal sought to design a protocol for diagnosis and comprehensive treatment that complied with international standards and the standards of Cuba's National Public Health System. Other areas of focus included increased multidisciplinary research on transsexuality, the development of educational programs to increase respect for sexual diversity, and the implementation of training and awareness-building programs regarding trans persons. Significantly, the national commission was supported by the Cuban Communist Party and the National Assembly.

Resolution 126 and sexual reassignment surgery

On June 4, 2008, MINSAP issued Resolution 126. Consisting of 11 articles aimed at resolving the ongoing health issues faced by Cuba's trans community, the resolution cites preexisting legislation that protects the right to health of all Cuban citizens. It notes that "the National Commission for the Comprehensive Care of Transsexuals will be the primary institution within the National Public Health System authorized to provide medical treatments, including reassignment surgery." It goes on to state that this commission will work "within the pre-existing structures and operations established within the General Hospital Regulations." Specifically, article 5 explains that it is the responsibility of the national commission to provide comprehensive health care to "all transsexual citizens." This includes diagnosis, psychological and psychiatric care, the provision of necessary medications, therapy, and reassignment surgery. It is also worth noting that one of the articles contains a glossary that defines various terms associated with health care for transsexual and transgender persons.

With regard to the numbers of those treated, by the end of 2008, the National Commission for the Comprehensive Care of Transsexuals had reportedly received 92 applications for assistance and care. As described by the commission, of those applications, 27 corresponded to transsexual individuals; 2 corresponded to "transvestites"; 2 corresponded to effeminate homosexual men; 8 corresponded to individuals who had left Cuba (4 of whom had previously received diagnoses, while the others had left before one could be made); and 57 corresponded to individuals in the process of diagnosis. Of those individuals who were diagnosed, 24 were officially in the "process of changing" (living as the gender with which they identified) from a man to a woman; 2 were in the official process of changing from a woman to a man; and 1 had completed male-to-female sexual reassignment surgery. By 2011, the commission had received 120 applications for treatment, and over a dozen successful sexual reassignment surgeries had been performed.

In addition to MINSAP, other important ministries have been involved in improving the health and well-being of the trans community, including the Ministry of Justice and the Ministry of the Interior. For example, the Ministry of Justice played a particularly important role in changing legislation concerning identity cards and official photos. For example, article 31 of the Law on the Registry of Civil Status (passed in 1985) required a person's gender on official documents to reflect their sexual organs. As a result of the efforts of the National Center for Sexual Education and the Ministry of Justice, this provision was amended to allow changes to personal information, such as gender markers on national identification cards. Other means of support for trans Cubans have also continued to deepen. Of particular note, in 2013 the National Center for Sexual Education founded the Transgender Network (also known as Trans Cuba), a network of trans persons and supporters. The primary aims of the Transgender Network are health promotion, support, and consciousness raising. The network includes some 700 participants who work mainly in five of Cuba's fifteen provinces. In addition, since 2014 the National Program for Sexual Education and Sexual Health has been taught in all schools and includes information on Cuba's trans community in an effort to normalize sexual diversity. In effect, the health-based approach embraced by MINSAP in the early 1980s and reinvigorated in the 2000s is having a carry-over effect to normalizing trans health in other areas of Cuban society, from justice to education.

Conclusion

In 1993, a transsexual man known as JR sent a letter to the minister of public health, who at the time was Julio Teja Pérez. In it, he wrote of his struggles, explaining:

> *You cannot know what I suffer day after day because of my situation. I am now 44 years old. I often think that if I were to have a heart attack and they were to take me to the hospital and discover what sex I am, they would make fun of me and talk about me. I am Cuban and my need for an operation is not some passing whim, but rather is based on human*

need. Only by having this operation will I be able to be a true person.

It would be another 15 years before MINSAP would issue Resolution 126 providing for sexual reassignment surgery and related medical care. Acknowledging the discrimination in Cuba during the 1990s, the official line is that the 20-year hiatus on such surgery was the result of a lack of resources and technology. Nonetheless, what is clear is that the health-based approach to trans health of the early 1980s received a second wind thanks to the National Center for Sexual Education in normalizing the needs of the trans community as health-related needs. Cuba is well equipped to respond to the dynamic health needs of individuals, and by placing trans health in this context, it created the opportunity to significantly advance trans health rights. The Cuban case provides a telling story of a unique road toward trans health rights.

The question remains as to how imitable the Cuban experience is. Can other health systems in the Americas benefit from approaching transsexuality as a health issue? Are the outcomes in terms of quality of life and acceptance truly better in Cuba than in other nations of similar socioeconomic stature? Is there potential to approach other social challenges, ones often grounded in rights-based advocacy, through a health-based approach? With regard to these questions, Cuba has provided an example of how the right to health for all moves toward breaking down the barriers of stigma.

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Eradicating Female Genital Mutilation/Cutting: Human Rights-Based Approaches of Legislation, Education, and Community Empowerment

BETH D. WILLIAMS-BREAULT

Abstract

Female genital mutilation/cutting is a form of violence against women and girls. It includes all procedures that involve the partial or total removal of external genitalia or other injury to the female genital organs for non-medical reasons. It is estimated that over 200 million girls and women worldwide have suffered the effects of this practice and that approximately 3.6 million girls and women are at risk each year. Female genital mutilation/cutting violates several human rights outlined under the Universal Declaration of Human Rights, the Convention on the Elimination of all Forms of Discrimination against Women, and the Convention on the Rights of the Child. Human rights-based approaches to eradication include, but are not limited to, the enforcement of laws, education programs focused on empowerment, and campaigns to recruit change agents from within communities.

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Introduction

Violence against women and girls affects females throughout the world and crosses cultural and economic boundaries. Throughout the past 20 years, extensive research has been done on such violence and its underlying causes and risk factors.[1] Interventions in health care, justice systems, and the social sphere have grown rapidly to address violence against women and girls worldwide. These interventions include large-scale campaigns, education programs, skills building and economic empowerment programming, community mobilization, and participatory group education efforts. Such interventions aim to change attitudes and norms that support violence against women and girls, thereby empowering women and girls economically and socially, as well as promoting nonviolent, gender-equitable behaviors.[2]

The United Nations (UN) and the European Union have recently started a global multiyear initiative focused on eliminating all forms of violence against women and girls. This effort, titled "The Spotlight Initiative," brings attention to violence against women and girls in order to achieve gender equality and women's empowerment and is in line with the 2030 Agenda for Sustainable Development.[3] It also highlights the importance of targeted investments in women and girls to achieve sustainable development, making this renewed commitment of the UN and the European Union visible worldwide. While the initiative addresses all forms of violence against women and girls, it focuses in particular on domestic and family violence, sexual and gender-based violence and harmful practices, femicide, trafficking in human beings, and sexual and economic exploitation.

One major indicator of gender inequality is female genital mutilation/cutting (FGM/C). FGM/C is linked to child marriage, forced sexual debut, and health complications across the life course.[4] In order to eliminate the practice, addressing the empowerment of girls and women is key. This can have a positive impact on gender relations, sexual and reproductive health choices, and health-related behavior in general, thus accelerating progress in abandonment of the practice.[5] The UN, United Nations Children's Fund, World Health Organization (WHO), and other anti-FGM/C organizations have adopted various strategies in order to raise awareness of and work toward ending FGM/C.[6]

Definition of female genital mutilation/cutting

FGM/C includes all procedures that involve the partial or total removal of external genitalia or other injury to the female genital organs for non-medical reasons.[7]

Different types of FGM/C

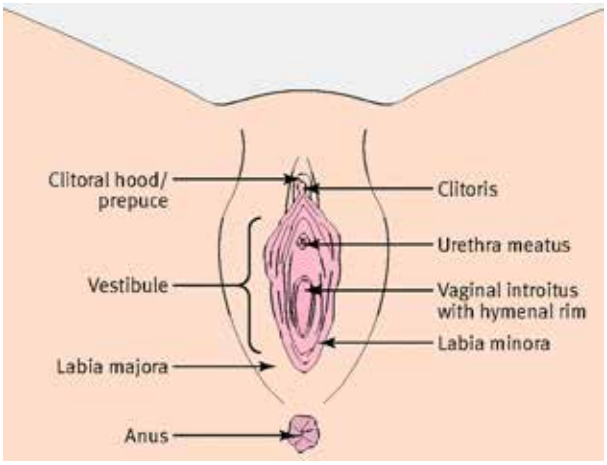
WHO classifies FGM/C into four types:

- Type I: partial or total removal of the clitoris (clitoridectomy) or prepuce
- Type II: partial or total removal of the clitoris and labia minora, with or without excision of the labia majora (excision)
- Type III: narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora or labia majora, with or without excision of the clitoris (infibulation)
- Re-infibulation: a procedure to narrow the vaginal opening after a woman has been deinfibulated (for example, after childbirth), also known as re-suturing
- Type IV: all other harmful procedures done to the female genitalia for non-medical purposes (for example pricking, pulling, piercing, incising, scraping, and cauterization)[8]

