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Big Data, Technology, Artificial Intelligence and the Right to Health

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Table of Contents

BIG DATA, TECHNOLOGY, ARTIFICIAL INTELLIGENCE, AND THE RIGHT TO HEALTH

- 1 EDITORIAL
Enter the Cyborgs: Health and Human Rights in the Digital Age
Sara L. M. Davis and Carmel Williams
- 7 Analyzing the Human Rights Impact of Increased Digital Public Health Surveillance during the COVID-19 Crisis
Sharifah Sekalala, Stéphanie Dagrón, Lisa Forman, and Benjamin Mason Meier
- 21 Human Rights and Digital Health Technologies
Nina Sun, Kenechukwu Esom, Mandeep Dhaliwal, and Joseph J. Amon

PERSPECTIVES

- 33 Digital Phenotyping and Digital Psychotropic Drugs: Mental Health Surveillance Tools That Threaten Human Rights
Lisa Cosgrove, Justin M. Karter, Mallaigh McGinley, and Zenobia Morrill
- 41 The Trojan Horse: Digital Health, Human Rights, and Global Health Governance
Sara L. M. (Meg) Davis
- 49 Health in the Digital Age: Where Do Children's Rights Fit In?
Louise Holly
- 55 A Health Rights Impact Assessment Guide for Artificial Intelligence Projects
Carmel Williams

VIEWPOINTS

- 63 Technology, Health, and Human Rights: A Cautionary Tale for the Post-Pandemic World
Rajat Khosla
- 67 From Information to Valuable Asset: The Commercialization of Health Data as a Human Rights Issue
Amy Dickens
- 71 Participatory Machine Learning Using Community-Based System Dynamics
Vinodkumar Prabhakaran and Donald Martin Jr.
- 75 An Invitation to a Feminist Approach to Global Health Data
Shirin Heidari and Heather Doyle
- 79 The Human Rights Challenges of Digital COVID-19 Surveillance
Akarsh Venkatasubramanian

GENERAL PAPERS

- 85 Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action
Naomi Braine
- 99 Toward Human Rights-Consistent Responses to Health Emergencies: What Is the Overlap between Core Right to Health Obligations and Core International Health Regulation Capacities?
Brigit Toebes, Lisa Forman, and Giulio Bartolini

- 113 Beyond Reproduction: The “First 1,000 Days” Approach to Nutrition through a Gendered Rights-Based Lens
Mai-Lei Woo Kinshella, Sophie E. Moore, and Rajavel Elango
- 125 A Right-to-Health Lens on Perinatal Mental Health Care in South Africa
Shelley Brown, Gillian MacNaughton, and Courtenay Sprague
- 139 Establishing Good Practice for Human Rights-Based Approaches to Mental Health Care and Psychosocial Support in Kenya
Faraaz Mahomed, Jacqueline Bhabha, Michael Ashley Stein, and Dainius Pūras
- 155 Intimate Partner Violence, Human Rights Violations, and HIV among Women in Nairobi, Kenya
Courtney Andrews, Tina Kempin Reuter, Lauren Marsh, Judith M. Velazquez, Walter Jaoko, and Pauline Jolly
- 167 Assessing a Human Rights-Based Approach to HIV Testing and Partner Notification in Kenya: A Qualitative Study to Examine How Kenya’s Policies and Practices Implement a Rights-Based Approach to Health
Neiloy R. Sircar and Allan A. Maleche
- 177 Identifying Strategies to Advance Health Equity through Action on Social Determinants of Health and Human Rights for Street-Connected Children and Youth in Kenya
Lonnie Embleton, Pooja Shah, Allison Amin Gayapersad, Reuben Kiptui, David Ayuku, and Paula Braitstein
- 199 Police Discrimination, Misconduct, and Stigmatization of Female Sex Workers in Kenya: Associations with Delayed and Avoided Health Care Utilization and Lower Consistent Condom Use
David Kuria Mbote, Laura Nyblade, Caroline Kemunto, Kayla Giger, Joshua Kimani, Pia Mingkwan, Stella Njuguna, Emmanuel Oga, and John D. Kraemer
- 213 Community Mobilization to Promote and Protect the Sexual and Reproductive Rights of Women Living with HIV in Latin America
Tamil Kendall, Jimena Avalos Capin, Nazneen Damji, and Eugenia Lopez Uribe
- 227 The Right to Health in Times of Pandemic: What Can We Learn from the UK’s Response to the COVID-19 Outbreak?
Lisa Montel, Anuj Kapilashrami, Michel P. Coleman, and Claudia Allemani
- 243 A Health-Based Case against Canadian Arms Transfers to Saudi Arabia
Rhonda Ferguson and Zarlisht Jamal
- 257 Underreporting of Violence to Police among Women Sex Workers in Canada: Amplified Inequities for Im/migrant and In-Call Workers Prior to and Following End-Demand Legislation
Bronwyn McBride, Kate Shannon, Brittany Bingham, Melissa Braschel, Steffanie Strathdee, and Shira M. Goldenberg
- 271 Regulating Conscientious Objection to Legal Abortion in Argentina: Taking into Consideration Its Uses and Consequences
Agustina Ramón Michel, Stephanie Kung, Alyse López-Salm, and Sonia Ariza Navarrete

PERSPECTIVES

- 285 COVID-19 Clinical Bias, Persons with Disabilities, and Human Rights
Omar Sultan Haque and Michael Ashley Stein
- 291 EU Migration Pact Fails to Address Human Rights Concerns in Lesbos, Greece
Vasileia Digidiki and Jacqueline Bhabha
- 297 Book Review: Preparing the Next Generation to Advance Human Rights in Global Health
Paul Hunt

STUDENT ESSAY

- 299 The Disproportional Impact of COVID-19 on African Americans
Maritza Vasquez Reyes

VIEWPOINTS

- 309 Paradigm Under Threat: Health and Human Rights Today
Jonathan Cohen
- 313 Address Exacerbated Health Disparities and Risks to LGBTQ+ Individuals during COVID-19
Sara Wallach, Alex Garner, Sean Howell, Tyler Adamson, Stefan Baral, and Chris Beyrer
- 317 Good Health Indicators are Not Enough: Lessons from COVID-19 in Peru
Camila Gianella, Ruth Iguñiz-Romero, María José Romero, and Jasmine Gideon
- 321 Revisiting Restrictions of Rights after COVID-19
Leonard Rubenstein and Matthew DeCamp
- 325 COVID-19 in Turkmenistan: No Data, No Health Rights
Aynabat Yaylymova
- 329 Ameliorating COVID-19's Disproportionate Impact on Black and Hispanic Communities: Proposed Policy Initiatives for the United States
Audrey Chapman

VIRTUAL ROUNDTABLE

- 333 A Virtual Roundtable with Special Rapporteurs on the Right to Health
Carmel Williams and Joseph J. Amon

EDITORIAL

Enter the Cyborgs: Health and Human Rights in the Digital Age

SARA L. M. DAVIS AND CARMEL WILLIAMS

In Donna Haraway's 1992 *A Cyborg Manifesto*, the medical anthropologist describes the cyborg as a "hybrid of machine and organism" living "on the boundary between fact and fiction": "We are all chimeras, theorized and fabricated hybrids of machine and organism."¹ In 2020, the world that Haraway imagined has arrived, accelerated by the isolation and surveillance enforced in the COVID-19 pandemic. In this special section, contributors explore the role of big data, technology, and artificial intelligence in the prevention, detection, tracing, and treatment of COVID-19 in a world being rapidly reshaped by this pandemic.

In 1992, Haraway observed that medicine was already witnessing the growth of people's dependency on computers or other machinery. But as of late 2020, the computer and the mobile phone have moved fully into the center of our lives. In order to mitigate the risk of COVID-19 transmission, a significant portion of the world's population now works, socializes, shops, and seeks entertainment and love online. Recall the feelings of despair and the very real, immediate social isolation that follows the loss of your phone or internet connection. These increasingly essential tools today contribute to what Netherlands informatician Sennay Ghebream calls an "exocortex," or artificially intelligent (AI)-driven information that now shapes and mediates our human judgments and behavior, making us vulnerable to manipulation and to perpetuating racial and gender discrimination.² Health has also digitized, with digital contact tracing, real-time epidemiology, and remote diagnosis rapidly scaling up in many countries. Even after COVID-19 passes into history, the world is never going back to the days when a phone was something attached to a wall instead of being a constant companion and essential tool for looking up health information, including the latest local incidence rates.

Our call for papers for this special section predated COVID-19. We invited authors to examine, for example, links between new technologies and the protection of economic, social, and cultural rights, because we believed that the impact of technologies on social rights was underexplored. We sought reflection on the risks posed by the global reliance on data and the way that new technologies are changing power relations between states and the private sector. We did not foresee, of course, how quickly this would accelerate. As the papers in this section demonstrate, we were already well down this path before COVID-19, but the pandemic has provided the urgency, financial resources, government support, and often public compliance, to accelerate the trends.

So if many of us are now cyborgs, mentally dependent on digital tools even if not physically attached to them, then what does the cumbersome 20th-century structure of human rights have to offer? Does

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it promote resistance toward big data and digital technologies altogether? Some human rights activists argue forcefully for this (for instance, Stop LAPD Spying, a US-based nongovernmental organization that advocates against predictive policing and discriminatory data-driven prosecution, as well as the Feminist Data Manifest-No, which “refuses harmful data regimes”).³ The authors of the articles in this special section largely accept that digital health is here to stay; but they agree that there are both real threats and real boundaries that human rights tools, norms, and court decisions can help us manage in the digital age.

These risks are significant and frightening, as Lisa Cosgrove, Justin M. Karter, Mallaigh McGinley, and Zenobia Morrill describe in their analysis of mental health surveillance. They describe two new technology tools—digital phenotyping, which predicts mood based on how a person taps, scrolls, and types on their phone, and the first-ever “digital” drug, an antipsychotic medication embedded with a sensor to monitor compliance. These authors, and many others in this collection, express concern at how such intimate data is used beyond its first purpose. Nearly all mental health apps, they find, send the data they collect to Facebook or Google for use in data analytics or marketing. Not only do vulnerable users of these mental health apps have no agency over their own data, but there is absolutely no guarantee that the data will not be used to discriminate against them in the future.

Referring to COVID-19 as the “Pandemic Shock Doctrine,” Naomi Klein described the high-tech response to the pandemic as “a living laboratory for a permanent—and highly profitable—no-touch future.”⁴ She characterized such a dystopic future as one in which our every move, our every word, our every relationship is trackable, traceable, and data mineable by unprecedented collaborations between government and tech giants. As Sara (Meg) Davis notes in her perspective, Shoshana Zuboff shows in *Surveillance Capitalism* how tech giants use social media data and notifications to manipulate individual behavior for profit, as frighteningly illustrated in Netflix’s film *The Social Dilemma*.⁵ Davis and Rajat Khosla both

identify the risks of partnerships between governments or global agencies, on the one hand, and data mining companies such as Palantir, on the other, where data previously collected for humanitarian efforts are then used, for example, to prosecute the parents of immigrant children.

Related risks explored in this special issue include threats to privacy, autonomy, and nondiscrimination. Several papers refer to human rights abuses that have been a direct result of egregious data-sharing instances. In his viewpoint, Khosla describes the important work of Amnesty International’s Amnesty Tech program in monitoring the unlawful use of digital surveillance to “spy on, intimidate, threaten, or silence activists or to locate, detain, or imprison them.”

Several authors in the collection describe discrimination and other abuses linked to gap-filled and inaccurate health data and algorithms, and to the commodification of data. Amy Dickens looks at the risks of public-private partnerships in which state agencies provide the public’s health or other data to the private sector to develop AI products that they can then sell back to the state. Such arrangements draw parallels with the pharmaceutical sector that historically, and for COVID-19 vaccine development, uses state funding to develop products for private profit. It is incumbent upon states to recognize the high value of data, as well as the human rights implications of any data-sharing arrangements they enter into. There is, as Dickens explains, much more at stake than civil and political rights—the big risk is that private actors are gaining ever more expansive monopoly powers that threaten future socioeconomic rights entitlements.

There is clearly something here that needs governing: cyborgs need rights, too. To address these risks, these authors find rich resources in the human rights tradition, which can be used to better manage the promise and threats of digital technologies and AI in health. Sharifah Sekalala, Stéphanie Dagrón, Lisa Forman, and Benjamin Mason Meier examine these principles in their paper and take the view that surveillance and tracing technologies are more readily accepted by the public when they are clearly shaped and underpinned with transparency

and other human rights features. They outline how the Siracusa Principles could be used to inform technology-related health decisions in an outbreak: Sekalala and colleagues' recommendations could be invaluable to the committee engaged in the review of the International Health Regulations, which incorporates a reference to Siracusa.⁶

In response to Sekalala and colleagues' recommendations, writing from a tech perspective, Akarsh Venkatasubramanian agrees that there is a need for more robust global regulation. COVID-19, he suggests, offers an opportunity to build and strengthen a global rights-based, equitable, inclusive governance structure, such as an international health data regulation, that is designed with geographical and sectoral representation and that promotes responsible and appropriate digital health surveillance during and beyond emergencies. He also calls for the creation of registers or indices of approved technologies, similar to the Access to Medicines Index. He challenges us to think about how tech could be used to fulfill and promote the right to health, and how the law needs to create space for rapid changes in technology.

Nina Sun, Kenekwue Esom, Mandeep Dhaliwal, and Joseph J. Amon outline these much-needed ethical and human rights standards relevant to the use of digital health technologies. They present practical strategies to mitigate risks, and review mechanisms of accountability, showing how the International Covenant on Economic, Social and Cultural Rights, judicial rulings, and lessons learned from the work to address human rights and HIV could inform the governance of digital health. Importantly, their paper addresses the human rights obligations of the private sector, positioning the obligation not to cause adverse human rights impacts as a legal compliance issue. They stress the need for health technology assessments to prevent rights violations arising from data breaches, biases, and "function creep," whereby data are used for purposes other than that for which they were collected. While acknowledging the potential of data technology to reduce health care costs and transform health systems, Sun et

al. warn that the risk of rights violations is real and grounded in the experiences of populations who are already subject to discrimination, social marginalization, and surveillance. In the future development of digital health technologies, they urge that attention be given to the development of community-owned technologies, aligned with ethical and human rights principles, to advance accountability and justice.

For Louise Holly, the Convention on the Rights of the Child offers principles and guidance that could help ensure that children and youth are at the center of digital health policy. Data from a multitude of digital devices are captured about children even before they are born. While such data are usually captured for public health purposes (for example, biometric data are used to boost vaccination rates), Holly argues there is insufficient consideration of any unintended consequences on the enjoyment of other rights. Health data that enable people to be located, she explains, can put children—particularly those from marginalized groups—at risk of discrimination or persecution. Information relating to a child's health status may later be used by employers, insurance companies, and other third parties, again potentially breaching their equitable access to health care and other social rights.

Furthermore, with regard to planning, priority setting, and providing guidance and technical support, Davis and Carmel Williams each outline responsibilities for the World Health Organization (WHO), the Global Fund, and states to improve their assessment of needs and risks before scaling up (or financing the scale-up of) digital health. Looking at more immediate right to health issues arising with the urgency that WHO and other agencies are placing on low- and middle-income countries to digitize their health systems, Williams recommends that health rights impact assessments be conducted before any AI or data-driven projects are embarked upon. These assessments are necessary not just to examine future ownership and costs of products but also to ensure that switching to data-driven systems will not weaken health

systems by overlooking fundamental issues, such as whether the system has the capacity to sustain such initiatives. She warns that digital development projects are at risk of being designed from afar without regard for local knowledge or local contextual constraints. Both Williams and Davis contend that WHO and the multiagency AI for Good initiative, which encourages the use of data-driven technology to achieve the Sustainable Development Goals, limit their concerns about AI primarily to digital divide issues.