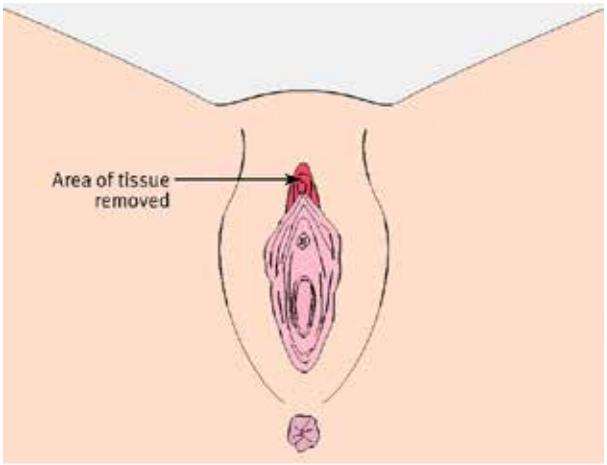
Prevalence

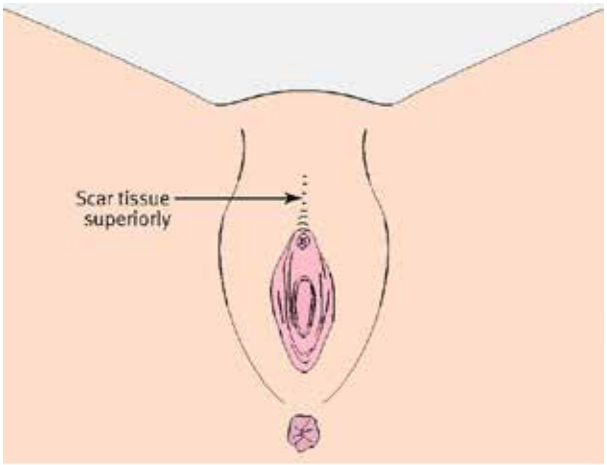
FGM/C is prevalent in 30 countries in Africa and several countries in Asia and the Middle East.[9] The practice has also been reported among certain ethnic groups in Central and South America.[10] The rise in international migration has increased the number of girls and women in Europe, the United States, Australia, and Canada who have undergone

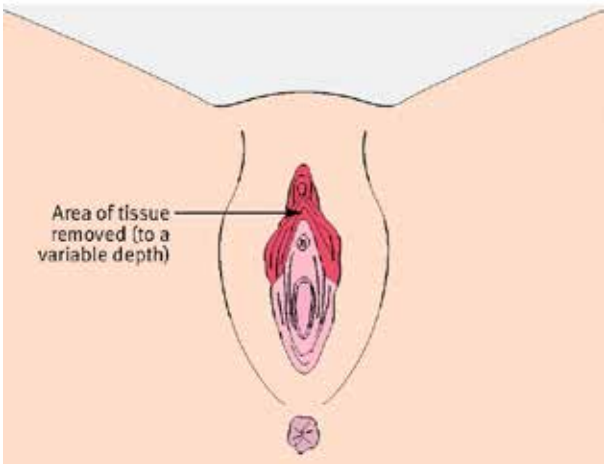
FIGURE 1. Types of female genital mutilation/cutting

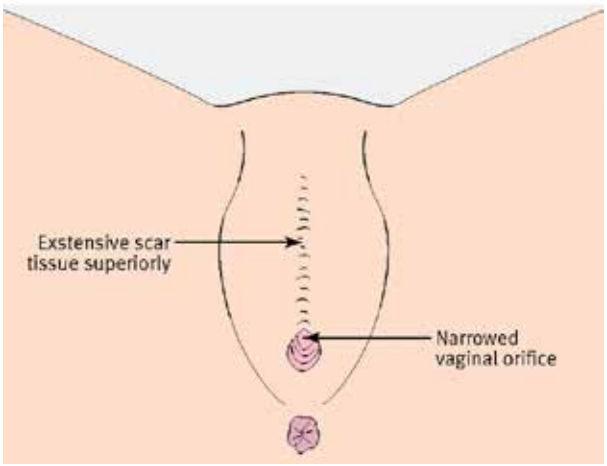


Unaltered female genitalia









Tissue removed in type 1 FGM/C (top) and type 2 FGM/C (bottom)

Appearance of type 2 FGM/C (top) and type 3 FGM/C (bottom)

Source: J. Simpson, K. Robinson, S. Creighton, and D. Hodes, "Female genital mutilation: The role of health professionals in prevention, assessment, and management," BMJ 344/e1361 (2012).

or may undergo the practice.[11] The greatest prevalence of FGM/C among women and girls aged 15–49 is reported in Somalia (98%), Guinea (97%), and Djibouti (93%).[12] The greatest prevalence of FGM/C among girls under 14 years is reported in Gambia (56%), Mauritania (54%), and Indonesia (~50%).[13] Despite overall declines in rates of FGM/C, high rates of population growth in practicing countries means that the number of affected women and girls will likely increase by 2030.[14] It is estimated that more than 200 million girls and women worldwide are living with the effects of FGM/C and that every year approximately 3.6 million girls and women are at risk of FGM/C.[15]

Health complications for girls and women

FGM/C is performed mainly on children and adolescents and has a ritual origin. The procedure is painful and traumatic, and there are no health benefits. It violates a series of human rights principles, including the principles of equality and non-discrimination on the basis of sex, the right to life (when the procedure results in death), the right to freedom from torture and cruel, inhuman, or degrading treatment or punishment, and the rights of the child.[16]

All forms of FGM/C carry the risk of adverse health consequences. Almost all girls and women who have undergone the procedure experience pain and bleeding.[17] Immediate health complications include shock, hemorrhage, and infection. FGM/C can also cause death, disability, miscarriage, stillbirth, problems during urination, infertility, ovarian cysts, open sores in the genital region, bacterial infections (tetanus or sepsis) during and after pregnancy, and increased risk of newborn deaths.[18] The intervention itself is traumatic, as girls are usually physically held down during the procedure.[19] Those who are infibulated often have their legs bound together for several days or weeks. The immediate consequences, such as infections, are usually documented only when girls and women seek hospital treatment.[20]

The long-term health risks of FGM/C include chronic pain, infection, keloids, fibrosis, primary infertility, and psychological suffering, such as post-traumatic stress disorder.[21] FGM/C is often performed under unsterile conditions by a traditional female practitioner who has little knowledge of female anatomy or how to manage possible adverse events.[22] Of all types of FGM/C, type III appears to pose the greatest risk of immediate harm, and these events tend to be considerably underreported.[23]

A 2006 WHO study in which more than 28,000 women participated concluded that women living with FGM/C are significantly more likely than those not living with FGM/C to experience adverse obstetric outcomes and that this risk seems to be greater with more extreme forms of the procedure.[24] Given that some types of FGM/C involve the removal of or injury to sexually sensitive structures, including the clitoral glans and part of the labia minora, some women report a reduction in sexual response and diminished sexual satisfaction. In addition, scarring of the vulvar area may result in pain, including during sexual intercourse.[25] Other findings from the WHO study confirm that women who have undergone FGM/C are at significantly increased risk of adverse events during childbirth.[26] Such women also experience higher rates of Caesarean section and post-partum hemorrhage compared to those who have not undergone the procedure, and this risk increases with the severity of the procedure.[27]

Cultural reasons for FGM/C

The practice of FGM/C dates back thousands of years, with mummies in Egypt showing that it was a routine practice.[28] There is evidence that FGM/C goes back at least to Pharaonic times and that the practice is prevalent among animists, Catholics, Jews, Muslims, Protestants, and those without religious beliefs.[29] Some communities believe that FGM/C is a religious requirement, although it is not mentioned in major religious texts such as the Quran or the Bible.[30] In the United Kingdom, clitoridectomy was used in the management of epilepsy, sterility, and masturbation as recently as the 19th century.[31] One of the first-known formal oppositions to the practice came from medical doctors in

Egypt and from missionaries in Kenya, both in the early 20th century.[32]

In many societies, FGM/C is a rite of passage to womanhood with strong ancestral and sociocultural roots. Rationalizations for the procedure's perpetuation include the preservation of ethnic and gender identity, femininity, female "purity," and family honor; the maintenance of cleanliness and health; and assurance of women's marriageability.[33] In many contexts, social acceptance is the primary reason for continuing the practice. Other reasons include ensuring fidelity after marriage, preventing rape, providing a source of income for circumcisers, and enhancing aesthetic appeal.[34]