How could human rights experts and tech developers work together? Is there common ground to be found in these very different fields? Researchers from the tech community argue that indeed there is. It is an often-quoted truism in human rights that political problems cannot be fixed with technical solutions, but Vinodkumar Prabhakaran and Donald Martin Jr. make a compelling case for doing exactly that. While Cosgrove describes how Google extracts our most private data for its private gain, these two Google researchers propose combatting racial and other forms of discrimination by cracking open the mysteries of algorithms through participatory approaches to machine learning design. They claim that this more diverse and inclusive approach helps overcome what Ghebreab argues is a weakness in the technological “exocortex”—namely, the algorithmic errors that arise when machine learning systems are informed by the biased understandings of only one gender, one ethnicity, or one socioeconomic demographic.

In their paper on feminist data, Shirin Heidari and Heather Doyle urge the use of an intersectional feminist lens to data itself, arguing that it is not sufficient to consider the intersection of gender with other dimensions of oppression regarding what data are collected. Rather, they urge a critical reflection on the ways that data are collected and evidence is produced, calling for the adoption of feminist principles to shape global health data.

As Heidari and Doyle conclude, on a positive note, COVID-19 presents an opportunity to reshape our future, including our digital future. This

opportunity, they say, is not a utopian dream. But, as they caution, the time to act is now. As many of the contributors to this special section make clear, if we do not protect human rights in the digital space, we risk not only the health and well-being of people today but also those of future generations.

These multidisciplinary voices are sorely needed. As the boundaries separating computers from humans blur, the disciplines engaged in governing new technologies also must begin to cross boundaries. The human rights linked to health must expand and adapt to a new domain with new standards that build on the old norms and that encompass rapidly changing capabilities. Lawyers, feminists, anti-racists, decolonizers, social scientists, tech researchers, and patients’ advocates will need to find common languages to communicate with one another. Rather than generals fighting the last war, rights scholars and advocates will need to be able to think ahead to a future shaped by technologies that are not in laboratories yet: a future in which our rapidly evolving and fragile cyborg selves will need protections and powers we cannot even imagine. This special section is a first step into this brave new world of digital health and human rights, but it must not be the last.

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Analyzing the Human Rights Impact of Increased Digital Public Health Surveillance during the COVID-19 Crisis

SHARIFAH SEKALALA, STÉPHANIE DAGRON, LISA FORMAN, AND BENJAMIN MASON MEIER

Abstract

The COVID-19 pandemic has led policy makers to expand traditional public health surveillance to take advantage of new technologies, such as tracking apps, to control the spread of SARS-CoV-2. This article explores the human rights dimensions of how these new surveillance technologies are being used and assesses the extent to which they entail legitimate restrictions to a range of human rights, including the rights to health, life, and privacy. We argue that human rights offer a crucial framework for protecting the public from regulatory overreach by ensuring that digital health surveillance does not undermine fundamental features of democratic society. First, we describe the surveillance technologies being used to address COVID-19 and reposition these technologies within the evolution of public health surveillance tools and the emergence of discussions concerning the compatibility of such tools with human rights. We then evaluate the potential human rights implications of the surveillance tools being used today by analyzing the extent to which they pass the tests of necessity and proportionality enshrined in international human rights law. We conclude by recommending ways in which the harmful human rights effects associated with these technologies might be reduced and public trust in their use enhanced.

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Introduction

The COVID-19 public health crisis is the first truly global infectious disease threat in over a century. The scale of the pandemic has deepened the imperative for policy makers to expand beyond traditional public health mechanisms of surveillance to use new technologies, including global positioning systems, cell phone apps, and facial recognition to control the spread of SARS-CoV-2. These new surveillance technologies highlight longstanding tensions in public health between individual rights and collective interests. They also fall at the interface of multiple contemporary trends: the reduction of privacy online, the private monetization of online data, the use of big data in policymaking, and the abuse of online surveillance by governments. These trends are viewed as creating “surveillance states” and new forms of “surveillance capitalism” with the capacity to erode human rights and undermine democracy.¹ This context is important when it comes to digital public health surveillance mechanisms for COVID-19, since historical and contemporary rights abuses of surveillance mechanisms erode public trust and the solidarity necessary for the widespread adoption and public health efficacy of such mechanisms.

Human rights standards have evolved to ensure that public health surveillance mechanisms, even in the context of a public health emergency, meet human rights standards of legality, necessity, and proportionality. These standards require that adequate safeguards be put in place to ensure that such surveillance mechanisms, whether they are digital or traditional, do not illegitimately restrict the human rights to health, life, or privacy, and are not abused for the purposes of state control. In this light, the increased use of blanket enforcement measures, such as mass-scale video surveillance, drones, facial recognition, and even large-scale attempts at data mining, raise significant human rights concerns.

In this article, we explore the human rights dimensions of how these new technologies are being used to address the COVID-19 pandemic, and in particular, the extent to which they are legitimate restrictions on a range of human rights, including

the right to privacy, the right to health, and other social and economic rights. We argue that human rights serve two important functions in the context of public health surveillance: first, by offering an important framework for safeguarding the public from overreach, and second, by enhancing the efficacy of the mechanisms themselves to the extent that their use in democratic constitutional contexts relies on widescale consensual public opt-in. We begin with mapping the surveillance technologies being used in the wake of the COVID-19 crisis, before analyzing the evolution and potential human rights implications of these tools. In doing so, we analyze the extent to which surveillance tools meet necessity and proportionality criteria in international human rights law. At the same time, we acknowledge the functional limitations of this assessment—international human rights law primarily binds states that ratify its instruments, yet it is often private corporate actors who create and use these tools. We discuss to what extent this balancing of human rights and public health imperatives extends to such nonstate actors. We close with recommendations to mitigate the human rights effects of these technologies and increase public trust in their use.

Public health surveillance during COVID-19

Public health surveillance is the systematic collection, storage, usage, and dissemination of personal information to identify an outbreak and mitigate the spread of disease.² In light of the global spread of COVID-19, the World Health Organization (WHO) has stated that the main objectives of surveillance during this pandemic are

*to enable rapid detection, isolation, testing, and management of cases, to monitor trends in COVID-19 deaths, to identify, follow-up and quarantine of contacts, to detect and contain clusters and outbreaks, ... monitor longer term epidemiologic trends and evolution of SARS-CoV-2 virus.*³

In further guidance on public health surveillance

during the COVID-19 crisis, WHO has also argued that digital technologies may support rapid reporting, contact tracing, and data management.⁴ The use of digital tools in public health surveillance is not unique to the COVID-19 crisis. During the outbreak of severe acute respiratory syndrome in 2003, Hong Kong identified clusters of disease using electronic data systems.⁵ During the Ebola outbreaks in West Africa in 2014–2016, mobile phone data were also used to model travel patterns and increase the viability of contact tracing.⁶

The current COVID-19 crisis has come at a time of digital revolution, with huge growth in mobile phone and social media use, and sophisticated technologies that can support widespread public health surveillance.⁷ Digital surveillance tools can far more easily enable governments to identify disease outbreaks and engage in case identification.⁸

Outbreak surveillance

Digital surveillance tools have revolutionized the way in which public health systems can identify and respond to outbreaks. Tools such as WHO's Go.Data use real time data to register cases and their contacts, facilitating the analysis of contact tracing data and chains of transmission to better understand epidemics.⁹ Tools are often run by third parties, such as technology companies and research institutes, which then have the capacity to mine data through machine learning and crowdsourcing.¹⁰ For instance, the private Toronto-based corporation Blue Dot reported the emergence of COVID-19 through its early detection system before WHO declared a pandemic.¹¹ This was accomplished through the use of big data, which used natural language processing and machine learning to cull data from hundreds of thousands of sources, including statements from official public health organizations, digital media, global airline ticketing data, livestock health reports, and population demographics.¹²

While these new innovative systems can provide quick and often informative data, they can also suffer from problems of accuracy due to sample bias, over-interpretation of findings, and fragmentation among competing systems that lack

a centralized approach to data collection.¹³

Case identification

Early and rapid case identification is crucial during a pandemic for the isolation of cases and tracing of contacts in order to reduce disease transmission.¹⁴ Digital technologies can supplement clinical and laboratory notification through the automated use of symptom-based case identification, accelerating reporting to public health databases.¹⁵ During the COVID-19 crisis, digital tools for case identification have been used through online symptom reporting apps in numerous countries, such as Singapore, Malaysia, the UK, and South Africa. Such tools can easily be integrated within national databases.¹⁶

During this crisis, we are also seeing the increasing use of wearable technologies, such as bracelets, which enable public health authorities to check people's temperatures and other symptoms in order to ascertain whether they may be experiencing COVID-19 symptoms. Liechtenstein, for example, plans to roll out such bracelets to the entire population.¹⁷ Sensors, including thermal imaging cameras and infrared sensors, are being deployed within public spaces in Taiwan and Singapore (and by private companies in the United States and Canada) to identify potential cases on the basis of symptoms such as temperature.¹⁸ Several airports, bus shelters, and train stations have installed these technologies, although there are concerns about the number of false positives that these schemes could generate.¹⁹

The tracing of contacts, which is designed to reduce onward transmission, is part of the case identification strategy. Previously, states relied primarily on manual contact tracing—interviewing an infected person, tracking down the recent contacts that they could recall, and advising those people to self-isolate. However, given the high proportion of pre-symptomatic transmission for COVID-19 and the scale of national and global infections, it was argued that manual contact tracing would be too slow to stop the progression of infection through the population.²⁰ This led to the development of digital tools to support faster contact tracing, primarily through the use of mobile smartphones or

other wearable devices with geolocation capability. Mobile phone contact tracing apps can thus make contact tracing and notification instantaneous, since, by keeping a record of proximity events between individuals, it can immediately alert recent close contacts of diagnosed cases and prompt them to self-isolate.²¹

Human rights concerns raised by evolving surveillance technologies

During pandemics, public health surveillance is considered critical for averting and containing the spread of a disease. However, these public health data are often personally identifiable and sensitive and may reveal details about a person's lifestyle, behaviors, and health.²² Thus, the evolution of such surveillance technologies has always been accompanied by rights-based concerns about how the data are used.

Discrimination against vulnerable and marginalized populations was entrenched by early surveillance efforts. For instance, nationalist governments employed public health surveillance to legitimize discriminatory public health policies against migrants during the Industrial Revolution. The rapid spread of diseases in urban centers was often attributed to racial minorities, whether Roma populations in Europe or Chinese immigrants in the United States.²³ For instance, the rapid spread of smallpox in San Francisco in 1876 was falsely attributed to Chinese Americans living in the city, leading to quarantine orders on the basis of race. Public health officials produced reports that blamed the outbreak on the refusal of Chinese Americans to assimilate into Western society, highlighting their deviance from white society to further stigmatization and justify discrimination.²⁴ Following from the genocidal horrors of World War II, with Nazi eugenics laws massively violating the rights of minority populations under the purported public health justification of "healing the state," countries came together under the postwar United Nations (UN) to codify protections of individual rights.

Nondiscrimination and equality would be-

come core elements of international human rights law. Article 2 of the 1948 Universal Declaration of Human Rights (UDHR) states that every human being is entitled to all rights and freedoms "without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." Similarly, the 1966 International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) require state parties to guarantee the enjoyment of all rights without discrimination of any kind.

These human rights developments would also look to protect individual privacy, first in the UDHR and culminating in the ICCPR.²⁵ The ICCPR created a legal imperative for states to ensure that no one is "subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation."²⁶ In developing these ICCPR provisions, states debated the conditions under which it would be acceptable when facing a national crisis (such as a public health emergency) to limit or suspend individual rights and freedoms—such as the right to privacy—seeking to balance the responsibility to protect their citizens and the imperative to uphold civil and political liberties.²⁷

UN member states came to recognize that "public health may be invoked as a ground for limiting certain rights."²⁸ Through the Siracusa Principles, a nonbinding document developed by nongovernmental organizations and adopted by the UN Economic and Social Council in 1984, scholars developed a set of principles to ensure that any limitations on civil and political rights occur only "in narrowly defined circumstances," holding that such human rights infringements may be made only under the following conditions: (1) when applied as a last resort; (2) when prescribed by law (that is, not imposed arbitrarily); (3) when related to a compelling public interest (for example, the protection of public health); and (4) when found to be necessary, proportional to the public interest, and without less intrusive or restrictive measures available.²⁹

The Siracusa Principles have become central to understandings of human rights derogation in the field of “health and human rights” and critical to understanding how human rights law should align with global health governance pursuant to the International Health Regulations. Developed by states as an international legal framework to address public health emergencies, the International Health Regulations’ purpose is to prevent, protect against, control, and facilitate public health responses to the international spread of disease, and they make surveillance central to guiding effective public health action against cross-border disease threats.³⁰ Balancing the societal benefit of public health surveillance against the state infringement of individual rights, the revised International Health Regulations (2005) for the first time incorporated human rights into infectious disease control, focusing on human rights considerations in disease surveillance. The regulations structure state responses to public health emergencies of international concern in ways that are commensurate with, and restricted to, public health risks and which avoid unnecessary interference with international traffic, trade, and human rights.

Concerns raised by digital health surveillance during COVID-19

The scale and complexity of digital health surveillance raises four main concerns for human rights, and these human rights concerns risk undermining the public health surveillance system due to the erosion of public trust.

First, the efficacy of digital tools for global health surveillance is questionable, since many of these tools are still in the experimental phase.³¹ For instance, at least 40 countries are using contact tracing apps, but there is not yet sufficient evidence about their ability to mitigate the spread of disease.³²

Second, the fact that third-party actors are creating, using, and storing data poses questions of accountability. While traditional public health surveillance involved primarily the state, the rise of emerging digital surveillance tools has led to the involvement of a large number of third-party private actors that have access to personal health data

that could be exploited in ways that irreparably damage trust in public health surveillance.³³ In the UK, for instance, private companies Serco, SITEL, and Amazon Web Services will all have access to users’ data, and these data will reportedly be held for 20 years. It is currently unclear whether these companies will be allowed to privately benefit from the use of these data.³⁴

Third, beyond threats to the general public, increased digital health surveillance may exacerbate specific harms to minority groups such as LGBTQ people and migrants. This may be in the form of increased violations to their rights of privacy, increased discrimination, and the reinforcement of inequalities. While aggregated location data can monitor population flows in real time, identify potential transmission hotspots, and give insight into the effectiveness of other public health interventions, such as travel restrictions, it can also harm vulnerable users by identifying their physical locations. This is extremely concerning given that a recent analysis of 50 COVID-19-related apps in the Google store showed that only 16 explicitly stated in their policies their intent to anonymize user data.³⁵ Minority groups are particularly at risk of abuse of privacy; for instance, contact tracing for a COVID-19 outbreak in South Korea led to homophobic abuse targeted at the South Korean LGBTQ community.³⁶ There are already reports that some minority groups have been disproportionately affected by COVID-19 and, in many places, are already less likely to seek health care due to a history of discrimination.³⁷

Making private and public service provision contingent on downloading digital surveillance tools (such as contact tracing apps) could not only constitute a threat to personal autonomy but also be discriminatory toward already disadvantaged groups. For instance, employers may demand that staff download apps before being allowed into work, people may need these apps in order to use public services (such as health services), and landlords could demand that people download apps before being able to rent a property. These examples are all problematic, not just because they are coercive but also because they reinforce inequality, often ex-

cluding poor and vulnerable groups of people, such as migrants who may not be able to access or use the apps. In India, for instance, the contact tracing app Aarogya Setu has now become mandatory for all employees, rendering the concept of meaningful consent irrelevant.³⁸ In Singapore, employers are told to encourage all workers to download the TraceTogether app, but it is mandatory for certain groups of migrant workers, making them particularly vulnerable as they often have fewer rights than other citizens.³⁹ Many migrants in these countries, especially those employed in the informal sector, are often poor and on precarious contracts. Mandatory requirements to download and use such apps would mean that they have to buy newer models of smartphones which are expensive. The use of digital surveillance tools could also disproportionately affect some groups, such as those with lower socioeconomic status and those who are older and who may not have adequate internet access.⁴⁰ For instance, the Qatari contact tracing app EHTER-AZ is another example of a mandatory app that requires users to have compatible smartphones, which is problematic when many citizens and migrant workers live in poverty. In Qatar, people who fail to download the app could face up to three years in prison and a fine of QR200,000 (US\$55,000). Such impositions disproportionately affect the 88% migrant population in Qatar, exacerbating existing social inequalities.