FGM/C is usually carried out by an older woman in the community, such as a relative or a traditional birth attendant, without the use of anesthetics, analgesics, aseptic techniques, or antibiotics. Immediate and long-term complications are common and can have a significant effect on the individual.[35] Women who have undergone the procedure often refer to it as "cutting" or "being cut." Nurses have heard patients use traditional names for FGM/C, such as *halalays* and *qodiin* (Somalia), *kutairi* (Kenya), *megrez* (Ethiopia), *niaka* (Gambia), *thara* (Egypt), and *sunna* (Nigeria and Sierra Leone).[36] The English expression "female genital mutilation" emerged in the 1970s and eventually proved to be problematic, as parents resented the suggestion that they were mutilating their daughters. After the UN addressed the risk of demonizing certain cultures and traditions in 1999, the term "cutting" has been increasingly used to avoid alienating communities, hence the use of the more inclusive acronym FGM/C.[37]

Non-cultural and non-historical reasons for perpetuating FGM/C also exist. For example, people in countries such as Mali and Burkina Faso, as well as in most of West Africa, perceive the clitoris as a dangerous organ and require its removal.[38] According to this view, the clitoris is poisonous and causes a man to become ill or die if it comes in contact with his penis. Other beliefs suggest that an uncut clitoris creates male impotency and kills babies upon delivery.[39] Performing FGM/C is also perceived as a way to minimize a woman's libido and assist her in resisting sexual activity by preventing her from acting promiscuously, thereby making her more appealing to her future husband.[40]

Human rights violations

A 2008 UN interagency statement defines FGM/C as a violation of human rights, a form of discrimination on the basis of gender, and a form of violence against girls.[41] The practice violates several human rights outlined under the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Convention on the Rights of the Child.[42] Article 3 of the Universal Declaration of Human Rights states that everyone has the right to life, liberty, and security of person. Unfortunately, in many countries, women and girls are not in full control of their lives, their liberty, or their bodies.[43]

On December 18, 1979, the United Nations General Assembly adopted CEDAW, which became effective on September 3, 1981.[44] CEDAW defines discrimination against women and outlines an agenda for international action to end such discrimination.[45] The convention's underlying philosophy is that "discrimination against women violates the principles of equality of rights and respect for human dignity."[46] Article 5 requires states parties to take measures to achieve "the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes."[47]

Although CEDAW is intended to change the "social and cultural patterns of conduct of men and women," not all countries are willing participants. Somalia is one of the few countries that has neither signed nor ratified this convention, indicating an unwillingness to recognize certain basic human rights. Somalia's lack of participation in CEDAW may also suggest that the country's political activity and traditions need to evolve from a legislative perspective.[48]

The Convention on the Rights of the Child refers to the ever-evolving capacity of children to make their own decisions regarding matters that directly affect them. However, in terms of FGM/C, even in

cases where there is an apparent agreement by girls to undergo the procedure, the decision is a direct result of social pressure and community expectations. A girl's decision to undergo FGM/C therefore cannot be deemed free, informed, or free of coercion.[49] One of the guiding principles of the Convention on the Rights of the Child is the primary consideration of "the best interest of the child."[50] Some parents who decide to subject their daughters to FGM/C believe that the benefits outweigh the risks. However, this perception does not justify a permanent and life-changing practice that constitutes a violation of girls' fundamental human rights.[51] The convention makes explicit reference to harmful traditional practices such as FGM/C. The Committee on the Rights of the Child, as well as other United Nations treaty monitoring bodies, has frequently stated that FGM/C is a violation of human rights, calling on states parties to take all effective and appropriate measures to abolish the practice.[52]

FGM/C violates a series of well-established human rights principles, norms, and standards, including the principles of equality and non-discrimination on the basis of sex, the right to life (when the procedure results in death), the right to freedom from torture and cruel, inhuman, or degrading treatment or punishment, and the rights of the child.[53] Because it interferes with healthy genital tissue in the absence of medical necessity and can lead to severe consequences for a woman's physical and mental health, FGM/C is also a violation of a person's right to the highest attainable standard of health.[54] Although many governments worldwide recognize FGM/C as an act of violence against women and girls and as a violation of human rights, the issue is clouded in debate because the practice is deeply entrenched in culture and tradition, making legislation difficult to approve and enforce.[55]

Legislation and resistance

Since 1965, 24 of the 29 countries with the highest prevalence of FGM/C have used a human rights-based approach to their legislation on FGM/C.[56] Penalties can range from three months to life in prison. Several countries also impose monetary fines. Twelve developed countries with substantial FGM/C-practicing populations have also passed laws criminalizing the practice.[57] Some laws ban the provision of FGM/C in government health facilities and by medical practitioners. Some criminalize FGM/C only when performed on minors, while others criminalize it in all cases. Fines may apply only to practitioners or to anyone who knows it is happening and does not report it. The crime may cover only cutting in the country itself or include taking a girl to another country to have it done.[58]

The right to participate in cultural life and the right to freedom of religion are protected by international law. However, international law stipulates that the freedom to manifest one's religion or beliefs might be subject to limitations necessary to protect the fundamental rights and freedoms of others. Therefore, social and cultural claims such as those protected in article 4 of the International Covenant on Civil and Political Rights cannot be evoked to justify FGM/C.[59] Legislation is an important tool for eradicating FGM/C, as it can challenge the traditional status quo by providing legitimacy to new behaviors—but unless it is accompanied by measures aimed at influencing cultural traditions and expectations, it tends to be ineffective.[60]

Individuals, communities, and countries go through transitional stages in terms of their desire to adhere to FGM/C, to contemplate abandoning the practice, and to completely abandon the practice. The readiness to abandon FGM/C varies across countries. For example, in Somalia, there is a high prevalence of FGM/C (98%) and a strong desire to adhere to the practice; in Egypt, two-thirds of women want to adhere to FGM/C, and almost one-quarter want to abandon it; and in Nigeria, almost equal proportions (about 40%) want to adhere to and to abandon the practice, with 14% "reluctantly adhering" and 13% contemplating abandonment.[61]

Among these transitional stages of abandoning FGM/C, tensions remain between those who aim to abolish FGM/C and those who desire to perpetuate it.[62] Since FGM/C is deeply embedded in culture and considered central to the identity of many Africans, the issue must be approached with great respect and effort on the part of Westerners to understand the

cultural context and rationale of this tradition. If FGM/C is to be completely eradicated, African communities and international support agencies must work collectively at the grassroots level to evaluate the implications of the practice.[63]

Support for a culture of FGM/C is expressed through a reluctance to comply with anti-FGM/C laws and to present evidence against family members, friends, or neighbors, as well as criticism or sarcasm directed toward law enforcers.[64] In a number of cases, local law enforcers and anti-FGM/C crusaders (such as pastors, chiefs, assistant chiefs, and other leaders) may experience a conflict of loyalty by enforcing the law, as it puts them at odds with the local culture, a process sometimes referred to as "social nullification."[65] While criminalizing harmful cultural practices such as FGM/C is necessary, it can equally generate rebellion geared toward circumventing or resisting the law.[66]

Education

Educational rights-based approaches to eradicating FGM/C present communities with a package of opportunities for learning. However, such interventions can sometimes be perceived by communities as an unsolicited top-down approach.[67] Therefore, working with communities prior to implementation is of utmost importance. This increases community acceptance of an intervention, leading to its success.[68]

Education is often favored over other rights-based approaches, such as legislation, because it is less repressive.[69] Although legal restrictions have been found to reduce the rate of FGM/C, they have also been found to drive the practice underground.[70] In other instances, the law has led to parents subjecting their daughters to FGM/C at a younger age before they become susceptible to anti-FGM/C messages.