Fourth, the use of digital health surveillance measures may lead to abuses by states and nonstate party actors if such measures become embedded in other processes different from their original purposes. The long-term nature of the COVID-19 crisis has led to fears that a new extended regime of health surveillance could entail permanent, intrusive surveillance, lasting well beyond the “temporary” measures justified by an “emergency” context.⁴¹ Digital surveillance apps could be linked to comprehensive medical records and used to enable health care access. In Hangzhou, China, authorities have reportedly started to link data from surveillance apps to citizens’ medical records. There are also reports that authorities in Shanghai are considering integrating a personal health index

into an app, which will rank citizens on indicators such as how much they sleep, how many daily steps they take, and how much they smoke and drink.⁴² These extensions lead to concerns that the ability to access public services could be tied to the app, thereby making it easier to deny health care and other essential services to members of the public.⁴³ Furthermore, the commercialization of health data drawn from long-term surveillance could also lead to discriminatory exclusions and differential pricing by insurance companies.

Digital tools could also be securitized in a way that exceeds legitimate public health objectives. Some data from public health surveillance tools have already been shared with security officials. The governments of Israel, Kenya, Mexico, and Turkey, among others, have reportedly used the COVID-19 pandemic as an opportunity to analyze telecommunications data under the guise of “contact tracing.”⁴⁴ The Pakistani government has repurposed an anti-terrorism system designed by the country’s spy agency to trace suspected COVID-19 cases.⁴⁵ There are dangers that some of these surveillance mechanisms will become structurally embedded as they did in the US War on Terror—a modern example of how emergency measures may be abused to become permanent fixtures within societies.⁴⁶

Finally, abuses due to the misuse of data, privacy violations, and discrimination due to the uneven coverage and consequences of digital health surveillance measures might not only damage public trust in public health surveillance but also lead to fragmented responses caused by competing actors promoting different digital tools

Human rights obligations and digital surveillance

Under international human rights law, states are required to have robust public health surveillance measures in order to safeguard the rights to life and health.⁴⁷ In the case of COVID-19, these obligations are critical, as surveillance is necessary to break chains of transmission and learn as much as possible in order to be able to develop better medical interventions, drugs, and vaccines.

As discussed above, digital surveillance can threaten the right to privacy, as enshrined in international human rights law, beginning in article 12 of the UDHR and confirmed in article 17 of the ICCPR.⁴⁸ Article 8 of the European Convention on Human Rights also protects privacy.⁴⁹ The right to privacy has been interpreted as covering the compilation, storage, use, processing, and dissemination of data relating to private life.⁵⁰ Any restrictions to the right to privacy should be legal and non-arbitrary; necessary and proportionate; and compliant with other rights guaranteed in these human rights instruments.⁵¹ The European Court of Human Rights has held that the mere storing of data relating to the private life of an individual would constitute a violation of the right to privacy; it does not matter whether the information is sensitive.⁵² The Siracusa Principles recognize that public health may be invoked as a ground for limiting certain rights (such as privacy) in order to allow a state to deal with a serious threat to the health of the population or individual people. Human rights derogations under the Siracusa Principles would need to meet three criteria: legality, necessity, and proportionality.⁵³ We will explore how the problems posed by digital tools stack up against these criteria below.

Legality

All restrictions to privacy must be non-arbitrary and prescribed by law.⁵⁴ The UN Human Rights Committee, which is mandated with monitoring and implementing the ICCPR, has argued that in order for law to be non-arbitrary, any interference provided for by the law should be in accordance with the aims and objectives of the ICCPR and reasonable in the particular circumstances.⁵⁵ In order to comply with legality, personal data must be processed in a transparent manner. Transparency is important within human rights discourse because it enables people to seek meaningful consent, monitor how data are used, and seek redress in instances where there are perceived violations of human rights.⁵⁶ Many governments have been accused of a lack of transparency. For instance, governments need to better explain what apps do, what data they collect, where they store the data, and the benefits

that apps give to the general public. For example, the Indian government has been criticized for enabling the data collected from its contact tracing app to potentially be used by any government agency for other purposes.⁵⁷ Therefore, states and data organizations must be clear about how they will use personal data. In Israel, the High Court of Justice found that digital surveillance during the COVID-19 pandemic, which used national security legal authority for the Ministry of Health to implement the digital tracking of individuals, was illegal because it was conducted under an executive order and lacked the scrutiny that would have been present through legislative approval.⁵⁸

Necessity

In order to limit rights through the use of digital technologies, states must show that the limitations are “strictly necessary,” in that they must respond to a pressing public or social need.⁵⁹ WHO has acknowledged that surveillance measures are necessary to “limit the spread of disease, enable public health authorities to manage the risk of COVID-19, and thereby enable economic and social activity to resume to the extent possible,” as well as to “monitor the longer-term trends of COVID-19 transmission and the changes in the virus.”⁶⁰

While there is excellent evidence that digital outbreak response tools are more efficient at providing epidemiological data for disease detection, the evidence on whether digital surveillance tools for contact tracing are actually effective remains inconclusive.⁶¹ Some modelling suggests that digital health surveillance is necessary because the rate of transmission for COVID-19 is so rapid that manual contact tracing would be inadequate, but more data are needed to prove the efficacy of the tools.⁶² The urgency of alleviating the pandemic does not remove the test of necessity, which requires proper scientific validity and accuracy.⁶³

Proportionality

Under the principle of proportionality, the limitation on human rights must be commensurate to the aim. Measures must therefore be timebound and purpose-limited to the specific aim of preventing

the spread of infectious diseases. It follows that any digital health surveillance that goes beyond public health surveillance would fail the proportionality test. This view was also taken by the UN General Assembly when it considered the indiscriminate mass surveillance by the UK and US governments in the wake of the September 11 attacks. The subsequent UN resolution stated that “surveillance and/or interception of communications ... as well as the collection of personal data, in particular when carried out on a mass scale, may have [a negative effect] on the exercise and enjoyment of human rights.”⁶⁴ The European Court of Human Rights has been more expansive on the concept of mass state surveillance, holding that legal discretion granted to the state to enact surveillance cannot be unfettered.⁶⁵ In practice, this means that surveillance laws must not include blanket provisions, must be clear, and can be used only for a legitimate aim in order to ensure that the individual is protected from arbitrary interference.

To meet the test of proportionality, data should be used only for legitimate public health surveillance purposes, such as prevention of disease through the tracking and monitoring of patients with COVID-19. Determining what amounts to a legitimate public health surveillance purpose may sometimes be complex. Under the proportionality test, data could legitimately be shared across government agencies for health-related purposes or used to perform targeted interventions, such as reaching out to people who are at risk of getting COVID-19, if they have informed consent from users. However, it is clear that many digital health surveillance tools rely on broad consent, which may legally allow data to be used for future purposes. In order for this broad consent to meet the requirements of informed consent and maintain public trust, the use of future applications should still be transparent, and there should be publicly accessible mechanisms that can enable participants who download health apps to scrutinize the way in which their data are being used even after they have consented.

Digital health surveillance data may legally be used for enforcement purposes. For instance,

test and trace data used to enforce quarantines and isolations serves a legitimate public purpose. Nevertheless, using data for enforcement would be considered human rights compliant only if done through a process that is transparent, nondiscriminatory, and time limited in order to help local authorities identify those at risk. Using criminal sanctions for enforcement would only legitimate and proportionate if used as a last resort.

Recommendations

This article has illustrated that new digital surveillance tools violate a number of human rights, such as the rights to privacy, freedom of movement, and health, in addition to committing several specific rights violations against vulnerable groups, such as migrants, LGBTQ populations, and the elderly. For digital surveillance tools to comply with human rights, they should be evidence based, contribute to a comprehensive public health surveillance system, include sunset clauses, be nondiscriminatory, and ensure mechanisms for greater transparency and accountability, including those aimed at nonstate actors such as private companies.

Evidence-based measures

To meet the criterion of necessity, states should insist on conducting rigorous pilot studies and risk assessments to ensure accurate, evidence-based decision-making.⁶⁶ Additionally, states should take advantage of national and regional evidence frameworks for digital health technologies.⁶⁷ WHO and regional bodies, such as the European Union, have started to give technical guidance about digital surveillance tools, but so far they have focused primarily on contact tracing apps; moving forward, they should also consider the wide range of additional digital surveillance tools that states may be using to monitor and control people.⁶⁸

Additionally, a greater reliance on evidence would compel states to show that they cannot achieve the goal of preventing the spread of COVID-19 through “less restrictive means,” including decentralized data within contact tracing apps or nontechnological measures. Some govern-

ments are using centralized approaches for contact tracing, in which data are stored on a central server managed by the authority that carries out the processing of the data. Under this model, once an individual comes into contact with an infected person, the state is notified and has the power to enforce quarantines and sanctions. Taiwan, for example, uses smartphone location tracking to detect and sanction quarantine violations.⁶⁹ However, other governments are opting for a decentralized approach in which most data are stored locally on an individual's phone, with the user having more control over how their data are shared with authorities.⁷⁰ Apple and Google are partnering with countries to promote the adoption of such a decentralized approach.⁷¹

Integrated public health surveillance measures

Digital technologies for surveillance must be integrated into the public health surveillance ecosystem. For instance, digital tools that offer symptom tracking or contact tracing must be followed by rapid testing, isolation or quarantine, treatment, and follow-up where necessary.⁷² South Korea and Singapore have successfully introduced contact tracing apps to support large teams of manual contact tracers as one of many measures, including strict isolation of cases and quarantine.⁷³

Temporality

States must ensure that digital health surveillance does not become a new norm. Given the risks to privacy, states must include a sunset clause to any laws that allow digital public health surveillance, which agrees ahead of time what data they are collecting, how long they should collect the data for, and when the permission to collect this data will expire. For instance, some states, such as Macedonia, have allowed users the power to delete all of their data after 14 days. Others, such as Australia, have made a provision for contact data stored on a device to be automatically deleted after 21 days.⁷⁴

Nondiscrimination

To meet the criteria for legality, necessity, and proportionality, digital technologies must not be

discriminatory. Digital health technologies can very easily collect large amounts of data about entire populations, with identifying markers such as race, ethnicity, gender, and sexual identity. Wrongly used, these data can lead to the stigmatization of already excluded minority or marginalized groups. Therefore, states have a human rights obligation to ensure that data from digital technologies are not misused at the expense of such groups.

Although there is an increasingly widespread use of digital technology, there is still unequal coverage, which may exclude vulnerable groups such as those who are poor or older people whose phones may not have the technology to support certain digital technology functions such as proximity tracing.⁷⁵ Thus, states should ensure that in opting for digital technologies, they are not excluding large parts of the population as this could affect access to health care services and heighten health inequalities.

Transparency and accountability

States relying on public health surveillance need to ensure that their digital public health surveillance follows a rights-based approach to transparency and accountability mechanisms. This would involve increased participation from a diversity of end users in the design and rollout of apps, independent oversight through civil society organizations, increased research into the human rights effects of these apps, and greater accountability for the holders of data, including third parties. For instance, in Italy, all of the data from public health surveillance tools is controlled by the Ministry of Health, and the government has committed to ensuring that data are not resold or used for commercial purposes. Some of these data “may be shared to facilitate scientific research, but only after its complete anonymisation and aggregation.”⁷⁶

Greater transparency also enables citizens to seek judicial scrutiny and appropriate remedies, particularly in the case of human rights violations. Transparency through strong multilateral and multistakeholder review frameworks is necessary to hold governments accountable where the use of contact tracing apps fails to meet the requirements

of international human rights law. Currently, there are some examples of domestic review processes that have managed to overturn excessive government surveillance during the COVID-19 pandemic. In Slovakia, the Constitutional Court declared the provisions of a newly amended telecommunications law passed in haste to be unconstitutional. The amendments sought to permit state authorities to access telecommunications data for the purposes of contact tracing; however, the provisions were struck down for being insufficiently clear and for lacking safeguards against misuse.⁷⁷

Accountability for how data are used at the national level can be facilitated through formal mechanisms, such as national human rights action plans, which offer a structured and practical approach to strengthening the realization of human rights through public policy. National human rights action plans could focus on the ways in which state actors are using digital surveillance tools to establish whether human rights abuses are taking place. The Universal Periodic Review (UPR) is a unique process that involves a review of the human rights records of all UN member states. As a state-driven process under the auspices of the Human Rights Council, the UPR provides each state the opportunity to declare what actions it has taken to improve the human rights situations in its territory and to realize its human rights obligations. This process has been recognized as a useful tool for achieving greater state compliance with the right to health.⁷⁸ The role of civil society actors in both of these processes could ensure greater scrutiny of the human rights impact of digital health surveillance at the national level.

Lastly, there is an increased need for empirical research in this area, especially in areas where data may be subject to commercialization or deanonimization in the future.

Human rights obligations of third-party actors

Most digital surveillances involve third-party actors such as technology firms. Although states are the primary duty-holders under international law, there has been some consensus that nonstate actors such as private corporations “have duties to prevent

human rights abuses . . . where they maintain close connections with potential victims or potential perpetrators.”⁷⁹ This broadens the scope of corporate responsibilities to ensure that firms’ actions do not, however inadvertently, contribute to the systematic denial of human rights.⁸⁰ In 2011, the UN Human Rights Council endorsed a framework—the *Guiding Principles on Business and Human Rights*—allocating responsibility to corporations for human rights violations.⁸¹ The Special Representative of the Secretary-General on business and human rights thereafter released a framework in which he argued that the state had the duty to protect against human rights abuses by third parties, including businesses; private actors had the duty to respect human rights; and there was a need for more effective remedies. The *Guiding Principles* articulated the idea that corporate responsibility extended to all internationally recognized fundamental human rights and that it was necessary to distinguish the specific responsibilities of corporations from the responsibilities of states.⁸² The responsibility to respect involves effectively “doing no harm.” This goes beyond a passive responsibility and can entail taking positive steps.⁸³ Discharging the responsibility to respect human rights requires that private companies carry out due diligence. For companies engaged in digital surveillance, this means that, just like states, they too need to consider whether digital surveillance tools meet the criteria of legality, necessity, and proportionality.

Due to the nonbinding nature of the *Guiding Principles*, the nature and extent of these responsibilities—as well as their consequences on private actors—are still contested.⁸⁴ The complex responsibilities of private companies involved in digital surveillance would benefit from specialist guidance from the UN human rights system, including human rights treaty bodies and Special Procedures mandate holders such as Special Rapporteurs.

Conclusion

Numerous digital tools are currently being used by states and private actors for public health surveillance in response to COVID-19. Many of these

tools raise human rights concerns about privacy, autonomy, and nondiscrimination. To comply with human rights law, it is important that digital tools pass the tests of legality, necessity, and proportionality for the legitimate restriction of rights.

For digital surveillance tools to comply with human rights, six key considerations should be considered. In the absence of compelling evidence about the efficacy of digital surveillance tools, states should ensure that they are evidence-based and focus on the least restrictive measures, such as decentralized contact tracing. States must ensure that digital surveillance tools are used to complement a comprehensive public health surveillance system and used in conjunction with measures such as testing, tracing, quarantining, and treatment. Any regulations to promote digital health surveillance should include sunset clauses and ensure that there is no discrimination against vulnerable groups. Additionally, states should ensure mechanisms for greater transparency and accountability, including those aimed at preventing nonstate actors such as private companies from violating human rights.