While legal and political measures are necessary to ending FGM/C, community-based educational initiatives are also critical and have become a key component of campaigns worldwide. Government action is necessary to create a political and legal environment that deters people from practicing FGM/C, but it is ultimately the women, their families, and their communities who must be convinced to abandon the practice.[71]

Community empowerment

Consideration of the target population's characteristics must be present in order to contextualize educational interventions that use a rights-based approach. Contextualizing involves the full inclusion of the communities in planning the programs, such as by involving community members as facilitators or research assistants.[72] Religious and other key leaders must be empowered by helping promote the interventions. In addition, community members can help disseminate information to relatives and friends, therefore encouraging public awareness and resistance to FGM/C.[73] Furthermore, information about FGM/C must be tailored to fit the needs of the target populations, as this increases the acceptability of the program and leads to quicker dissemination of information among communities.[74]

Cultural competency training can help improve health outcomes and the quality of care. However, further research is needed to understand how best to involve different demographic groups, including non-practicing communities, in rights-based educational interventions in order to maximize the prevention of FGM/C.[75] Multipronged, community-led programs in conjunction with legal efforts have been found to be successful in eradicating FGM/C. The largest decline has been seen in Kenya and Burkina Faso, where there has been a very strong legal response, as well as community-based education efforts.[76]

The first program for the prevention of FGM/C, which began in the mid-1970s, focused on informing and motivating communities about the adverse health effects of FGM/C in order to break the taboo. To transmit the message, the program used information, education, and communication materials, such as leaflets, booklets, training manuals, and guidebooks for professionals. Its emphasis was on awareness raising rather than behavior change and thus focused on short-term results, since behavior change takes time.[77] Interventions must be directed toward the alleviation of stigma and provide technical and financial materials at the community

level.[78] Religious and community leaders must play a significant role in arranging trainings, workshops, media campaigns, and outreach in order to bring about the desired behavioral change. Moreover, it is important that programs address the long-term health consequences of FGM/C, general reproductive health issues, gender-based violence, parenting strategies, and communication and relationships skills. Community members must actively take part in these programs, while the government must ensure that the law is enforced. Finally, in rural areas, it is important that local organizations establish anti-FGM/C support groups in order to facilitate positive behavioral change.[79]

One successful rights-based health intervention has been to respect the importance of passage rites and promote alternatives that do not involve cutting.[80] For example, grassroots campaigners in Sierra Leone are changing cultural practices by recognizing the importance of *soweis*, the women leaders who perform FGM/C. The goal is to find alternative income sources for these women and to reinvent their roles as the guardians of traditional culture, without the cutting. In Somalia, Save the Children and partners are supporting local nongovernmental organizations in modifying cultural perceptions of cutting as central to girls' rites of passage and in finding alternate ways to elevate the status and value of women in the family and community. These rights-based approaches preserve communities' cultural heritage and social values while shifting cultural beliefs away from FGM/C.[81]

Higher education, however, is the main factor associated with supporting the discontinuation of FGM/C.[82] For community leaders, empowerment combined with higher education plays a significant role in the elimination of FGM/C.[83] The interaction between empowerment and education is significant and predicts individuals' intention to discontinue the practice.[84]

Involvement of men

FGM/C affects men as well as women. Many men feel that they too are victims of this practice and want to see it end. A sense of social obligation is an important barrier to stopping FGM/C, while higher educational attainment is one of the most important indicators for men's support for abandoning the practice.[85] Several studies demonstrate that men generally respond positively to being involved in sexual and reproductive health programs.[86]

The Global Alliance against FGM is an organization based in France and Switzerland that maintains a focus on men's involvement in eliminating the practice. The alliance is at the forefront of the international effort to accelerate the total elimination of violence against women and girls worldwide. It works closely with WHO, UNESCO, the UN General Assembly, Permanent Missions to the UN, nongovernmental organizations, and individuals all over the world. Since 2009, the Global Alliance against FGM has hosted conferences and events focusing on men who said "no" to FGM/C. The alliance advocates for support and strengthened grassroots work with a priority on developing tools that help optimize efforts at the local, regional, national, and international levels.[87]

The involvement of men must complement current rights-based programs focusing on education and the empowerment of girls and women. Influential males in communities where the practice is prevalent must lead programs as advocates while facilitating dialogue between men and women, their communities, and government bodies.[88]

Conclusion

FGM/C is a manifestation of gender inequality, and the empowerment of women is of utmost importance to the elimination of the practice. A range of documented programmatic, research, and policy interventions—led by a variety of national and international nongovernmental organizations and UN agencies—is being implemented to encourage communities, families, and individuals to abandon FGM/C.[89] These strategies have encompassed advocacy and education interventions aimed at communities and leaders, legislative interventions, capacity-building interventions, health care interventions, media interventions, and community dialogue.[90]

Addressing FGM/C through education brings to light the human rights of girls and women and

the differential treatment of boys and men. Education can serve to influence gender relations and thus accelerate progress in the abandonment of the practice. Human rights-based programs that foster women's economic empowerment contribute to progress, as they provide incentives for changing patterns of traditional behavior to which women and girls are bound as dependent members of the household. Gainful employment empowers women in various spheres of their lives, influencing their sexual and reproductive health choices, their education, and their health-related behavior in general.

There is a positive relationship between empowerment, community interventions, and knowledge about the health consequences of FGM/C. Rights-based programs must be community led and must be tailored to take into consideration the ideological structure and ethnic and socioeconomic differences of each community. Responding to communities' needs and priorities plays an integral part in gaining people's trust and making change relevant.[91]

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Child Labor in Global Tobacco Production: A Human Rights Approach to an Enduring Dilemma

ATHENA K. RAMOS

Abstract

Tobacco production is a multi-billion-dollar global industry. Unfortunately, the cultivation of tobacco engages the labor of children throughout the world in extremely dangerous environments, which has both immediate and long-term consequences for children and society. This paper explores the human rights concerns associated with child labor in tobacco production by highlighting three countries—the United States, Kazakhstan, and Malawi—and examines the impact that the United Nations Convention on the Rights of the Child, the International Labour Organization's (ILO) Worst Forms of Child Labour Convention, and the ILO's Safety and Health in Agriculture Convention have on child labor practices in tobacco production. It also proposes general actions to address the human rights concerns related to child labor practices in tobacco production, as well as specific actions for selected countries. A human rights-based approach to reducing child labor in agriculture could create meaningful changes that improve lives and opportunities for health, education, and economic stability among children and families across the globe.

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The tobacco industry is a multi-billion-dollar business.[1] It is dominated by large multinational companies, including Phillip Morris International, British American Tobacco, Japan Tobacco International, Altria (formally known as Phillip Morris USA), the China National Tobacco Corporation, and the Imperial Tobacco Group, which together posted profits exceeding US$62 billion in 2015.[2]

Tobacco production and consumption are public health issues with human rights implications.[3] Global tobacco giants, through a complex supply system, engage the labor of children throughout the world in extremely dangerous environments, which has both immediate and long-term consequences for the children being employed and for society. This paper explores the human rights concerns associated with child labor in tobacco production by reviewing three countries—the United States, Kazakhstan, and Malawi—which were chosen as examples that highlight different levels of human and economic development. It also examines the impact that the United Nations Convention on the Rights of the Child (CRC), the International Labour Organization's (ILO) Worst Forms of Child Labour Convention (C-182), and the ILO's Safety and Health in Agriculture Convention (C-184) have on child labor practices in tobacco production. It concludes by proposing actions to address the human rights concerns related to child labor practices in tobacco production. Although this article focuses specifically on child labor in tobacco production, the human rights-based solutions discussed have crosscutting implications for child labor throughout the agricultural industry.

Agricultural industry

Agriculture is one of the few industries that exempts some employers from mandates to provide safe working environments for employees in the United States and across the globe.[4] There are substantially fewer protections for those working in agriculture than in other industries. Research has shown that agriculture is one of the most dangerous industries in the world.[5] Within the United States, the agricultural industry has the second-highest fatality rate among young workers.[6] Nearly half of the total occupational fatalities among children occur in agriculture.[7]

Child labor in agriculture

International law defines a child as a person under the age of 18, unless the age of majority is attained earlier under the law.[8] Child labor is "work that deprives children of their childhood, their potential, and their dignity, and that is harmful to physical and mental development."[9] Globally, about 152 million children are involved in child labor and 73 million children are involved in hazardous work.[10] Across the world, more children work in agriculture than in any other sector of the economy, and the majority of full-time working children are in the commercial agriculture sector.[11]

Child labor remains relatively unaddressed within the agricultural industry and is the product of the triangulation of employers, parents, governments, and an overarching international and national legal structure that allows such practices to exist.[12] Child labor is profitable. In some cases, parents employed in low-wage agricultural jobs may be forced to have their children work because child care is unavailable or too costly. In other cases, parents may need their children to work in order to help support the family. Some governments allow child labor in order to promote investment or stabilize the national economy. Further, international actors such as the World Bank and the International Monetary Fund continue to influence social and economic policies, which may inadvertently result in weak national legal structures and poor enforcement of labor laws, especially those protecting children. Finally, the tobacco industry and its allies have effectively lobbied, at multiple levels, against policies and regulations that protect workers.[13]

Tobacco production: A commodity market

Tobacco is an agricultural commodity product. Up until the 1960s, the United States dominated global tobacco production; however, now China, Brazil, and India lead the United States.[14] Much of US tobacco production has been outsourced to the developing world.[15] In fact, tobacco is now