There is growing evidence that private companies need to respect human rights obligations by carrying out due diligence, which would require them to analyze whether digital tools meet the requirements of legality, necessity, and proportionality. The increased role of private corporate actors, who have less robust obligations than those borne by states, is concerning in digital health surveillance, and there is an urgent need for international human rights bodies to provide updated guidance on how private actors can be held accountable for human rights violations.

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Human Rights and Digital Health Technologies

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Abstract

Digital health technologies have been heralded as a critical solution to challenges and gaps in the delivery of quality health care and essential to achieving the Sustainable Development Goals. Yet they also present threats to privacy and confidentiality, which can lead to discrimination and violence, resulting in violations of the rights to health, housing, employment, freedom of assembly, expression, protection from arbitrary detention, bodily autonomy, and security. More broadly, without proper planning and safeguards, digital health technologies can contribute to expanding health inequity, widening the “digital divide” that separates those who can and cannot access such interventions. This article outlines key harms related to digital technologies for health, as well as ethical and human rights standards relevant to their use. It also presents several strategies for mitigating risks from digital health technologies and reviews mechanisms of accountability, including recent judicial rulings.

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Introduction

In early 2020, facing the challenge of limiting transmission from a poorly understood and fast-moving virus, governments took steps to implement measures to reduce mobility—including lockdowns, travel bans, and restrictions on large gatherings. Without a vaccine or cure, countries sought to increase social distancing; identify and isolate individuals infected by the SARS-CoV-2 virus that causes COVID-19 disease; and quarantine close contacts of those infected and individuals coming from areas with high levels of transmission.¹

Many countries also turned to the development and use of digital technologies to support their COVID-19 response. Basic eHealth approaches, including online COVID-19 data dashboards and mobile phone apps for symptom screening and case management, have complemented new digital technologies such as infrared thermal screening cameras and wearables (for example, smartwatches) that monitor temperature, pulse, and sleep to screen for the disease.² The use of artificial intelligence (AI) and machine learning has allowed for the analysis of large data sets (“big data”) for prediction, forecasting, contact tracing, and drug and vaccine development.

The development of digital apps for contact tracing and for the monitoring and enforcement of quarantine and social distancing orders has been especially prevalent—and controversial—in national responses and in global discussions of how to control COVID-19 and reconcile individual rights to privacy and confidentiality with control efforts. For example, in March 2020, Ecuador’s health ministry released an app for individuals to report COVID-19 symptoms. The application can connect individuals with a health care worker—however, to use the app, users must provide personal information, as well as their geolocated address. Human rights organizations raised concerns about the country’s lack of legislation or independent oversight body to protect the sensitive data collected.³ Similarly, in Israel, an emergency law authorized Israel’s internal security service to collect information, without user consent, to predict which citizens may have been exposed to the virus.⁴ Un-

der the program, the health ministry sends alerts to people’s phones ordering them to self-quarantine. In the United Kingdom, the development of a contact tracing app by the National Health Service was met with concerns from parliamentarians about the lack of legal protections and clarity in terms of what data would be collected, what that data will be used for, who will have access to it, and how it will be safeguarded from hacking.⁵

Apps have also been developed to enforce quarantine and social distancing orders. For example, in China, the government funded private tech companies to jointly develop an app that determines who needs to quarantine and for how long.⁶ The app assigns users one of three colors: green enables unrestricted movement, yellow requires seven days of quarantine, and red requires fourteen days of quarantine. Users must scan a QR code in order to enter buildings (including their homes), go to the supermarket, or use public transport. Human rights organizations have raised concerns that the app shares data on users’ locations with the police and that the app’s decisions can be arbitrary and difficult to appeal, leaving some individuals confined to their homes indefinitely.⁷ South Korea, Singapore, Germany, France, Australia, and India have also piloted or adopted mobile phone apps to support COVID-19 contact tracing.⁸

These examples from the COVID-19 response did not emerge from nowhere. For the past few decades, digital health technologies have been increasingly employed in clinical medicine and public health practice. While not new, the profile of digital technologies for health has risen with the COVID-19 pandemic, alongside questions and concerns about what safeguards exist that adequately balance potential benefits and harms. The HIV response has long had discussions related to how to best advance public health, taking a right-based approach to mitigate harms.⁹ Many of these HIV and human rights standards are also relevant across other health issues, including COVID-19. Building on that framework, this article provides an overview of some potential harms related to digital health technologies and then describes the ethical and human rights standards that can guide

governments and other stakeholders in mitigating the rights-related concerns of these technologies.

Key harms related to digital health technologies

There are various potential human rights-related concerns that may arise out of the use of digital technologies for health, including lack of access (the “digital divide”) and the privatization of health information and services. Three potential harms related to digital health technologies that can relate to privatization, as well as public health systems, include data breach, bias, and function creep. Understanding each is critical to minimizing the harms of digital health technologies.

Data breach

A data breach refers to any breach of security that leads to the “accidental or unlawful destruction, loss, alteration, unauthorised disclosure of or access to personal data.”¹⁰ Data breaches are common in the health sector and have a variety of causes—from malware and hacks to accidental or purposeful disclosure of personal health information by health care employees.¹¹ One study found that in 2016 and 2017, there were over 1,300 recorded incidents of protected health information data breaches across 27 countries.¹² In 2019, a data breach in Singapore resulted in the release of the personal information of more than 14,000 people living with HIV.¹³ Data breaches violate an individual’s right to privacy and erode trust in the health care system. As technology evolves and health systems become more complex, the likelihood of data breaches increases. To combat this risk, health systems must invest in information security and data protection, but not all health systems may have the resources to do so.

Bias and discrimination

Differentiated treatment has been repeatedly documented as a result of algorithmic biases in AI and other automated processes. This phenomenon can, for example, amplify discrimination in criminal justice proceedings and predictive policing, facil-

itate discriminatory hiring decisions, or produce targeted online marketing campaigns with discriminatory effects.¹⁴ Within health care, studies examining applications of AI have also demonstrated that algorithms do not provide equally accurate predictions of health outcomes across race, gender, or socioeconomic status.¹⁵ This raises concerns that AI will further entrench discrimination and prejudice against individuals based on these grounds. To highlight these concerns, the United Nations Special Rapporteur on contemporary forms of racism is developing a report on new information technologies, nondiscrimination, and racial equality.¹⁶ Additionally, certain types of algorithmic decisions evade current nondiscrimination laws, leading to unfair differentiation that is technically legal (for example, offering differing prices for the same product based on speed of internet access) but can undermine the goal of achieving the right to health for all.¹⁷

Function creep

Function creep occurs when data that are collected for a specific purpose (for instance, personal information provided as a part of medical screening) are used for another purpose (such as to check immigration status). Concerns about function creep are relevant for all forms of digital health technologies but are especially pertinent to biometrics, where, for example, biometric data collected for digital health purposes could be used for forensics or criminal proceedings.¹⁸ This concern has been highlighted in the HIV response, where many communities disproportionately affected by HIV may be stigmatized or criminalized groups.¹⁹ Function creep can also lead to data breaches, when, for example, wearables such as fitness apps reveal information that can be used to identify individuals’ homes, places of work and worship, or businesses frequented. Government partnerships with private companies, including big technology companies, have also raised alarms related to the potential for function creep with the exploitation of data for surveillance or commercial purposes.²⁰

Global overview: Ethics and human rights approaches

To date, discussions around strategies to address potential harms from digital health technologies have emphasized the adoption of ethical principles and guidelines. There have also been discussions around the application of legally binding international human rights obligations.²¹ While there may be some conceptual overlap in principles, ethics and human rights should be seen as separate yet complementary systems that aim to protect individuals and promote accountability for effective, just, and people-centered digital health technologies.

Ethical approaches

Various groups, such as the Institute of Electrical and Electronics Engineers, the World Economic Forum, and the European Commission's High-Level Expert Group on Artificial Intelligence, have developed resources related to ethics and digital technologies.²² The United Nations' Chief Executive Board is also currently in the process of developing recommendations on the ethics of artificial intelligence.²³ Key ethical principles coming from these organizations highlight ethical principles familiar to public health and biomedical researchers, including beneficence, autonomy, consent, privacy, participation, transparency, nondiscrimination, equity, and accountability.

Most ethical frameworks emphasize that digital health technologies should “do no harm,” and they include an obligation to be aware of, and mitigate, any harms that may occur. In addition to minimizing harmful effects, technologies should also maximize benefits for humanity.²⁴ The frameworks also stress that all individuals should be recognized as having agency over themselves and their personal information; that any personal information collected should be done with fully informed consent; and that safeguards should exist to protect the integrity and security of personal information.

Ethical frameworks also encourage inclusiveness and participation, calling on developers and government authorities to ensure that end users are meaningfully engaged in the development of digital technologies. Further, the development, adoption,

and implementation of digital health technologies should be done in an open, discoverable manner that allows for public feedback, monitoring, and consultation—including, for example, ensuring algorithmic transparency. Ethical frameworks also emphasize that digital health technologies should not deliberately or unintentionally discriminate against individuals. Moreover, ethics underscore the importance of equity and encourage those developing digital technologies to account for the needs of vulnerable and marginalized groups, including women, children, racial and ethnic minorities, and migrants. This includes ensuring that effective nondigital options be available and accessible to all as an alternative to digital technologies.

Establishing ethical frameworks on digital health technologies can be important for advancing rights and mitigating harms, and these frameworks are often used to regulate private actors, whether individuals or organizations. However, ethical principles can lack specificity, and enforcement mechanisms can be weak. Thus, adopting and implementing human rights norms and standards that enshrine basic ethical principles into law can provide important opportunities for enforceability and accountability.

International human rights framework

While there is no specific global human rights agreement for digital technologies, many existing human rights obligations are applicable. Within the context of health, the HIV movement has been a leader in integrating human rights to facilitate more just, effective responses. This has also included discussion on the rights-related standards on the use of digital technologies for populations at increased risk of HIV. Based on this work, as well as the discussion raised by COVID-19, the most relevant standards in the adoption of digital health technologies are the rights to health, nondiscrimination, benefit from scientific progress, and privacy.

Right to health

The adoption of digital technologies for health must align with the right to health. Enshrined in

several human rights treaties, the right to health outlines four key elements: availability, accessibility, acceptability, and quality.²⁵ The use of digital technologies for health must, at minimum, satisfy these four key elements. These obligations mean that governments should ensure the availability and accessibility of digital infrastructure throughout the country, both in terms of hardware (for example, computers, mobile phones, mobile phone towers, internet, and broadband accessibility) and in terms of software (for example, applications). This also includes providing digital literacy trainings for all users, including those in leadership, health care, and communities.²⁶ Addressing the availability and accessibility of digital health technologies supports efforts to bridge the digital divide. Digital health technologies should be a step toward supporting countries in realizing the right to health, which means that they must be acceptable to all communities and must be of good quality (meaning that they must be able to deliver on their clinical or public health purpose).

Right to nondiscrimination

Emerging and new technologies raise two main categories of concerns related to nondiscrimination. The first relates to access and availability of the technologies, while the second centers on implicit biases within the technologies themselves. On access and availability, due to a myriad of issues—including limited technical infrastructure (for example, broadband access, satellite towers, and electricity), lack of digital literacy, expense, and lack of access to digital hardware (for example, mobile smart phones and computers)—relying on digital technologies as a primary system or strategy within the health sector may inadvertently exacerbate inequalities, contributing to the digital divide.²⁷ On biases within digital technologies, human rights and technology experts recognize that the design of various technologies may include implicit and inadvertent biases. Engineers and software developers tend to design technologies with limited engagement and input from communities with diverse backgrounds, such as racial, gender, and socioeconomic backgrounds.²⁸

To realize the right to nondiscrimination in the context of digital technologies, states and technology companies alike should proactively identify risks of discrimination in access to and the availability of technologies. If violations occur, states should hold private businesses to account for preempting, identifying, mitigating, and redressing discriminatory outcomes.²⁹ States should also ensure transparency and accountability related to the development, adoption, implementation, and evaluation of digital technologies for health, as well as provide access to justice where the right to nondiscrimination or other rights have been violated. Finally, there should be an effective, nondigital option that achieves the same goal for those who are unwilling or unable to use digital technologies.³⁰

Right to benefit from scientific progress

The right to enjoy the benefits from scientific progress can be a critical component in achieving the right to health. Countries have a duty to ensure the availability and accessibility of “all the best available applications of scientific progress necessary to enjoy the highest attainable standard of health,” on a nondiscriminatory basis, with a focus on the most marginalized.³¹ On emerging and new technologies, states should balance the benefits and risks. New technologies should be developed and used within an inclusive, rights-based framework, highlighting the principles of transparency, nondiscrimination, accountability, and respect for human dignity. States should also develop laws that impose an obligation for human rights due diligence on private and other nonstate actors (see section below on obligations of private enterprises). Finally, states should regulate the control and ownership of data collected through new technologies to prevent misuse and exploitation, as well as ensure informed consent and privacy.³²

Right to privacy

Human rights law recognizes the right to be free from arbitrary or unlawful interference with one’s privacy.³³ Any lawful interference with this right must be precisely outlined in relevant legislation.³⁴ Moreover, states must regulate the collection and

storage of personal information—these measures must be effective in preventing the unauthorized disclosure or use of personal information.³⁵ Such information can never be used for any purpose that is incompatible with the aims of human rights law. In addition, individuals have the right to know what personal data is stored in databases, and the purposes of such storage. They also have the right to request the rectification or elimination of files that contain incorrect personal information or “have been collected or processed contrary to the provisions of the law.”³⁶ These obligations are further built on by regional agreements on data privacy and protection (see corresponding section below). Moreover, the Special Rapporteur on the right to privacy’s *Recommendation on the Protection and Use of Health-Related Data* also outlines important rights-related considerations.³⁷ It covers key topics such as rights of the data subject, security and interoperability, transborder data flow, and considerations related to data and gender, indigenous populations, and persons with disabilities.

Human rights-related obligations of private enterprises

States have specific human rights obligations related to private businesses. First, states must protect against human rights abuses by third parties, an obligation that covers private actors. This includes ensuring access to justice when business-related human rights violations arise. Governments should also set expectations for businesses domiciled or operating within their jurisdiction to respect human rights, including through crafting, monitoring, and enforcing protective legislation, as well as conducting human rights due diligence that accounts for issues related to gender and marginalization.

Private companies also have human rights-related obligations, including, at a minimum, the duty to respect human rights standards.³⁸ Respecting human rights means that private companies must

(a) avoid causing or contributing to adverse human rights impacts through their own activities, and address such impacts when they occur; [and] (b) seek to prevent or mitigate adverse human rights impacts that are directly linked to their operations,

*products or services by their business relationships, even if they have not contributed to those impacts.*³⁹

In alignment with these principles, companies should develop and enact human rights policy commitments and conduct human rights due diligence. This due diligence comprises ongoing processes that assess the human rights impacts of companies’ operations, preventing or mitigating impacts, tracking to see how concerns are addressed, and remedying any actual violations that the operations caused or to which they contributed.⁴⁰ Rather than framing private sector obligations solely within the realm of voluntary or unenforceable ethical standards, business enterprises should treat the obligation to respect human rights as a legal compliance issue.

Regional data-protection frameworks

One human right that has been firmly established in regional-level agreements is the right to privacy. Such agreements include the African Union Convention on Cyber Security and Personal Data Protection, Asia-Pacific Economic Cooperation Privacy Framework, European Union’s General Data Protection Regulation, Standards for Personal Data Protection for Ibero-American States, and Council of Europe’s Modernised Convention for the Protection of Individuals with regard to the Processing of Personal Data.⁴¹ Many of these frameworks have a specific focus on data privacy and surveillance and have developed safeguards related to data processing and the rights of individuals whose data are collected (that is, the “data subjects”).