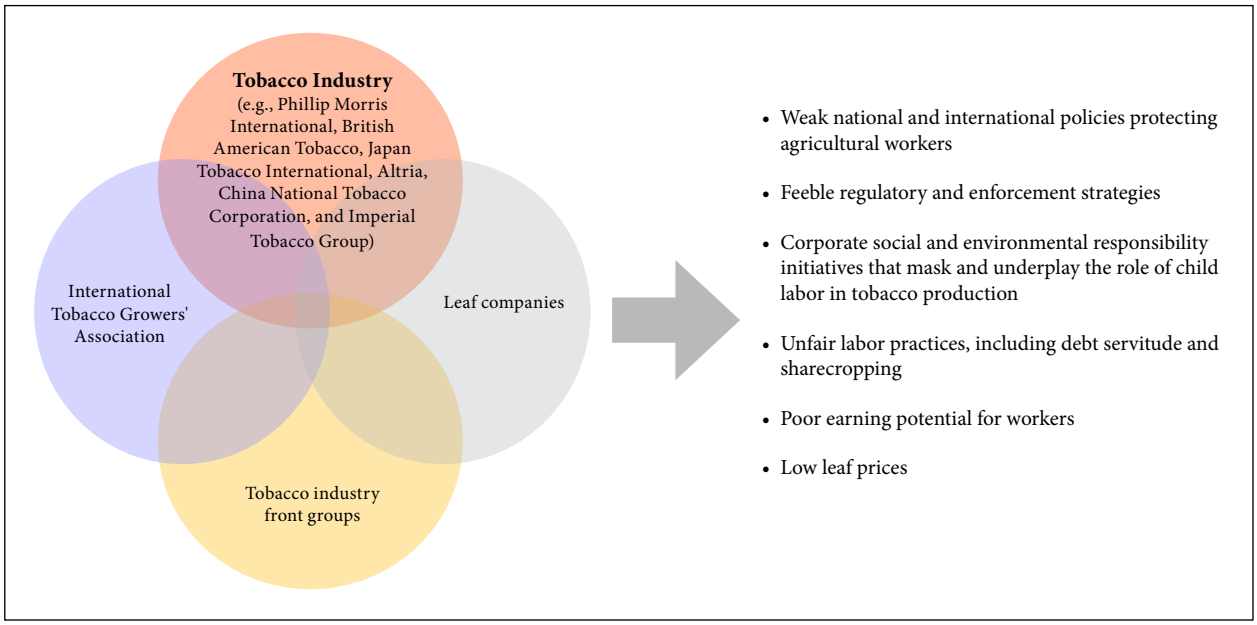
produced in 125 countries, including Argentina, Guatemala, Indonesia, Italy, Kenya, Pakistan, Poland, Thailand, Turkey, and Zimbabwe.[16] In a quest to lower production costs and increase shareholder value, multinational companies move into less regulated countries, where they negotiate extremely low prices that often result in debt servitude or the producers' use of child labor. Sharecropping is also commonly used as a mechanism to gain access to cheaper labor and to transfer the risk from landowners to workers.[17] Tobacco companies benefit from these unfair labor practices.[18] Figure 1 highlights the confluence of factors that influence child labor in tobacco production. The circles in the figure overlap to signify the collusion between the tobacco industry and their front groups, leaf companies, and the International Tobacco Growers' Association.

There are several reasons for the lack of accurate data on the number of children working in tobacco production. These include children working as unpaid family members, underreporting, and a lack of labor law enforcement. Additional research is needed to more precisely estimate the number of child farmworkers in tobacco production across the world.

Tobacco production: Dangerous health consequences

Tobacco production is a dangerous endeavor for adults, and even more so for children. Children working on tobacco farms may face a variety of hazardous exposures, including long hours, lacerations and piercings from equipment, chemicals, heavy lifting, climbing, and extreme weather conditions.[19] They may also lack access to water, appropriate nutrition, and sanitation facilities.[20] Children are especially vulnerable to the impacts of these exposures because of their physical stage of development. An immediate health risk to children working on tobacco farms is green tobacco sickness. This sickness is an occupational illness caused by dermal absorption of nicotine from the leaves of the tobacco plant.[21] It is a form of nicotine poisoning and is exacerbated by working in wet or damp environments.[22] Numerous reports have highlighted stories of farmworkers, both children and adults, who have experienced the illness. A recent study of farmworkers in North Carolina found that tobacco farmworkers had higher levels of cotinine (a nicotine metabolite) than actual smokers.[23] Green tobacco sickness can have serious and acute implications, such as dizziness, headaches, nausea,

FIGURE 1. Factors influencing child labor in tobacco production



vomiting, dehydration, anorexia, and insomnia. Adding to the dangers of the illness, the application of and exposure to chemicals such as pesticides, herbicides, fumigants, and growth inhibitors without the use of appropriate personal protective equipment may increase risk. Children who work on tobacco farms may face serious chronic health consequences, including a higher risk of cancer, reproductive health issues, mood disorders, and permanent neurological damage.[24]

Child labor in the United States

There are still thousands of children in the United States (mainly in Kentucky, North Carolina, Tennessee, and Virginia) working in tobacco fields.[25] Although child labor in agriculture is a hotly debated topic, the fact is that many labor laws do not equally protect children working in agriculture compared to other industries. This is an example of "agricultural exceptionalism." According to US federal labor law, "A child of any age may be employed by his or her parent or person standing in place of the parent at any time in any occupation on a farm owned or operated by that parent or person standing in place of that parent."[26] Table 1 highlights the age restrictions on the employment of children in agriculture as part of the Fair Labor Standards Act. It is also important to note that federal child labor provisions do not require minors to obtain work permits and do not limit the number of hours or times of day (other than outside of school hours) that young farmworkers may legally work. Minimum-wage standards do not apply to all farmworkers, and workers under the age of 20 can be paid a mere US$4.25 per hour during their first consecutive 90 calendar days of employment with a particular employer. In essence, children as young as 12 can work unlimited hours on a tobacco farm and be paid less than other workers as long as it does not interfere with school and they have parental permission.[27]

Although the Fair Labor Standards Act identifies a number of "hazardous" tasks through the Hazardous Occupations Orders for Agricultural Employment (HO/As), tobacco production tasks are not included. In 1998, the National Research Council and the Institute of Medicine issued recommendations to increase the minimum age for hazardous work from 16 to 18 for all children, regardless of whether they are employed in agriculture, and to require compulsory compliance with the HO/As by all agricultural employers.[28] Recently, there was a proposal to create a new HO/A to prohibit children from being involved in the production and curing of tobacco. Finally, in late 2014, a bill was introduced in Congress to prohibit children under 18 from working in tobacco fields; however, no changes in policy or regulations have ensued.[29]

In early 2015, the US Department of Labor released recommendations developed by the Occupational Safety and Health Administration and the National Institute for Occupational Safety

TABLE 1. Provisions of the US Fair Labor Standards Act regarding child labor in agriculture

Age of child	Stipulation
Under 12	Children under 12 may be employed outside of school hours with parental consent on a farm where employees are exempt from the federal minimum-wage provisions.
12–13	Children aged 12–13 may be employed outside of school hours with written parental consent or on a farm where their parent or person standing in place of the parent is also employed.
14	Fourteen is the minimum age for employment outside of school hours in any agricultural occupation except those declared hazardous by the Secretary of Labor.
16	Minors who are at least 16 years of age may perform any farm job, including agricultural occupations declared hazardous by the Secretary of Labor, at any time, including during school hours.

Source: US Department of Labor, "Child labor requirements in agricultural occupations under the Fair Labor Standards Act," *Child Labor Bulletin* 102 (2016). Available at https://www.dol.gov/whd/regs/compliance/childlabor102.pdf.

and Health that specified the personal protective equipment—such as long-sleeve shirts, long pants, gloves, and water-resistant clothing—that should be utilized when handling tobacco leaves; however, the document did not mention the use of child labor in the production process. It is clear that the US government is not adequately protecting child tobacco farmworkers nor upholding its responsibilities under various international standards.

Child labor in Kazakhstan

Over 25% of Kazakhstan's population works in agriculture.[30] A significant number of these workers, especially migrant children, are employed on tobacco farms. In 2006, children were thought to make up about 60% of the country's tobacco workforce; however, no exact number of child tobacco farmworkers is currently available.[31] Based on a study conducted in 2009, child labor on Phillip Morris International farms was found to be widespread, and many workers were paid by the piece.[32] Moreover, most tobacco farmworkers were uninformed of the potential occupational risks or health consequences that they faced. Due to increasing pressure, Phillip Morris International contracted with a local nongovernmental organization, the Local Community Foundation, to directly handle farmworkers' grievances and set up a hotline to receive complaints and provide supportive services.[33]

Although the Ministry of Labor and Social Protection restricts the employment of children under 18 in tobacco production and the Labor Code of Kazakhstan prohibits the employment of people under 18 in hazardous conditions, the employment of children on tobacco farms still occurs. A case documenting labor abuses was presented to the United Nations Committee on Economic, Social and Cultural Rights in 2010, and information on this issue was presented to the United Nations Special Rapporteur on contemporary forms of slavery in 2012.[34] In 2014, the US Department of Labor declared that Kazakhstan had made a minimal advancement in efforts to eliminate the worst forms of child labor, such as that found in agriculture.[35]

Child labor in Malawi

According to Marty Otañez, Adeline Lambert, and Raphael Sandramu, "Malawi is the most tobacco-dependent country in the world."[36] In fact, tobacco accounts for more than half of the country's exports.[37] Most tobacco workers have no contract with their employers and make a mere US$1.25 per day.[38] Tobacco workers are sometimes part of a repressive tenancy system, and those unable to repay their debts may face debt bondage.[39] When the United Nations Special Rapporteur on the right to food visited Malawi in 2013, he noted that 78,000 child laborers were employed in plucking tobacco leaves.[40] The Special Rapporteur also noted that collusion among global tobacco companies over leaf prices was a human rights issue.[41] Further, in 2015, over 50% of children on tobacco estates were found to be involved in stitching tobacco leaves as unpaid family members.[42] Between 2000 and 2010, child labor is estimated to have saved the tobacco industry in Malawi over US$10 million.[43]

The problem of child labor in tobacco production in Malawi is rampant and well known. In 2010, Malawi-produced tobacco was listed by the US Department of Labor as having been produced using child labor, and this practice continues today.[44] In a recent study, 63% of children from tobacco-growing families were found to be involved in child labor.[45] According to Malawi's Employment Act of 2000, child labor refers to any economic activity that involves a child under 14 years old. Although the Constitution states that children under 16 are entitled to protection from hazardous work and the Employment Act sets the minimum age for hazardous labor at 18, these provisions are not enforced. While there is a formal mechanism for reporting child labor complaints, most child labor cases are resolved through out-of-court settlements and fines.[46] Clearly, even though mechanisms to address child labor exist, real change in practice has been elusive. Many nongovernmental groups have urged Malawi's Parliament to pass the Tenancy Labor Bill or abolish the tenancy labor system in an effort to improve employment and health conditions on to-

bacco farms. They have also advocated for the right to organize under the Tobacco and Allied Workers Union. To date, however, no such legislation has been passed.[47]

Tobacco industry response

Tobacco companies understand the need to address child labor concerns throughout their supply chain. Altria, British American Tobacco, China National Tobacco, Imperial Tobacco Group, Japan Tobacco Group, Lorillard, and Phillip Morris International all purchase tobacco through direct contracts with growers or through tobacco leaf supply companies.[48] In 2010, Phillip Morris unveiled a new global agricultural labor policy to prohibit child labor and develop guidelines and requirements for farmers, growers, and suppliers.[49] In 2014, Altria signed a global pledge to eliminate all forms of child labor in its worldwide supply chain as part of an initiative promoted by the Eliminating Child Labour in Tobacco Growing Foundation, a foundation created by British American Tobacco. More recently, in 2016, the Sustainable Tobacco Program, an industry-wide initiative, was unveiled to address tobacco crop production, environmental concerns, labor issues (including child labor), health and safety facilities, and supply chain governance; however, it is still too early to evaluate what impact this initiative will have.[50]

Unfortunately, these types of moves, although framed as corporate social responsibility, represent more of a public relations strategy than any real meaningful change in practice. For example, in 2014, Phillip Morris International noted that it would buy tobacco only from third-party leaf companies rather than from direct contracts with growers, which was promoted as way to increase accountability, oversight, and implementation of strict standards regarding child labor. However, this transferred responsibility for monitoring child labor from the tobacco companies to the leaf companies, while allowing the tobacco companies to reap the benefit of cheap leaf products and continue to escape culpability for the problem. By promoting these types of initiatives, tobacco companies stand to gain political support and weaken opposition, especially in low-income and middle-income countries, where there may be less external monitoring by civil society and where financial contributions from these companies may have a greater impact.[51]

Human rights conventions

Tobacco production labor practices have significant implications for human rights, specifically the right to equality, the right to health, and the rights of children. Child labor on tobacco farms must be framed as part of the human rights agenda. This section examines three international treaties to assess their positions on child labor and their effectiveness in eliminating the practice.

United Nations Convention on the Rights of a Child

With 196 parties, the CRC is the most universally ratified human rights convention in the world; the United States is the only country that has not ratified it.[52] Although the United States has not ratified the CRC, it has signed it, thereby requiring the country to refrain from engaging in practices that undermine and defeat the objective and purpose of the convention.

The CRC defines a child as a person under the age of 18. Accordingly, children are in need of special care and protection. The CRC establishes that children should be able to enjoy the highest standard of health.[53] Article 32 states that parties to the CRC are obligated to

> *[r]ecognize the right of the child to be protected from economic exploitation and from performing any work that is likely to be hazardous or to interfere with the child's education, or to be harmful to the child's health or physical, mental, spiritual, moral, or social development.*[54]

Numerous studies have documented that children working on tobacco farms are exploited and work in hazardous conditions that may interfere with their health, education, and well-being. It is time

for states parties to act to protect these children by passing effective national legislation to abolish child labor in tobacco production and ensure that all organizations and individuals within their boundaries do not violate the rights of children as outlined in the CRC, including the rights to health, education, and relaxation and play. Without such action, states parties are liable for the breach of human rights obligations under international law.

International Labour Organization's Worst Forms of Child Labor Convention (C-182)

The ILO's Worst Forms of Child Labor Convention prohibits children under the age of 18 from engaging in hazardous labor that is likely to harm their health, safety, or morals.[55] While this convention prohibits hazardous child labor, it is up to each national government to define what constitutes "hazardous work." Parties to C-182 are required to design and implement a national action plan on the elimination of child labor and to set up a mechanism to oversee, monitor, and report on its implementation.[56] Nearly every country in the world, including the United States, has ratified this convention.[57] Although the United States has ratified this convention, it has not passed any laws to formally protect child tobacco farmworkers, such as an age restriction for working in tobacco production. Other countries, such as India and Brazil, have ruled that children cannot work on tobacco farms.[58] According to interviews conducted in Brazil by Human Rights Watch, farmworker families know and understand that children under 18 cannot work legally in the fields or the families will face penalties.[59] Enforcement of these penalties is lacking, but the threat of enforcement has begun to change practices in Brazil, even if child labor has not been completely eliminated.[60]

International Labour Organization's Safety and Health in Agriculture Convention (C-184)

The ILO's Safety and Health in Agriculture Convention provides a series of guidelines to protect agricultural workers and directs countries to develop national policies to this end.[61] Article 16 specifically addresses young workers and hazardous work:

> *The minimum age for assignment to work in agriculture which by its nature or the circumstances in which it is carried out is likely to harm the safety and health of young persons shall not be less than 18 years.*[62]

In some cases, a person as young as 16 may work in agriculture if appropriate training is provided and their health and safety is fully protected. Only 16 countries have ratified C-184—and, not surprisingly, the three studied here (United States, Kazakhstan, and Malawi) are not among them.[63] Recent research from the World Bank suggests that in countries where agriculture is a key economic activity, support for industry regulations and safety controls, such as C-184, may be weak.[64]

Proposed actions

When child labor in tobacco production is examined through a human rights lens, it is clearly wrong and violates the rights of children. Child farmworkers should not be treated as a mere means to financial gain. Employers are receiving a financial benefit from using child farmworkers; however, families and society are paying the price for these actions in terms of lost potential and negative health, social, and educational outcomes. All children deserve to be treated with dignity and respect. Current tobacco production processes pose a risk to workers' health, especially the health of child farmworkers, and as a result it is a violation of international law for children to be working in these conditions. Child labor in tobacco production is an enduring global dilemma that needs to be resolved from a human rights perspective.

Governments have a responsibility to protect their citizens and fulfill their obligations under international human rights law, but politics and the tobacco industry's lobbying efforts have had a large influence on tobacco control policy around the world. These efforts have allowed the tobacco industry to evade accountability for their actions.

Even though human rights advocacy has been found to raise awareness, a comprehensive multisectoral strategy using a rights-based approach is needed to fully eliminate child labor. Below is a list of recommended actions grouped by sector.

International legal system

Utilize international treaty mechanisms. The United Nations Ad Hoc Interagency Task Force on Tobacco Control meets every two years and is supportive of a human rights-based approach to tobacco control.[65] The human rights-based approach is based on a number of principles: universality, indivisibility, interdependence, participation and inclusion, equality and non-discrimination, and accountability.[66] Such an approach requires cross-sector collaboration and multilevel strategies.[67]

A number of strategies could be used to address child labor through international law. At a minimum, current international treaty obligations should be enforced. There should also be a standardization of what constitutes "hazardous" work under C-182. Tobacco production should be listed as hazardous given the plethora of science that shows the serious health consequences—both acute and long term—of working with tobacco. Reporting on child labor in tobacco production should be integrated into the Universal Periodic Review process for countries reporting before the United Nations Human Rights Council. This process provides "the opportunity for each State to declare what actions they have taken to improve the human rights situations in their countries and to fulfil their human rights obligations."[68] In addition, increased civil society monitoring of child labor on tobacco farms and the incorporation of these results into shadow reports for the CRC and C-182 could help raise awareness of this issue. Indeed, tobacco control issues have already been included in shadow reports for the Convention on the Elimination of Discrimination against Women and the CRC.[69] Many useful tools have also been developed to help civil society participate in human rights monitoring and reporting.