Under these regional frameworks, data should be collected and processed in a manner that (1) is lawful, fair, and transparent to the data subject; (2) aligns with a legitimate purpose that is clearly specified and agreed to by the data subject; (3) is the minimum necessary for the legitimate purpose; (4) is stored only for as long as necessary for the specified, legitimate purpose; (5) ensures appropriate security, as well as data integrity and accuracy; and (6) ensures that the entity that controls the data demonstrates compliance with all principles

of data processing.⁴² Informed consent must also be obtained prior to data collection and processing. This consent must be voluntarily given—an unambiguous agreement to a request presented in clear and plain language.⁴³ Furthermore, entities (that is, states or companies) that process data must implement safeguards to ensure data security, including anonymization or pseudonymization, as well as the encryption of personal data.⁴⁴

These regional frameworks also enshrine a set of positive rights for data subjects. These “rights of the data subject” include the following:

- right to be informed about what data are and are not collected;
- right to access stored data;
- right to rectification;
- right to erasure (commonly known as the “right to be forgotten”);
- right to restriction of processing;
- right to be notified of rectification or erasure or restriction of processing;
- right to data portability;
- right to object; and
- rights related to automated decision-making and profiling.⁴⁵

Strengthening human rights-aligned governance of digital health technologies at the national level

To ensure that all individuals can enjoy the benefits of digital health technologies while mitigating the harms, it is critical for all stakeholders—including governments, civil society, and the private sector—to take steps to protect human rights in this context. Part of the solution, especially related to concerns around data breaches and function creep, is to establish safeguards aligned with regional and global human rights and ethical standards in national legal frameworks on data collection and processing, as well as on the rights of the data

subject. But these are minimum standards—a floor on which to build. Not only should digital health technologies ensure privacy, but they should be leveraged to advance the right to health in an equitable, nondiscriminatory manner. There are three opportunities that allow countries to assess whether there is sufficient consideration of ethical principles and integration of human rights protections when digital health technologies are adopted: health technology assessments (HTAs), national digital health strategies, and judicial review.

Health technology assessments

One strategy for preventing rights violations arising from data breaches, biases, and function creep is the requirement for a robust system of HTA prior to the authorization for use of a new (or updated) digital health technology. An HTA is a multidisciplinary process that evaluates the “value of health technology at different points in its lifecycle” (including the technology’s properties, effects, and impacts).⁴⁶ It aims to inform policy makers and influence decision-making in health care, with a focus on how best to allocate funding for health programs and technologies. Components of such an assessment include the validation of technical aspects (for example, the accuracy of the product or system), clinical considerations (for example, contribution toward improving or maintaining a specific health condition), and systems compatibility (for example, connection with or integration into patients’ lives, health service provision, and health systems, including medical records).⁴⁷ It can be applied to different types of interventions, such as piloting tests, medicines, vaccines, procedures, and programs.

Applying HTAs to digital technologies provides an opportunity for governments to assess the ethical and human rights risks of these technologies, including considerations related to equity. HTAs can face challenges in this role, however, as digital health technologies evolve rapidly and the technology sector’s ethos of “moving fast and breaking things” stands in contrast with the conventional process of health technology devel-

opment and testing for patient safety and clinical efficiency (upholding a “do no harm” approach).⁴⁸ To better tailor HTAs to digital health technologies with a focus on ensuring equity in availability and access, there are several key considerations. In addition to assessing the traditional technical, clinical, and systems elements, integrating a strong focus on usability and human-centered design is critical. Digital technologies should be co-designed with end users (for example, health care providers, systems administrators, patients, and communities) and should have effective mechanisms for subsequent feedback and iteration. This speaks to a cornerstone of product design, which is that they must meet the needs of end users. This also facilitates the uptake and effectiveness of digital technologies and fulfills the key ethics and human rights principle of meaningful participation and engagement. HTAs should also assess the risks for bias or discrimination as a result of access to and use of the digital health intervention. This includes reviewing a digital technology’s accessibility and availability for all users, including those most left behind.

National digital health strategies

Another approach to review country-level standards for digital health technologies is the development of a national digital health strategy. These strategies facilitate coordination, set standards for interoperability, and establish policies related to digital health.⁴⁹ A country-wide strategy is also helpful for identifying gaps and opportunities where digital technologies can be best leveraged to improve health outcomes. The process of developing a national digital health strategy is an opportunity to define the human rights standards, advance rights-based principles (such as participation via broad-based consultations), and develop the trust necessary for effective implementation. According to the World Health Organization’s 2015 global survey on eHealth, 72 countries have national digital health strategies and corresponding implementation plans.⁵⁰ The 2019 report of the Global Digital Health Index (GDHI) indicates that out of the 22 current GDHI countries, Jordan, Portugal, Bangla-

desh, Thailand, Malaysia, and the Philippines have the most advanced processes, policies, and practices for digital health.⁵¹

Accountability through the judicial system

Courts have historically played a key role in protecting human rights and clarifying the obligations of states, particularly on the right to health.⁵² Within the HIV response, for example, judicial decisions have advanced a range of rights and freedoms, including the right to access antiretroviral treatment.⁵³ Similarly, for the use of digital technologies, some judiciaries have led the way in weighing the need for digital technologies while mandating the protection of human rights. While the cases below are not focused specifically on health issues, their rulings have a direct impact on the adoption and use of digital health technologies.

The Indian Supreme Court’s decision in *Justice K.S. Puttaswamy (Rtd) v. Union of India and Others* is noteworthy because the court read the right to privacy into the Indian Constitution, which otherwise does not explicitly enshrine this right. It noted that “[p]rivacy is concomitant of the right of the individual to exercise control over his or her personality” and that privacy is “the necessary condition precedent to the enjoyment of any guarantees in Part III [fundamental rights].”⁵⁴ The court underscored that fundamental rights and freedoms such as those to life, dignity, and equality cannot be enjoyed without respecting the right to privacy. In elaborating on this right, the court noted that a critical aspect of the right to privacy is control over the dissemination of personal information. It also noted that every individual should have the right to exercise control over his or her own life and image as portrayed in the world and to control the commercial use of his or her identity.⁵⁵

The Supreme Court’s judgment paved the way for the development of a comprehensive privacy and data protection bill in India. The bill, released in mid-2018, has many positive features, including data-protection impact assessments, a right to be forgotten, and enforcement penalties. But there are also concerns, such as the use of personal data by law enforcement; while the bill notes that this use

should be “necessary and proportionate,” it nevertheless contains broad exemptions.⁵⁶

In the context of data and digital technologies, the Supreme Court of Jamaica considered legal standards within an explicit constitutional right to privacy in the case of *Julian Robinson v. The Attorney General of Jamaica*.⁵⁷ Specifically, the case analyzed the legality of the National Identification Registration Act (NIRA), which aimed to facilitate people’s enrollment in a national identification system. Enrollment in the national identification system was mandatory for all citizens and residents of Jamaica, with the failure to enroll subject to criminal sanctions. In *Robinson*, the court struck down the NIRA, holding that the law violated the country’s constitutional Charter of Fundamental Rights and Freedoms. It found that the act did not “provide sufficient safeguards against misuse and abuse of the data collected” and that the compulsory collection of biographical and biometric data violated various rights under the charter, including the rights to privacy and nondiscrimination. The court also found that the NIRA did not comply with the standard of data minimization (in other words, taking no more data than necessary for a legitimate purpose).⁵⁸

Similarly, on the topic of biometrics, the High Court of Kenya, in January 2020, held that the government’s initiative to assign each citizen a unique biometric ID, known as Huduma Namba, needed stronger privacy and data protections before it could proceed. Moreover, the court prohibited the government from collecting individuals’ DNA and location data as part of this initiative.⁵⁹

On privacy and differentiated treatment, the Hague District Court in the Netherlands struck down the government’s use of SyRI, an “automated program that analyzes a wide range of personal and sensitive data to predict how likely people are to commit tax or benefits fraud.”⁶⁰ SyRI’s risk calculation system was kept secret by the Dutch government so that surveilled individuals could not challenge the fraud investigations against them. The court ruled that the government must respect citizens’ right to privacy and that transparency is critical as a safeguard against intrusion. It also

noted that because SyRI was implemented only in low-income neighborhoods, this use could amount to discrimination on the basis of socioeconomic or immigrant status.⁶¹

Conclusion

Digital technologies hold much promise for addressing inequities and barriers to health care quality and access. They have the potential to reduce health care costs, transform health systems to provide more accurate and responsive care, and break down silos between sectors. But fears about digital technologies resulting in rights violations are real and grounded in the experiences of populations who are already subject to discrimination, social marginalization, and surveillance. In the future development of digital health technologies, more attention should be given to the development of community-owned technologies, aligned with ethical principles, that explicitly seek to advance accountability and justice. For example, within the HIV response, eHealth apps may be used by community members to monitor medication stockouts (for example, antiretroviral therapies) or to address discriminatory treatment in health care facilities.⁶² They may also facilitate reports of abusive law enforcement practices against vulnerable and key populations. Governments should also ensure that digital health interventions directly address the digital divide and inequities in access. Furthermore, governments should take advantage of the data provided by digital health technologies to advance transparency and facilitate dialogue with populations—to both inform and validate the findings.

The diversity and sophistication of digital health technologies can make it difficult for nonexperts—or anyone—to understand the consequences of hitting “accept” when a five-thousand-word notice in five-point font appears on the screen of their phone. Combatting this, and leveraging the potential of digital health technologies, requires the meaningful adoption of standards and principles that ensure that these technologies truly protect rights, empower individuals, and do no harm.

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PERSPECTIVE

Digital Phenotyping and Digital Psychotropic Drugs: Mental Health Surveillance Tools That Threaten Human Rights

LISA COSGROVE, JUSTIN M. KARTER, MALLAIGH MCGINLEY, AND ZENOBIA MORRILL

Introduction

Digital technologies and tools hold much promise. Indeed, the COVID-19 pandemic has shown us how helpful telehealth platforms and mental health applications (apps) can be in a time of quarantine and social distancing. However, such technologies also pose risks to human rights at both the individual and population levels. For example, there are concerns not just about privacy but also about the agency and autonomy of the person using mental health apps. In this paper, we describe what digital phenotyping is, how it is used to predict mood, and why we ought to exercise caution before embracing it as a means of mental health surveillance. We also discuss the United States' recent regulatory approval of the first-ever “digital” drug, an antipsychotic (aripiprazole) embedded with a sensor. Digital aripiprazole was developed in order to increase medication compliance, but we argue that it may undermine a rights-based approach in the mental health field by reinforcing coercive practices and power imbalances. The global dissemination and promotion of these apps raise human rights concerns.

Back to the future: Digital phenotyping replaces the search for genetic biomarkers

Subtle aspects of typing and scrolling, such as the latency between space and character or the interval between scroll and click, are surprisingly good surrogates for cognitive traits and affective states. I believe mental health will be the part of medicine most transformed by the digital revolution.¹

—Tom Insel, former head of the National Institute for
Mental Health and co-founder of Mindstrong

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The lack of biomarkers, or objective measurements, to determine mental disorders has plagued psychiatry and resulted in concerns about the validity of psychiatric disorders. Rather than rely on subjective self-reports and depression scales, psychiatrists and neuroscientists are turning their attention to digital phenotyping, promoted as an objective way to measure—and supposedly predict—traits, behavior, and mood. For example, Thomas Insel, a psychiatrist and former head of the National Institute for Mental Health, left the institute to help found a tech company with the aim of improving psychiatric taxonomy and research through artificial intelligence.

Digital phenotyping is defined as the “moment-by-moment quantification of the individual-level human phenotype in-situ using data from smartphones and other personal digital devices.”³ In other words, this technology uses sensors that can track an individual’s behavior, location, and speech patterns (e.g., intonation).² By analyzing human-computer interaction (for example, the use of a smartphone), the measurement focus is not on content (what you type) but *how* you type. These interactions—the patterns and timings of user activity on touch-screen devices—are aggregated and analyzed using machine learning.³ The results of these interactions are referred to as digital “biomarkers.” As Insel explains:

with data from sensors, speech analytics, and keyboard use, scientists are learning how to measure cognition, mood, and behavior passively from the smartphone ... offer[ing] a sort of digital smoke alarm for mental health issues ... [D]igital phenotyping can provide ethical and effective biomarkers that predict relapse or recovery, much the way we monitor progress in diabetes or hypertension.⁴

Insel, along with others from technology and pharmaceutical companies, founded Mindstrong, described as a health care and tech company.⁵ In 2018, the company developed a smartphone app that it claims not only can detect the worsening of symptoms but can *predict* them: “What if we can detect symptoms getting worse? What if we can predict it?”⁶ The company describes this as a break-

through technology that will help users access “targeted proactive care.” What is not emphasized is that mental health apps, like most apps, collect, use, and sell users’ data. In fact, research has shown that the majority of smartphone apps are not transparent about what information will be collected, how it is collected, and how it will be used and sold. A recent review of mental health apps found that 81% of them sent data to Facebook or Google for use in data analytics or marketing, and 92% sent data to other third parties. The authors concluded that “users are thus denied an informed choice about whether such sharing is acceptable to them.”⁷

Additionally, there is limited evidence to support the claim that digital phenotyping can predict behavior or symptoms. As previously noted, this technology is focused on how users interact with their smartphones. Scrolling, clicking, tapping, and other touch-screen behaviors are analyzed with machine learning to predict cognition and mood.⁸ However, there are insufficient data to support the claim that a human-computer interaction model—analyzing the way information is presented to the user and repeated measures of a user’s response time—can accurately predict an increase in mental health symptoms. For instance, one small (N=23) prospective cohort study has been registered on clinicaltrials.gov, regarding Mindstrong’s model, but no study results have been posted, and no peer-reviewed papers have been published.⁹ A recent review of the literature on the use of, and support for, digital phenotyping for the detection of mental health problems found that there is a clear gap between the theory that grounds this technology and the empirical data to support its use.¹⁰

The “first-ever” digital medication

In late 2017, the US Food and Drug Administration approved Otsuka’s application for digital aripiprazole, Abilify MyCite, a version of a second-generation antipsychotic embedded with an ingestible event marker. Both the nondigital and digital versions of aripiprazole have been approved for schizophrenic disorders and for adjunctive use in bipolar and major depressive disorders. It is expect-

ed that the ingestible sensor will transmit a signal when the drug-device combination is exposed to gastric acid in the stomach, thereby allowing for real-time information about medication ingestion. The rationale behind the development of this digital drug is that it will increase medication adherence and, in turn, result in improved health outcomes and decreased health care costs. However, there are currently no clinical trial data to show that the sensor can either consistently track real-time ingestion or increase medication adherence.¹¹ In fact, on the company's website, the following statement is made: "There may be a delay in the detection of the Abilify MyCite tablet and sometimes the detection of the tablet might not happen at all."¹²

Additionally, patients diagnosed with psychotic illnesses—those most likely to be prescribed digital aripiprazole—often experience paranoia. A digital psychotropic drug, particularly an antipsychotic that is used as a treatment for people who experience paranoia, is akin to a modern-day panopticon, a disciplinary apparatus that utilizes constant surveillance to impose a form of self-discipline and internalized authority.¹³ The potential for human rights violations, such as coercion (discussed in more detail in the next section), have not been adequately assessed. One could imagine that being asked to take a digital psychotropic medication could reinforce "subjectivities of disability" in people diagnosed with psychiatric disorders and, concomitantly, undermine their sense of agency. This technology may exacerbate the "subjective experience of structural stigma" that is imposed by medicalized interventions that gloss the complexity of human suffering.¹⁴

Many clinicians have pointed out that an antipsychotic medication was an odd choice for the "first-ever" digital drug.¹⁵ It is noteworthy that in 2014, aripiprazole was the best-selling drug in the United States, costing, on average, over US\$800 for a month's supply and generating over US\$7.5 billion in sales from October 2013 through September 2014.¹⁶ After the patent expired in the United States, sales revenues dropped by almost US\$7 billion in 2015, which is when Otsuka and Proteus first submitted an application for market approval of the

digital version. The generic oral version of aripiprazole costs approximately US\$20 per month, while Abilify MyCite costs almost US\$1,700 for a month's supply.¹⁷

Why both digital phenotyping and digital psychotropic drugs present threats to human rights

*Advances in digital technology are transforming the capabilities of States, global tech giants, including Google, Facebook, Apple and Amazon, and private entities to carry out surveillance on entire populations to an unprecedented degree ... Internet searches and social media, detailed personal information can be captured and analysed without the individual's permission or awareness. That information can then be used to categorize an individual for commercial, political or additional surveillance purposes.*¹⁸

—Dainius Pūras, United Nations Special Rapporteur on the right to health (2014–2020)

Morality and suffering are inexorably intertwined, for emotional distress always has a political and moral aspect as well as a medical one.¹⁹ As noted over a decade ago by the World Health Organization, "social injustice is killing people on a grand scale."²⁰ Unfortunately, the political and moral aspects of suffering are underappreciated, and there is an increased tendency to conflate access to psychiatric services with mental health equity.²¹ Such a conflation undermines an appreciation for the profound ways that neoliberal economic policies, systemic racism, and gendered violence (among other things) can impede emotional well-being.²² It is not only neoliberalism but also dominant ideas in psychiatry and common practices in mental health care that are profoundly shaped by institutional and systemic racism. Systemic and interpersonal racism both impede access to services (for example, for many women of color) and lead to over-representation in coercive and carceral services, as well as in forced treatment (for example, for many black men).²³ Thus, advocating for more people to be able to receive a psychiatric diagnosis and mental health treatment at the same time that such major advances in digital technology are taking place creates the

perfect storm for human rights violations. The most vulnerable and discriminated people in communities may be coerced into mental health care, leaving the societal causes of their suffering unaddressed.

The data being gathered and analyzed by tech giants through nontransparent surveillance can now be used to categorize people as “at risk” of committing crimes, including benefit fraud.²⁴ Now, with digital phenotyping, it is also possible to identify and categorize people as “at risk” of mental illness. When nontransparent surveillance tactics are used to identify potential criminal behavior, individuals have great difficulty achieving redress if identification errors are made.²⁵ Individuals who use mental health apps that employ digital phenotyping are vulnerable to such errors. For example, a bizarre but plausible outcome of using a mental health app is that when a person’s digital behavior correlates with suicidality, first responders will be called in to forcibly hospitalize them, even if they did not have the subjective experience of being suicidal. Indeed, the increased use of nontransparent surveillance tactics, and the difficulty correcting errors of identification and wrong information, poses a clear threat to human rights.

Emerging research has already suggested that passive data, such as time spent scrolling or tapping on a smartphone, may be used to identify users at risk for suicidal behavior or relapse of schizophrenic symptoms and that apps which collect such data may be helpful tools for alerting clinicians to the need for intervention using an interface that “has the advantage of not requiring the collaboration of the user.”²⁶ This “advantage” is more accurately described as a right to health violation. Additionally, it has been recommended that clinicians be prepared to act on any digital information that indicates risk for self-harm (for example, being prepared to involuntarily commit the person), demonstrating the genuine possibility for such use of passive data.²⁷ Scholars have drawn attention to the potential for harmful iatrogenic effects in passive data collection, particularly for users who are already vulnerable.²⁸ Marginalized populations may be overly pathologized because of how passive data use is normed and because algorithms do not account for the

established relationship between experiences of social injustice and emotional distress.²⁹ It is also noteworthy that recent research on adverse events related to the use of such digital sensing technology indicates that the very use of mental health apps may actually increase some users’ distress, including increased paranoia and fear of relapse.³⁰

In this way, digital surveillance is antithetical to basic principles of human rights—namely, individuals’ inherent dignity, as well as their autonomy and independence. Not surprisingly, proponents of digital technology argue that the opposite is true: that using this technology will enhance the ability to detect symptoms and increase adherence to treatment, thereby improving the quality of life for individuals who use mental health apps and drugs with sensors embedded in them.³¹ However, we should be cautious about such claims when they come from the developers of this technology who stand to profit from its uptake in the general population, and when such claims have not undergone robust empirical investigation. People with lived experience have long recognized that psychotropic drugs can be experienced as a form of chemical incarceration; the uncritical use of digital technologies may turn out to be a virtual form of incarceration.³²

Concerns about institutionalization and other coercive practices were a major focus of child psychiatrist Dainius Pūras during his six-year tenure as the United Nations Special Rapporteur on the right to health. He emphasized the urgent need to abandon outdated practices in mental health care, including medicalization, coercion, and institutionalization.³³ Medicalized approaches undermine an appreciation for the social realities, structural violence, and health inequities that produce emotional distress.³⁴ In his thematic reports, the Special Rapporteur consistently highlighted the importance of attending to structural and systemic issues, focusing on the global burden of *obstacles* to achieving good mental health rather than the global burden of disease in order to bring a robust rights-based approach to mental health to fruition. In addition to deflecting attention away from structural and systemic obstacles that undermine

the right to health, digital technologies, insofar as they are not transparent, also undermine a genuine informed consent process.³⁵ The lack of attention paid to maximizing informed decision-making for service-users parallels the ongoing controversies in psychiatry over consent to treatment. Traditional medical-model approaches to mental health care are premised on the assumption that service-users often “lack capacity.” As a result, policies have prioritized access to medical interventions over informed consent and the right to refuse treatment.³⁶ However, rights-based approaches to mental health, rooted in an alternative “social model of disability,” have contested this prioritization and advocated for individuals’ right to determine their own treatment decisions.³⁷

Therefore, we must take seriously the concern that digital phenotyping and digital psychotropic drugs, like other medicalized approaches, run the risk of further entrenching coercive practices. Such practices may undermine the autonomy and agency of persons using (or being forced to use) these technologies. Indeed, the boundary between predicting mood and shaping behavior is tenuous. It is noteworthy that Shoshanna Zuboff, author of *The Age of Surveillance Capitalism*, quoted one scientist working on digital technologies as saying, “We can engineer the context around a particular behaviour and force change that way ... We are learning how to write the music, and then we let the music make them dance.”³⁸ The end goal of surveillance technology is never above suspicion, even when it is cast in rhetoric about improving mental health or quality of life. Although digital technologies are promoted as tools, we must remember that tools are at *our* service; they neither demand anything of us nor manipulate us.³⁹ Digital technologies, on the other hand, are designed to shift and direct the behavior of the user, often without the user’s knowledge.

These technologies also reinforce the commodification of health care and promote practices that violate the right to freedom, including freedom from coercive or degrading treatment.⁴⁰ For example, if patients are incentivized to take the digital version of a psychotropic drug (such as by being offered outpatient treatment as an alternative to

compulsory inpatient treatment, or as a condition of parole), the line between incentivizing and coercion becomes blurred.⁴¹ Vulnerable populations—such as people in prison, in marginalized groups, or who use illicit drugs—are more likely to be coerced into using surveillance-based diagnostic technologies (for example, mental health apps) and taking surveillance-based psychotropic medications.

Such risks must be assessed seriously because people with psychosocial disabilities and other vulnerabilities have a long history of experiencing discrimination and inequality, and they have not enjoyed the freedom to make their own treatment choices.⁴² It is not yet fully researched or understood why individuals stop taking antipsychotic medications, although such medicines’ high discontinuation rate and difficult side effects have been well documented.⁴³ Unfortunately, the burden of antipsychotics is underappreciated, and the biomedical focus instead is on “increasing medication compliance.” But creating short-term technological solutions to increase medication compliance is anathema to a rights-based approach to mental health, which instead promotes and respects the autonomy and agency of all people, including those with psychosocial disabilities.

Conclusion

The efficacy of digital phenotyping to predict mood states has not been established, nor is it known whether a drug embedded with a sensor can track real-time ingestion, let alone improve medication adherence and improve quality of life. Even if these interventions achieve their stated objectives, digital drugs and phenotyping are part of a wider pattern of technological solutions—often profit-making quick fixes—that do not resolve the real causes of mental distress. Promoting these short-term fixes over societal transformation maintains the status quo and does not address inequality, discrimination, or other human rights failings. Not only are the unvalidated digital tools being promoted, but these mental health apps are using people as unwitting profit-makers. The apps gather data from people when they are vulnerable and makes them

part of a hidden supply chain for the tech giants' profits, while potentially compromising their agency and autonomy.⁴⁴ Similarly, the advent of digital psychotropic drugs marks a new age in surveillance and poses risks to privacy and human rights, possibly in ways yet unimagined.

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PERSPECTIVE

The Trojan Horse: Digital Health, Human Rights, and Global Health Governance

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The COVID-19 pandemic has massively accelerated a global shift toward new digital technologies in health, a trend underway before the crisis. In response to the pandemic, many countries are rapidly scaling up the use of new digital tools and artificial intelligence (AI) for tasks ranging from digital contact tracing, to diagnosis, to health information management, to the prediction of future outbreaks. This shift is taking place with the active support of numerous private actors and public actors. In particular, United Nations (UN) development agencies, such as the World Health Organization (WHO), are actively encouraging this trend through normative guidance and technical cooperation aimed at helping the governments of low- and middle-income countries to assess their needs for digital health, develop national digital health strategies, and scale up digital interventions.¹ At the same time, global health financing agencies, such as the Global Fund to Fight AIDS, TB and Malaria, are financing these technologies through aid to national health programs and through their own public-private partnerships. But in this major effort to spur low- and middle-income countries to race toward the digital future, are UN development agencies adequately considering the risks?

In 2019, UN Special Rapporteur on Extreme Poverty and Human Rights Phillip Alston cautioned that digital technologies could be a “trojan horse” for forces that seek to dismantle and privatize economic and social rights, undermining progress toward the Sustainable Development Goals (SDGs) instead of speeding it.² Similarly, in 2020, UN Special Rapporteur on Racism Tendayi Achiume warned that technology is shaped by and frequently worsens existing social inequalities.³

As this article explores, these and other serious social effects may be accelerated by the rapid scale-up of digital technologies in health. An enabling policy and legal environment that confronts these risks and judiciously plans for them should be a precondition to the scale-up of digital technologies, not an afterthought. As part of its normative and technical advice to governments on digital technologies and AI in health, WHO should be supporting governments in assessing risks and needs and in ensuring that these governments also receive the advice they need to put in place laws, policies, and governance mechanisms to protect and uphold human rights. But to date, the main equity and human rights risk that WHO and other UN development agencies appear to view with real urgency is the need to overcome the “digital divide”—inequitable access to digital technologies and internet connectivity that might undermine access to digital health for impoverished and marginalized populations. In June 2020, the UN Secretary-General warned

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that closing the digital divide is now “a matter of life or death.”⁴ While addressing the digital divide is a legitimate concern in an increasingly digital age, a disproportionate focus on this issue could itself become a trojan horse, a poisoned gift to low- and middle-income countries that legitimizes sweeping access for private actors and state power, while rolling back hard-won human rights protections.

This article explores four risks in particular: the expansion of state surveillance, the risk of malicious targeting, numerous challenges linked to the management of partnerships with powerful private companies, and the risks of scaling up digital interventions for which scientific evidence is weak.

A trojan horse for state surveillance

In 2013, the UN General Assembly adopted a resolution expressing concern over the negative impact of technological surveillance on human rights.⁵ A series of reports by UN Special Rapporteur on the Right to Freedom of Opinion and Expression David Kaye highlighted the systematic use of technologies to violate privacy rights.⁶ The COVID-19 response has intensified these concerns, as some states expand systems of surveillance that could later be utilized for political purposes.

Function creep has been highlighted as a risk whenever personal data is gathered.⁷ The Global Commission on HIV and the Law has particularly warned of the risk of digitally collected biometric information being used by the police.⁸ The proposed gathering of biometric data (such as fingerprints or iris scans) for an HIV study sparked specific concerns for marginalized and criminalized groups in Kenya—namely, sex workers, men who have sex with men, transgender people, and people who use drugs—about the use of the data to target individuals for arrest.⁹

China offers a cautionary example of this targeted use of biometric data. To manage the coronavirus, the Chinese government requires citizens to download an app from Alibaba, a US\$500 billion e-commerce company. The app was developed in partnership with the police and uses a color code to identify those free to travel, at risk, or in need of

immediate quarantine, based on data that includes travel history and time spent in proximity to others with the virus.¹⁰ Subway stations use thermal scanners to check for high temperatures, incorporating facial recognition technology.¹¹

These tools were developed by some of the same companies responsible for developing AI systems used to profile millions of Uighur Muslims.¹² The systems track individual communications, police records, patronage at mosques, and individual movements to identify people considered high risk and place them in forced labor camps.

Beijing now actively exports these surveillance technologies, through its Belt and Road Initiative, to over 60 countries as a form of development assistance.¹³ In August 2020, the International Telecommunication Union’s AI for Good Global Summit tweeted a promotional video praising China’s use of artificial intelligence without mentioning related abuses.¹⁴ WHO has also praised China’s response to COVID-19 without mentioning related rights abuses.¹⁵

Some humanitarian aid agencies, such as the International Committee of the Red Cross, have developed policies strictly limiting the gathering and use of biometric data, aiming to prevent state and nonstate actors using data gathered for humanitarian purposes to target people for harm.¹⁶ However, there is currently no agreed approach to the governance and use of biometrics and other sensitive data among normative agencies, such as WHO, and funding agencies, such as the Global Fund, which often provide advice to the same countries. In fact, WHO’s draft digital strategy, approved in 2020, appears to contravene its own data protection policy, according to an analysis by the Third World Network.¹⁷ To promote consistent and rights-respectful governance, agencies that normally work together to provide technical support and funding to low- and middle-income countries on health interventions should also work together to establish a common bottom line with regard to privacy, surveillance, and policing in the name of health, including policies on biometrics (potentially using the the International Committee of the Red Cross’s policy as a starting point); and

certainly, they should deplore China's use of technology and AI for abusive policing, not extoll it on social media as a model.

A trojan horse for malicious targeting

Security experts have documented the growing use of AI systems for malicious purposes, including to attack both digital security (through phishing attacks, speech synthesis for impersonation, automated hacking, and data poisoning) and physical security (attacks using autonomous weapons systems, using micro-drones, and subverting cyber-physical systems).¹⁸ UN High Commissioner for Human Rights Michele Bachelet has warned of the abuse of digital technologies to attack individuals and groups.¹⁹ There are now growing cyber attacks against medical facilities which take advantage of hospitals' growing dependence on digital systems.²⁰

Even where states do not retain the data, data gathered by digital contact tracing apps could enter the public domain, exposing women, girls, and other vulnerable groups such as LGBTI+ people or stigmatized groups to risks of stalking, extortion, or violence.²¹ In South Korea, for example, digital contact tracing app data was used to create a "coronamap" website showing the travel histories of anonymous confirmed patients and identifying them by gender and age; as this information was publicly accessible, individuals were accused of infidelity, fraud, and sex work, and some were the targets of online witch hunts aimed at identifying individuals who had spread the virus. Moreover, individual businesses were associated with COVID-19 transmission after they were identified through contact tracing, and some were targeted for extortion.²² Privacy International has documented data-exploitative tactics used by some organizations to target women with misinformation about contraception and abortion.²³ The International Committee of the Red Cross and Privacy International have further found that mobile technologies leave digital trails that could be used to target individuals.²⁴

The growing dependence of health systems on digital technologies and AI thus creates many new

vulnerabilities, and as Achiume has noted, due to inequalities that already exist in our societies, the risks are greater for some groups than for others. Incidents such as those documented in South Korea could undermine public trust and make many people reluctant to download or use mobile health apps. This may even have been the case in Singapore, where early downloads of the coronavirus app TraceTogether flatlined at just 20% of the population, leading the government to step back from promoting its use.²⁵

A trojan horse for the private sector

Public-private partnerships may significantly benefit private actors, raising questions about the appropriate use of taxpayer funds.