Exploring additional international legal advocacy mechanisms to increase awareness of and decrease the use of child labor in tobacco production could be beneficial. Richard Daynard, Rangita de Silva de Alwis, and Mark Gottlieb have suggested some examples of further advocacy, including (1) submitting NGO reports to treaty monitoring bodies; (2) discussing child labor issues at constructive dialogues and pre-session meetings of states parties as part of reporting processes; (3) petitioning treaty monitoring bodies to include tobacco labor practice recommendations in their concluding observations on state party reports; (4) advocating for a particular focus on child labor on tobacco farms by United Nations Special Procedures, especially the Special Rapporteur on the right to health and the Special Rapporteur on corporate social responsibility; and (5) collaborating to ensure joint human rights and health dialogues at both the World Health Assembly and the Office of the United Nations High Commissioner for Human Rights.[70]

Implement the Framework Convention on Tobacco Control. Full implementation of the World Health Organization Framework Convention on Tobacco Control, another one of the most widely embraced conventions, is obligatory. In force since 2005, the convention currently has 168 signatories and 181 parties. Of the world's top four tobacco-producing nations, three—China, Brazil, and India—have ratified the convention, while the United States has not.[71] Even though the convention does not explicitly address child labor, it does contain articles that could be clarified and expanded to formally address child labor within the supply chain. For example, article 17 calls for the promotion of economically viable alternatives for tobacco workers, growers, and individual sellers, and article 18 calls for protection of the environment and the health of people working in tobacco cultivation and manufacture. Both of these articles represent opportunities that could be leveraged to reduce child labor. A human rights-based approach could provide the necessary enforcement linkage between various human rights treaties and the Framework Convention on Tobacco Control since the latter does not provide for enforcement.[72]

International development community

Reduce dependence on tobacco. Fostering more awareness on the link between child labor, tobacco, and food security is necessary. Tobacco quickly depletes land's productive potential.[73] Helping farmers find alternative livelihoods through crop diversification and access to supportive social policies could help in the transition away from tobacco production. For example, accessible credit systems could be created for farmers so that they can afford to grow different crops, invest in appropriate equipment, and borrow at reasonable interest rates.

Reward education. Research has demonstrated that poverty is both a cause and a consequence of child labor across the world. Child labor creates and maintains the cycle of poverty.[74] As a global society, we should change social norms on child labor so that the long-term economic and social benefits of education outweigh the short-term financial payment of work. Rewarding families that send their children to school rather than to work may provide an incentive for education, especially in low-income and middle-income countries. Children have the right to education, and primary education should be universal. Extra fees for uniforms, books, and supplies or a lack of transportation should not be impediments to youth being able to attend school. Collaborative solutions between international actors, national governments, educational districts, and other interested partners should explore how this could be achieved as part of the United Nations Sustainable Development Goals.

Governments

Create parity under labor law. There should be equitable protection under the law for all farmworkers. Children should never work in hazardous environments, and children working in agriculture should have the same protections as children working in other industries. Therefore, legal changes may be needed to address and remedy the inequities that currently exist under national labor laws.

Promote and monitor farmworkers' health. States have a duty to protect and monitor the public's health. Most farmworkers never receive any safety training, health education, or personal protective equipment to help reduce their exposure to the tobacco plant. Assuring that all tobacco farmworkers have access to free personal protective equipment and are trained in how to properly use it could mitigate some of the associated health risks. At a minimum, gloves and water-resistant clothing should be provided. Additionally, a system to monitor farmworkers' health should be developed, especially in rural areas where there generally is less access to health care.[75]

Mainstream child labor into existing legal enforcement structures in all countries. Current national child labor laws should be enforced. Often, enforcement authorities are underfunded and lack appropriate resources to fully complete their responsibilities. Ensuring appropriate funding and staffing for these positions is imperative. Additionally, making child labor a mainstream issue globally would help increase awareness about child labor and promote enforcement.

Civil society

Support and strengthen farmworker labor organizing initiatives. Throughout history, labor unions have helped rebalance the power structures between employers and employees, especially within the agricultural industry. Unions such as the United Farm Workers and the Farm Labor Organizing Committee of the AFL-CIO have consistently fought for workers' rights. Unions could be a powerful mechanism for reducing child labor by raising such issues as part of the hiring processes or through the grievance-arbitration procedures set forth in collective bargaining agreements. Already, several thousand tobacco workers in North Carolina have joined the Farm Labor Organizing Committee.[76] This type of strategy could be especially powerful in the developing world in countries such as Malawi, where there is an active union organizing effort.

Educate farmworker families. Farmworker families often have limited access to education about

children's rights as well as the risks and dangers of child labor in tobacco production. Families have a right to information, and states and employers have a duty to provide this information, such as that related to the health and social risks of working in tobacco production.[77]

Litigate cases of exploitive child labor on tobacco farms. Litigation may decrease dangerous and inhumane child labor practices on tobacco farms. Attorneys and civil society organizations could provide litigation support to exposed children and families by filing claims of human rights abuses on tobacco farms before regional human rights courts.[78]

Collaborate with other civil society groups. Farmworkers represent one of the most marginalized populations in the world, and addressing the issues they face requires multisector collaboration. A human rights-based approach may help build partnerships to address these critical issues. Farmworker advocates could establish coalitions and collaborations with other civil society groups such as those that focus on marginalized populations—including children, women, and indigenous groups—in order to foster awareness of human rights and human rights abuses, as well as develop a joint agenda for action. Some ideas for collaborative action include an international media campaign highlighting "a day in the life of a child tobacco farmworker" or product-labeling certificates that demonstrate that no child labor was used to produce the product.[79] These types of activities could increase awareness of the human rights abuses occurring within tobacco production.

Employers

Pay living wages. Workers have a right to fair employment and to a standard of living adequate for the health and well-being of themselves and their families. Workers should not be compensated merely at minimum wage, which in many places is barely enough to survive. Instead, they should be paid a "living wage" that allows them to earn enough to maintain a decent standard of living.

Provide written contracts. Most tobacco workers never receive a written contract and therefore may become victims of wage theft, debt bondage, or other negative outcomes. A written contract can provide mutual clarity to workers and employers on the roles and responsibilities of each party, on working conditions, and on payment information.

Specific recommendations are proposed in Table 2 for each of the three countries highlighted previously.

Child labor is a violation of children's human rights. Responsible parties such as employers, parents, governments, and international and national actors should be held accountable for child labor in tobacco production. A comprehensive rights-based approach to reducing child labor in agriculture is needed to create meaningful changes that improve the lives and opportunities for health, education, and economic stability among children and families across the globe.

Farmworkers are an almost invisible population, hidden from the view of consumers and much of the world; however, they are essential to the global agricultural industry. In order to create a sustainable future, more attention must be paid to the plight of all farmworkers, especially children. Without this focus, this group of people will continue to be the invisible underclass, perpetuating the cycle of poverty. Farmworkers, although producing commodity products, are not and should not be considered commodities themselves. Upholding child tobacco farmworkers' human rights is vital, and tolerating child exploitation in tobacco production is no longer an acceptable option.