Shoshana Zuboff has shown how tech giants such as Facebook and Google have turned data into a source of profit through "surveillance capitalism."²⁶ Today, private companies of all sizes race to locate big datasets that they can either sell for profit or use to train and improve algorithms, developing profitable tools. However, the supply of big data in the Global North is not enough to meet the demand, and privacy regulations in Europe and North America are growing stricter, thanks to the European General Data Protection Regulation. Health systems in low-resource settings offer potentially vast, as-yet-untapped reserves of big data in countries with weaker regulatory controls.

Thus, the private sector has a strong interest in partnering with health agencies to roll out new AI-enabled digital health tools in low- and middle-income countries, thereby accessing big data that would be harder to access in countries with stronger regulation, a form of "data colonialism."²⁷ Private companies may benefit significantly from partnerships in which there is no immediate obvious financial gain.

These partnerships sometimes include companies with problematic track records. In 2018, the World Food Programme's five-year partnership with data-mining firm Palantir was criticized by civil society due to Palantir's history of collaboration with Cambridge Analytica, the Los Angeles

and New York Police Departments, Immigration and Customs Enforcement, and US intelligence agencies.²⁸ One internal Immigration and Customs Enforcement report revealed that Palantir data had been critical in locating and prosecuting the parents of immigrant children.²⁹ The World Food Programme issued a statement affirming that it would place controls on the use of data by Palantir, but critics continue to raise concerns about the risks for refugees and persons in displacement and to call for clearer standards for humanitarian programs.³⁰ In response to COVID-19, Palantir is now offering its services to public health agencies to track and analyze the spread of the coronavirus.³¹

A trojan horse for unsupervised experimentation

WHO's draft digital strategy argues that it hopes to “[build] a knowledge base ... enabl[ing] testing, validating and benchmarking artificial intelligence solutions and big data analyses across various parameters and settings.”³² But is it ethical to promote the testing, validating, and benchmarking of unproven health interventions in developing countries?

WHO's systematic literature reviews of evidence for new digital technologies tend to be consistent in praising the promise these offer, while also highlighting the need for further implementation research.³³ WHO has acknowledged in its guidelines that the quality of evidence for digital health interventions is sometimes weak, yet it nonetheless recommends them.³⁴

The Committee on Economic, Social and Cultural Rights' General Comment 14 on the right to health asserts that health facilities, goods, and services must be scientifically and medically appropriate and of good quality.³⁵ The rapid scale-up of new digital technologies, even those with promising pilots, should be promoted by WHO and financed by publicly funded agencies only if the evidence base is sufficient to justify bringing new tools to scale. Financing unproven digital interventions may leach resources away from interventions for

which the evidence base is stronger—for example, harm reduction services, which are proven to work but are chronically underfunded.³⁶

Conclusion

The digital strategies and guidance currently emerging from global health agencies unfortunately make only minimal reference to these and other human rights concerns.³⁷ The report from the UN Secretary-General's high-level panel on digital technologies set the tone with its emphasis on addressing the digital divide, recommending that “by 2030, every adult should have affordable access to digital networks, as well as digitally-enabled financial and health services, as a means to make a substantial contribution to meeting the SDGs.”³⁸ The panel's recommendations on human rights protection were far less precise, calling only for “an agencies-wide review of how existing human rights accords and standards apply to new and emerging digital technologies.”³⁹ A year later, the “agencies-wide review” has yet to be published.

Similarly, WHO's draft digital strategy and normative guidance to countries focus overwhelmingly on the promise, with little discussion of the risks discussed above.⁴⁰ The strategy's four principles focus on urging countries to commit to digital health, recognizing the need for an integrated strategy, promoting the appropriate use of digital technologies for health, and recognizing the need to address impediments faced by the least-developed countries, and they make little reference to the concerns raised by UN human rights experts.⁴¹ The strategy was approved by the WHO Executive Board in February 2020 and was on the agenda for approval by the World Health Assembly in November 2020.⁴²

Recognizing that trust and respect for human rights are critical to upholding the right to health and that it is crucial to ensure that the public feels secure in accessing health care, global health agencies such as WHO and the Global Fund should, following the Ruggie Framework, “know and show” that they have done due diligence in order to

identify, prevent, and address human rights abuses linked to digital technologies in health.⁴³ This includes the following:

- developing a common position across WHO, the Global Fund, and other UN development agencies on the risks linked to these technologies, and clearly committing to making respect for human rights standards a core principle of all strategies and guidance;
- integrating consideration of the above risks into normative guidance by WHO and UNAIDS and developing risk assessment tools for countries and donor agencies;
- integrating a robust approach to due diligence into ongoing technical assistance provided to low- and middle-income countries by such agencies as UNDP, UNAIDS, French 5%, and others to enable states to fully assess the track records of companies with which they do business;
- developing biometrics and data management policies that share consistent principles across UN health agencies and global health funders: committing to and recommending the minimal use of biometrics, setting out legitimate uses of health and biometric data, committing to impact assessments for data processing, and setting out constraints on private sector access to health data; and
- consulting with civil society—particularly affected communities—to ensure their involvement in the development and rollout of these policies.

Ultimately, states bear the responsibility to protect human rights; but UN development agencies and global health financing agencies, through the evidence-based normative guidance and technical cooperation they provide and the power they exercise as funders of health interventions, have significant influence on state decisions, and they cannot afford to be naive. As holders of the purse strings for billions in taxpayer contributions, they must do all they can to ensure that international cooperation does more good than harm. Given that technologies used in health will only continue to

evolve, it is critical that respect for human rights move to the center of digital health governance and not be left as an afterthought.

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PERSPECTIVE

Health in the Digital Age: Where Do Children's Rights Fit In?

LOUISE HOLLY

Introduction

The Universal Declaration on Human Rights, adopted in 1948, proclaims that children and childhood are entitled to special care and assistance. Almost four decades later, the United Nations Convention on the Rights of the Child (CRC) was developed to provide further guidance on the full spectrum of rights that children—defined as people under the age of 18 years—are entitled to.¹ The scale of digital transformation, and influence of digital technology in all aspects of our lives, could not have been imagined by those involved in creating these foundational human rights instruments related to children. Nevertheless, the guidance that these instruments provide is as valid in the digital age as it has ever been.

If states were already in conformance with the CRC, children's rights would be at the front and center of all decisions about the design, development, use, and governance of artificial intelligence, digital technologies, and the data they generate. However, as in the analog age, children's rights are often an afterthought, or ignored altogether. Too little consideration is given to how different aspects of digital transformation might concern children, including the potential influence on their right to health. This results in digital tools and approaches that are blind to the needs and views of children, or worse, that undermine their rights and cause harm.² Recent measures taken by social media platforms to reduce harmful content are recognition that insufficient attention to children's rights in the design of digital technologies can have tragic consequences for children's health and well-being.³

Children are major users of digital platforms: globally, it is estimated that at least one in three internet users are children.⁴ As digital infrastructure improves and the cost of connectivity falls, more children, particularly in low- and middle-income countries, are set to come online over the next decade. This opens up huge opportunities for children currently excluded from participating in the digital world and also for private companies or political groups that seek to exploit, market to, or harvest the data of this new cohort of digital natives. More and more aspects of childhood are taking place online, from play to learning to connecting with friends and family (a shift that has accelerated rapidly since the COVID-19 pandemic),

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which makes it increasingly urgent that states, technology companies, and other relevant actors be reminded of their obligations to promote and protect children's rights in the digital environment.

In recent years, a growing number of scholars and child rights advocates have been championing children's rights in a digital age.⁵ Children's rights specifically in relation to the digital transformation in health is an area that has not yet been considered in depth. This essay explores the need to protect and promote children's right to health in a digital age and to ensure that digital transformation in health promotes children's rights. The CRC is proposed as a framework for digital health actors to assess the potential impact of their decisions and actions on children's rights.

What are the implications of digital transformation for children's right to health?

Article 24 of the CRC recognizes the right of the child to the highest attainable standard of health. The digital transformation offers huge opportunities for realizing this right through improving the availability and quality of health services for children, strengthening health systems, and empowering children with the knowledge and tools to manage their own health. Children use a range of digital tools—such as websites, social media, mobile phone apps, and wearable devices—to find and share health advice, track their activity and well-being, and create health promotional content themselves.⁶ Social determinants of child health such as family income, education levels, and the environment that children live in can also be positively influenced by digitalization in other sectors.

Being digitally connected to friends, family, and the wider world is increasingly important for children's well-being.⁷ However, a growing body of evidence suggests that the improper application and use of digital technologies can have negative implications for children and their right to health. Without adequate knowledge, skills, and support from caregivers, children's exploration of the digital environment can expose them to harmful content,

misinformation, and multiple forms of abuse. Digital marketing is a rapidly growing business that makes children vulnerable to the promotion of unhealthy foods, harmful products, and damaging ideas about body image. New forms of digital marketing are particularly concerning, as they can be hard to distinguish from other content, particularly for younger children. Excessive time spent online is believed to be detrimental to the mental health and well-being of children and can displace other forms of physical activity, although there is no consensus on how much time online is too much.⁸

Asides from the direct hazards that the use of digital technology can present to children's right to health, there are also risks that digitalization and new innovations are not being harnessed to their full potential for children. Most digital tools and approaches are not developed with children in mind—as primary or even potential users—so opportunities are being missed for technology to contribute to their better health, well-being, empowerment, and participation.⁹ COVID-19 has revealed the huge digital divide between those who have access to the infrastructure, digital devices, and affordable data packages needed to get online, and those who do not. Without concerted efforts, further digital transformation may increase inequalities in health outcomes and other outcomes important for children to thrive.

Applying a child rights lens to digital health

Children's right to health should be taken into account at all stages of digital transformation, and, equally, children's rights in their entirety should be considered in relation to the transformation of different sectors, including health.

As in other sectors, digital transformation in health is driven by data. Children, and often their caregivers, have limited knowledge and power to control the increased datafication and monitoring of their lives.¹⁰ In the pursuit of valid health goals, state and nonstate actors use a multitude of digital devices to capture children's data, even before they are born.¹¹ Biometric data is captured, for ex-

ample, to boost vaccination rates with insufficient consideration of any unintended consequences on the enjoyment of other rights.¹² Health data that enable people to be located, for example, can put children—particularly those from marginalized groups—at risk of discrimination or persecution.¹³ Information in the public domain about a child's health status can be used against them in the future, such as by employers or insurance companies.

Existing normative and technical guidance on the digital transformation of health systems and health care does not apply, or encourage others to apply, a holistic child rights lens that takes into account the opportunities and risks of digital health for children. For example, the World Health Organization and International Telecommunication Union's *eHealth Strategy Toolkit*, a document that guides member states in the development of digital health strategies and approaches, includes no references to human rights or children's rights.¹⁴ The 2018 World Health Assembly resolution on digital health urges member states to consider human rights obligations only in relation to policies and legislation around data protection.¹⁵ The World Health Organization's forthcoming *Global Strategy on Digital Health 2020–2024* speaks only in general terms about the importance of the appropriate use of technologies to protect against human rights violations. Children are not referred to as potential beneficiaries to be prioritized in the digitalization process, or as a group of rights-holders requiring special protection. *UNICEF's Approach to Digital Health* is the strongest example of a digital health approach that is grounded in the right to health, although it does not explore all the ways in which digital health could promote or undermine children's other rights, such as their rights to protection, nondiscrimination, and participation.¹⁶

Using the CRC as a framework to evaluate digital health tools and approaches

The CRC provides a ready checklist for all digital health actors—including those involved in information and communications technology infrastructure, technology developers, policy

makers, regulators, health care providers, and civil society—to assess the potential positive and negative consequences of a digital health approach or intervention on children's rights. The four general principles of the CRC offer a starting point:

- *The right to life, survival, and development (article 6)*: Do digital health policies and investments prioritize children's right to life, survival, and development? How can digital health policies and interventions mitigate the risks to children's right to life, survival, and development within the broader digital environment?
- *The right to nondiscrimination (article 2)*: Will a digital health intervention be available and accessible to all children regardless of their or their parents' status? What measures will be put in place to ensure that automated decision-making to support children's health isn't based on biased algorithms or datasets? How will children's health data be protected so that it can't be used to discriminate against them in later life?
- *The best interests of the child (article 3)*: Is a digital health intervention being developed with the best interests of the child in mind? What potential harms to children, or violations of their rights, might arise from the application of a digital health intervention or from the collection or use of their health data?
- *The child's right to be heard in matters that affect them (article 12)*: How will children be involved in the design of a digital health policy or intervention? How will children's views be considered in each stage of its development and use? What knowledge and support do children need for informed and meaningful engagement in digital health development and governance?

Digital health actors should also ask how their approach or intervention will support other child rights and how any potential violation of these rights will be mitigated. This would include the rights to protection of identity and privacy (arts. 7 and 16); protection against harmful information and material (art. 17(e)); protection against physi-

cal and mental violence, injury or abuse, sexual exploitation and abuse, and all other forms of exploitation (arts. 19 and 34–37); freedom of expression and thought (arts. 13–14); information, knowledge, and education (arts. 17, 24, and 28–29); physical and psychological recovery and social reintegration of a child victim of neglect, exploitation, abuse, or armed conflict (art. 39); and play, leisure, and culture (arts. 30–31).

Several general comments have been developed by the Committee on the Rights of the Child that help interpret the CRC in the digital age and provide further guidance to state and nonstate actors about the potential effects of digital technology on children's right to health:

- *CRC General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health* calls on states to invest in innovative technologies as a way of reaching vulnerable groups of children. It also urges states to ensure that health information systems are reliable and transparent and protect the right to privacy. It calls on all nonstate actors engaged in health promotion and services to act in compliance with the CRC and to ensure compliance by any partners who deliver services on their behalf. Mass media organizations are called on to promote health and healthy lifestyles among children; to ensure the privacy and confidentiality of children and adolescents; and not to advertise substances or produce content that is harmful to health or that perpetuates health-related stigma.¹⁷
- *CRC General Comment 16 on state obligations regarding the impact of the business sector on children's rights* reinforces the call to businesses to strengthen the realization of children's rights (for example, through technological advances) and to meet their responsibilities regarding children's rights. It calls for digital media to be regulated to protect children from harmful information and material.¹⁸
- *CRC General Comment 20 on the implementation of the rights of the child during adolescence* notes

that the internet provides opportunities for adolescents to access health information, protective support, and counseling. It can also be used by states to communicate and engage with adolescents. The general comment calls on states to adopt measures to promote equal access to digital citizenship and to ensure that all adolescents have access, without discrimination, to different forms of media and support. It recommends digital literacy training and support as part of the basic education curriculum and encourages states to require businesses to undertake child rights due diligence with a view to identifying, preventing, and mitigating the impact of risks on children's rights when using digital media and information and communications technology.¹⁹

To protect and promote children's right to health in a digital age, and to ensure that digital health promotes children's rights, everyone involved in the digital transformation in health and other sectors must take proactive measures to implement the CRC and make children's rights a core guiding principle in the design, use, and governance of technology and data.

All relevant actors should use the CRC as a framework to assess the potential benefits and risks for children of any digital health technology or data-related policy or intervention. Indeed, Sonia Livingstone has proposed that a child rights impact assessment be required before any digital innovation is developed.²⁰ States that have ratified the CRC should fulfill their own obligations and use legislation and policies to ensure that nonstate actors involved in digital health also realize children's rights.

Further guidance on the horizon

The Committee on the Rights of the Child is currently developing a new general comment on children's rights in relation to the digital environment.²¹ The general comment, which is due to be published in 2021, will offer further direction to states on meeting their obligations to promote and

protect children's rights—including the right to health—in the digital environment and to ensure that other actors, including private businesses, also meet their responsibilities.