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TABLE 2. Key recommendations for reducing and eliminating child labor in tobacco production[80]

United States	Kazakhstan	Malawi
International treaty bodies		
Enforce current international treaty obligations: Require minimum age of 18 for hazardous work under C-182	Enforce current treaty obligations under CRC and C-182	Enforce current treaty obligations under CRC and C-182
International development community		
Advocate for sustainable international development financing	Offer microfinance and credit opportunities to the rural poor	Offer microfinance and credit opportunities to the rural poor
	Provide alternatives to farmworkers	Provide alternatives to farmworkers
	Incentivize parents to send children to school	Incentivize parents to send children to school
National governments		
Enforce Occupational Safety and Health Administration regulations on all farms	Enforce national labor laws under Ministry of Health and Social Development's Committee on Labor, Social Protection and Migration	Enforce national labor laws through Ministry of Labor's Child Labor Unit
Revise the Fair Labor Standards Act to change minimum-age rules so that they are consistent across industries	Train Ministry of Internal Affairs staff to investigate child labor complaints	Abolish the tenancy labor system
Enforce and strengthen Environmental Protection Agency's Worker Protection Standard regarding farmworker pesticide exposure	Ensure that the Ministry of Education and Science promotes the hotline for reporting child labor complaints, mediates all complaints, and makes appropriate referrals for assistance	Criminalize debt bondage perpetrators
Create an HO/A to prohibit children from working in tobacco production	Conduct unannounced inspections of farms where child labor is suspected of being used	Provide regular training for Ministry of Labor inspectors, especially in relation to new child labor laws
Mandate the provision of personal protective equipment for all farmworkers	Mandate the provision of personal protective equipment for all farmworkers	Mandate the provision of personal protective equipment for all farmworkers
Fund labor law enforcement authorities at local, state, and national levels	Fund labor law enforcement activities through the Ministry of Health and Social Development, Committee on Labor, Social Protection and Migration and the Ministry of Education and Science	Fund the Ministry of Labor's General Inspectorate enforcement activities
Use ILO process of social dialogue to engage employers and workers in discussion about child labor	Monitor the Joint Action Plan on the Elimination of the Worst Forms of Child Labor	Implement National Action Plan to Combat Child Labor
	Improve access to education for all children, especially migrant children	Improve access to education for all children, especially those from tobacco-growing families
Civil society		
Include child tobacco farm labor in shadow reports for C-182	Include child tobacco farm labor in shadow reports for CRC and C-182	Include child tobacco farm labor in shadow reports for CRC and C-182
Advocate for ratification of CRC, C-184, and Framework Convention on Tobacco Control	Advocate for ratification of C-184	Advocate for ratification of C-184 and Framework Convention on Tobacco Control
Integrate tobacco control and child labor discussions within the context of the Sustainable Development Goals	Incorporate discussions on child labor in tobacco production under the Framework Convention on Tobacco Control and within the context of the Sustainable Development Goals	Integrate tobacco control and child labor discussions within the context of the Sustainable Development Goals
Support and strengthen farmworker labor organizing, such as through the United Farm Workers and the Farm Labor Organizing Committee of the AFL-CIO	Support and strengthen farmworker labor organizing	Support and strengthen farmworker labor organizing, such as through the Tobacco and Allied Workers Union
Provide health and safety education and training to all farmworkers	Provide health and safety education and training to all farmworkers	Provide health and safety education and training to all farmworkers
Advocate for all tobacco and leaf companies to prohibit child labor on farms from which they grow or purchase leaves and monitor compliance	Advocate for all tobacco and leaf companies to prohibit child labor on farms from which they grow or purchase leaves and monitor compliance	Advocate for all tobacco and leaf companies to prohibit child labor on farms from which they grow or purchase leaves and monitor compliance

TABLE 2. *Continued*

United States	Kazakhstan	Malawi
Civil society		
Advocate for tobacco product labeling indicating that "no child labor" was used during production	Develop certification program for farms to be certified as "free from child labor"	Develop certification program for farms to be certified as "free from child labor"
Promote the reality of child tobacco farmworkers through reports and social media		
Employers		
Adhere to all labor laws	Adhere to all labor laws	Adhere to all labor laws
Remove children from hazardous work	Remove children from hazardous work	Remove children from hazardous work
Provide written contracts to all hired farmworkers	Provide written contracts to all hired farmworkers	Provide written contracts to all hired farmworkers

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LETTER TO THE EDITOR

Malnutrition, Poverty, and Climate Change are also Human Rights Issues in Child Labor

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Athena Ramos's paper "Child Labor in Global Tobacco Production: A Human Rights Approach to an Enduring Dilemma" highlights the critical issue of human rights for working children, especially those working in hazardous tobacco farming, where agriculture is intricately connected to global business interests.[1] The author includes an extensive review of the literature on child labor in tobacco farming and the human rights that are ignored in, as she writes, "an almost invisible population," particularly children who are part of the "invisible underclass, perpetuating the cycle of poverty."

I would like to highlight two further issues that should be considered in the discussion of child labor in tobacco and other large-scale industrial monocropping: the first is the relationship between child workers' malnutrition and poverty, and the second is the impact of climate change on agriculture and livelihoods. Focusing the discussion here on Malawi (the case used by Ramos), we see a tobacco-dependent country that is the world's sixth-largest tobacco producer and that earns 60% of its GDP from tobacco farming—a crop that, in some quarters, is promoted as a solution to poverty.

Around half of Malawi's 5.6 million children are laborers. Approximately two million children work in agriculture, with an estimated 100,000 of them working on tobacco farms.[2] Along with the World Health Organization—which warns of the negative impacts of tobacco farming on health and the environment, as well as its counterproductivity in terms of the Sustainable Development Goals (SDGs)—the International Labour Organization stresses the risks for child laborers caught in the cycle of poverty, which forces them into precarious work on monocrop plantations, especially tobacco and sugar, where, increasingly, climate change affects the most vulnerable, particularly in low-income countries.[3]

Children in agriculture, malnutrition, and climate-change-related events

The *Global Hunger Index* reports Malawi's hunger situation as serious, with 6.5 million (out of a total population of 19 million) unable to meet nutritional requirements.[4] Thirty-seven percent of children under five are stunted, with malnutrition one of Malawi's top ten risk factors and causes of child death.[5] Food insecurity and malnutrition continue to be serious problems, which is why school-feeding and under-five breakfast programs are widespread. In addition to causing impaired cognitive development, malnutrition leaves child farmers susceptible to endemic infectious diseases, including malaria and cholera (aggravated by climate change), and particularly vulnerable when exposed to vector-borne infectious and non-communicable diseases, on top of the threat of "green tobacco sickness."[6]

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Systematic reviews indicate a significant association between extreme weather events, nutritional status, and infant mortality.[7] For example, maize crops—one of Malawi's staple foods—are affected by poor seasonal rains and prolonged dry periods, while environmental shocks such as the 2017 "army worm" plague have resulted in agricultural disaster for countries of eastern Africa, further aggravating food insecurity.

The *Lancet* has declared climate change and its related health effects as the biggest global health threat of this century, with Southern Africa one of the most vulnerable regions, as it is highly dependent on rain-fed agriculture and has a low adaptive capacity.[8] Ninety-two percent of Malawians rely on rain-fed sources of water, which are heavily affected by floods and droughts. Further, the late onset of rains negatively affects agriculture, which increases food poverty and, in turn, affects children's nutritional status.[9] Deforestation—a critical issue in Southern and Eastern Africa—brings its own environmental impacts. For example, clearing for monocropping means less arable land for food crops, and deforestation has been associated with landslide vulnerability and carbon dioxide emissions.[10]

The way land is used by the poor in farming is an important consideration in the discussion of climate change and its impact on child labor in agriculture. Tenancy (sharecropping in Ramos's paper) is an indirect but important reason for child labor. In Malawi, large-scale monocropping in crops such as tobacco and sugar is responsible for changes in land use and in farm size, as well as land fragmentation, thus changing the face of farming. In effect, household and community land is used for commodity crops instead of subsistence farming, leaving families to purchase food that would have previously been self-produced, gathered, or hunted. With crops negatively affected by climate change, and international conglomerates regulating agriculture, family farms are being increasingly converted into farms for commodity crops such as tobacco. Complex land tenure and compounded interest on loans, added to climate unpredictability and fluctuating prices tied to export-focused markets, aggravate the already dire socioeconomic situation for tenant farmers.

With a clear link to malnutrition, climate change in such scenarios critically affects the livelihood and health of children who are indentured or coopted into agricultural work, whether it be periodic work (such as to see the family through a difficult season) or permanent work. In all, the risk of poor children in Malawi being affected by natural disasters has been estimated as six times greater than for non-poor children, meaning that child laborers are especially vulnerable to and affected by climate change.[11]

Conclusion

While governments acknowledge climate change realities, in Malawi uncontrolled deforestation continues unchecked, with forests making way for large-scale estates that require water diversion, further affecting subsistence farming and native habitats. Traditional sources of nutrition are depleted as jungles disappear, and subsistence farming, hunting, and fishing are no longer the norm, with, for example, unsustainable fishing techniques destroying fish stocks that are already threatened by global warming.

The issue that must be addressed if child labor is to be eliminated by 2030, as proposed in the SDGs (ninety percent of which have targets linked to international human rights and labor standards), is the complex interaction of poverty, climate change, and big business.

While Ramos has outlined various legal, diplomatic, and civil actions to counteract child labor in tobacco farming, the topic must be considered in a wider context that focuses on health rights and climate change. There are positive signs toward climate change mitigation in Africa, as evidenced by civil society initiatives such as Greening Africa Together, but government and agricultural industry compliance is critical to any international, regional, or national protocol addressing child labor, which will become an even more critical issue as climate change increases.[12] Multinational corporations are key to addressing the situation, especially in low-income countries, and, as Ramos concludes,

agricultural alternatives are necessary. However, it is essential that sustainable, integrated agricultural systems become part of national adaptation plans that address the health and rights of child workers who are facing the growing impacts of climate change.[13]

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