Clarity on children's rights in the digital environment will not automatically lead to those rights being protected. States and regional bodies need to develop stronger policies and regulations to safeguard children and their data in the digital environment and to hold those who fail to realize children's rights to account. Children's views must be regularly sought and acted on by policy makers and technology developers. Stronger global governance and technical cooperation is also needed to ensure that the achievement of global health goals is not pursued at the expense of other rights. The Governing Health Futures 2030: Growing Up in a Digital World commission convened by the *Lancet* and *Financial Times* will supply urgently needed recommendations on the governance of digital technologies in relation to health, human rights, and public goods.²²

Digital technology and data analytics continue to advance at speeds that policy makers can rarely keep up with. The opportunities and risks around health in the digital age are not yet fully known and will continue to evolve. The environment that children are growing up in may be changing, but their rights remain unassailable both on and offline. That is why the CRC and other human rights instruments must continue to provide a compass for everyone involved in digital development. When children's rights are at the front and center of all decisions about the design, development, use, and governance of digital health technologies and health data, then we will all fully benefit from their transformative potential.

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PERSPECTIVE

A Health Rights Impact Assessment Guide for Artificial Intelligence Projects

CARMEL WILLIAMS

Introduction

Artificial intelligence (AI) is being hailed by various actors, including United Nations agencies, as having the potential to alleviate poverty, reduce inequalities, and help attain the Sustainable Development Goals (SDGs).¹ Many AI projects are promoted as making important contributions to health care and to reducing global and national health inequities.

However, one of the risks of AI-driven health projects is that they can be singularly focused on one health problem and implemented to resolve that one problem, without consideration of how a whole health system is needed to enable any one “solution” to function in both the short and long term. Health projects that have not been designed in participation with local people have a history of failing, and externally funded development projects are especially vulnerable. In terms of human rights, such failings can be attributed to a lack of participation, an imbalance of power, and failure to observe the critically important role of key institutions such as the health system in fulfilling people’s health rights.

Health projects that fail can have negative consequences beyond their own failed missions, and they risk harming human rights generally and the right to health specifically. Equitable access to quality health care is dependent on a well-functioning health system; and such a system is regarded as the core institution through which the right to health can be fulfilled.² If a new project weakens the health system, perhaps by attracting a disproportionate number of health workers to it, or overloading diagnostic or supply chain services, or drawing finances away from other core services, then it is negatively affecting state obligations to fulfill the right to health. These risks may be greatest where health systems are weakest—usually in low- and middle-income countries.

This perspective argues that the way to mitigate these risks is to conduct a health rights impact assessment prior to their implementation. It introduces a tool that enables a systematic process of health rights assessment to take place.

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Background: WHO guideline

In 2019, the World Health Organization (WHO) introduced a guideline on how to use digital technology to strengthen health systems.³ The guideline provides useful indicators for assessing some of the impacts of AI on health systems, but it fails to locate the centrality of health systems to the fulfilment of the right to health.

The guideline followed a resolution brought to the World Health Assembly in 2018 that recognized the value of digital technologies (including AI) and their capacity to advance universal health coverage and the SDGs.⁴ However, the guideline concedes that enthusiasm for digital health has seen many short-lived implementations, an overwhelming diversity of digital tools, and a limited understanding of their impact on health systems and people's well-being.⁵ It stresses the need to evaluate the positive and negative impacts of proposed digital health technologies and to ensure that such investments do not inappropriately divert resources from alternative, nondigital approaches and thereby increase health inequities.⁶

The guideline advises that digital health technologies should complement and enhance health system functions, rather than replace the fundamental components needed by health systems, such as the health workforce, financing, leadership and governance, and access to essential medicines.⁷ It calls for an assessment of the health system's ability to absorb digital interventions and warns that new technology must not jeopardize the provision of quality nondigital services in places where digital technologies cannot be deployed. It demonstrates the assessment of various applications of health-related technology based on effectiveness, acceptability, feasibility, resource use, and "gender, equity and human rights." The guideline encourages technology developers to work with users and to think broadly about context both within and beyond the health system, as well as to consider whether a given digital health intervention will improve universal health coverage. Although human rights are included with the "gender, equity and human rights" component for impact analysis, the specific indicator selected to assess this component

is limited to the technology's impact on equity.⁸

But equity—important as it may be—is only one human rights consideration. It is also necessary to examine other key principles of the right to health when assessing health interventions.⁹ Although the WHO guideline examines various components of a health system when the component is directly affected by the technology, it fails to systematically examine the whole health system to identify any less obvious, indirect impacts of the proposed new technology.

In response, this paper presents an expanded tool to help states and other actors undertake a right to health impact assessment prior to implementing AI projects. The tool, informed by the WHO guideline, is a refinement of an earlier impact assessment tool of aid-funded health projects in low-resource settings.¹⁰ It accommodates additional considerations necessary when AI health projects are under development. It explores possible impacts, specifically on the right to health, moving beyond the civil and political rights most frequently associated with digital health, big data, and AI—namely, data privacy and protection, security, and algorithm transparency. It is a guide that provides a sample of the type of questions across the health system that need to be explored—but each project will need its own context-specific adjustments.

The right to health and health systems

Because the health system is the core institution through which the right to health can be realized, governments and other agencies have a duty to ensure that health systems are enabled to fulfill people's entitlements to available, accessible, acceptable, and quality health services (AAAQ).¹¹ Accordingly, governments have a human rights obligation to ensure that health systems are never weakened but rather continually improved as part of their progressive realization duties, as detailed in General Comment 14 of the Committee on Economic, Social and Cultural Rights.¹² One way to prevent a weakening of the health system while demonstrating a commitment to the progressive realization of the right to health is to carry out

human rights impact assessments prior to adopting and implementing policies and programs.¹³ This applies to projects relating to digital health, projects driven by AI (irrespective of whether they are government or nonstate initiatives), and projects driven by local funding or through international assistance and cooperation.

In order to conduct a health rights impact assessment on a health system, it is convenient to compartmentalize the system to enable impacts to be measured across its many functions. A useful schematic devised by WHO identifies the component parts that contribute to the delivery of health care: health services and facilities; health workers; health financing; medicines, products, and other supplies; health information systems; and management and governance.¹⁴ Importantly, there is more to a health system than these technocratic elements: people and communities must also be included, as the right to health entitles them to participate in a meaningful way in the planning, delivery, and monitoring of health care and health promotion. Human rights-based approaches to health care and health projects promote the active engagement of people who will be using services, as well as the understanding that people are legally entitled to these services as a function of their right to health. Without people's participation, health services cannot achieve AAAQ for all.

Health rights impact assessment

A health rights impact assessment is a systematic examination of a project, undertaken prior to its implementation, to anticipate the effect that it will have on human rights and health, including and extending beyond its own project-related goals. It should not be confused with, nor replaced by, a needs assessment, which is a narrower exercise that does not assess risks. A health rights impact assessment predicts immediate and longer-term impacts on the whole health system by examining each of the system's component parts and assessing the ways in which the project could strengthen or weaken that component. If risks are identified, an impact assessment considers ways to mitigate them. The purpose of such an assessment is at least twofold: it aims to strengthen the project by ensuring that it is in alignment with the health system and its governing strategies and plans; and it aims to strengthen the health system by helping design projects that will be sustainable and contribute to the protection and fulfilment of health rights.¹⁵

Conducting a health rights impact assessment when a project is being designed can help governments adopt and implement policies, programs, and projects that will best meet their obligations to take deliberate and concrete steps toward the progressive realization of human rights.¹⁶ It serves a further purpose as well, by promoting engagement with the key features of the right to health, outlined in Table 1.¹⁷

TABLE 1. Key features of the right to health

1. Laws, norms, and standards
2. Dignity, equality, and nondiscrimination
3. Participation
4. Accountability
5. International assistance and cooperation
6. Respect for, protection of, and fulfillment of all human rights
7. Progressive realization, maximum available resources, and non-retrogression
8. Obligations of immediate effect
9. Availability, accessibility, acceptability, and quality
10. Health system strengthening

AI for health care in low-resource settings

Even before the extraordinary pressures of the COVID-19 pandemic, health systems worldwide were facing challenges, including greater demands for services with the rising burden of disease, increasing costs, and poor productivity and overstretched human resources. It would therefore be of great benefit to health systems and communities if technological advances could help reduce burdens on systems and health care costs while increasing accessibility and equity.¹⁸ In an opening address to the “AI for Good Summit” in 2019, the secretary-general of the International Telecommunications Union, Houlin Zhao, urged the audience to “turn [the] data revolution into a development revolution.”¹⁹ To achieve this revolution, though, it is imperative that the development context is fully understood and reflected in the data solutions. Development has a long history of failed projects, especially those dependent on technology.²⁰ Enthusiastic donors can be persuasive partners when seeking to test new technologies in low-resource settings, and governments in these settings are presently indicating that they are “open for business” when it comes to AI partnerships.²¹ Not only are the well-known pitfalls arising from a lack of ongoing technical or health worker support, or funding for maintenance, present with AI-based technology partnerships, but additional traps as yet unknown can arise from downstream data ownership, sharing, and reuse.²²

AI is being used in health care in various ways, including in diagnosis (especially imaging), patient management, treatment (for example, robotics in surgery), and new drug development.²³ In the wake of COVID-19, technology is also playing a large part in contact tracing, where it monitors the spread of the epidemic, and in the race to develop a vaccine.²⁴ But many of these uses demand a level of technical capacity well beyond that available to health systems in low-resource settings. Even if the technology is designed elsewhere and imported, its ongoing use requires an adequate, well-trained, and available workforce; infrastructure (including, at the very least, electricity and internet); and accessible health facilities so that the benefits of

such advances are equitably available to all people. Designing data-driven technological projects for health care in low-resource settings requires a detailed understanding of their challenging contexts; otherwise, the interventions will almost certainly be inappropriate or unsustainable. It is difficult to acquire such an understanding from afar. But even locally developed AI-based technological solutions can fail to respect and protect human rights if they are not supporting the local health system in meeting the health rights of the people in its jurisdiction.²⁵

Thus, regardless of whether AI health projects are being introduced in a development context (a focus of AI for Good) or in high-income countries, it is imperative that systematic health rights impact assessments are undertaken and that they are broad enough to anticipate impacts on the health system components, as well as on civil and political rights relating to data privacy, ownership, and security.

Adapting a health rights impact assessment tool for technology projects

Presented in Table 2, this assessment tool is framed to guide the development of AI for health projects that comply with a right to health framework in local contexts. Each of the proposed questions is linked to at least one of the key features of the right to health. Therefore, indicators are selected to assess impact on the health system and on the right to health.

Discussion

This perspective has presented a rationale for undertaking a right to health impact assessment before implementing AI health projects in high- or low-resource settings. Such assessments are in keeping with the United Nations’ draft business and human rights instrument to regulate the activities of businesses and transnational corporations.²⁶ The tool in Table 2 demonstrates the range of questions that need to be addressed before implementing AI projects to determine how a new technology might affect the health system and, therefore, the right to health.

TABLE 2. A right to health impact assessment for AI health projects

	Question to probe impact	Rationale for inclusion in the assessment	Specific right to health or human rights principle invoked
	Legal context		
1	Is the software or app compliant with relevant national and regional legal requirements, including algorithmic transparency?	To ensure compliance with legal context	Laws, norms, and standards
2	What protocols are in place to inform patients, gain consent, protect privacy, and store data securely?	To ensure that standard operating procedures have been established for patient consent, data protection and storage, and verifying provider licensing and credentials (WHO guideline)	Rights to information and privacy
3	Who owns the data, and what protections are in place regarding future use, ownership, and price protections?	To ensure that patients are aware of who owns their data and whether the data may be used by a third party, as well as to ensure their consent to such ownership and use	Privacy and informed consent Future availability and access AAAQ
	Health services, facilities, and goods		
4	Could the project affect the availability, accessibility, acceptability, and quality of other health goods and services in the country?	To explore the possibility of the new technology distorting other services: Will pre-AI services remain available and supported in case new services cannot reach everyone? Will staff or resources move from other services to this new one?	AAAQ Non-retrogression Equality and nondiscrimination
5	Is the project addressing priority health areas as identified in national health plans?	To protect against distortions in national health plans with nonprioritized health care services being introduced because technology partners seek their inclusion	Progressive realization Non-retrogression Health system strengthening
6	Does the project address the sustainability of new services?	To determine how the technology will be supported when IT partners exit	AAAQ
7	Has the community been consulted to assess the technology's acceptability and accessibility?	To ensure the participation of the population in designing the project, its implementation, and its monitoring	Participation Acceptability and accessibility Transparency and accountability
	Health workforce		
8	Have health care workers been consulted on whether the project aligns with the national health workforce strategy?	To ensure that state plans and strategies, health care management, and health care workers been consulted about the technology	Participation Availability (of health workers)
9	Could the project affect the number of health workers available to meet primary health care obligations or core obligations?	To ensure that the new technology-driven project will not draw health workers away from other essential services	Obligations of immediate effect AAAQ
10	What cadres of health workers will use the technology?	To ensure that the use of digital technology is for tasks already defined as within the scope of practice for the health worker (WHO recommendation)	Availability (of health workers)
11	How will health workers be trained and provided with ongoing support in their use of the technology?	To consider who pays for training, ongoing support, and the cost of data: Is this sustainable?	AAAQ Quality (of health care)
	Health information systems		
12	Were departments and hospitals consulted on whether the project strengthens the present health information system?	To ensure that departments and divisions in the health system and referral hospital are consulted prior to the technology's design	Participation Quality
13	How does the project collect patient data, and can the data be integrated into patient records and the broader health information system?	To ensure that the data are stored securely and integrated within the health system	Health system strengthening Laws, norms, and standards Privacy

TABLE 2. *Continued*

	Question to probe impact	Rationale for inclusion in the assessment	Specific right to health or human rights principle invoked
14	Does the project involve the digital tracking of patient health status and use of health services?	To ensure that this technology is deployed only in settings where the health system can support its implementation in an integrated manner; is used for tasks that are already defined as within the scope of practice for health workers; and is deployed in settings where concerns about data privacy and transmission of sensitive content can be addressed (WHO guideline)	Laws, norms, and standards Privacy Availability
Medical products, vaccines, and technologies			
15	Can this technology function within the current infrastructure?	To ensure that the context is assessed to determine the geographic range of internet access, uptake by different communities, gender use differences, and any other concerns that could increase inequitable health outcomes	AAAQ
16	How will this technology be updated?	To ensure that the technology remains accessible and available	AAAQ Non-retrogression
National financing			
17	Will the local health system have to pay for this technology (for example, after a pilot period)?	To make transparent who will have to bear the costs of the AI and the impacts that this will entail on that source	AAAQ Accountability
18	Has this cost been accepted by health authorities and factored into budgets?	To ensure sustainable funding	Participation Accountability Non-retrogression
19	Will patients be charged user fees?	To assess whether user fees will affect accessibility	Participation AAAQ
20	Will the state own the data generated from the use of the technology?	To ensure that the state is not losing ownership of data, which could cause sustainability and privacy issues in the future	Laws, norms, and standards Non-retrogression Privacy
Governance and leadership			
21	Were national or local health plans and leaders consulted before designing this technology, to ensure its alignment with plans?	To ensure that the AI project is designed to further the health plan and not the profits of the AI developer	Participation
22	Who will own, manage, and protect the data collected in the project?	To ensure that the state does not transfer public goods to private owners, thereby reducing state capacity to achieve full realization of the right to health	Accountability Maximum available resources
23	Are management systems and capacities sufficiently robust to accommodate the demands of this new technology?	To ensure that there is adequate capacity within the health system to take on additional work without reducing quality or equity	Accountability Equality and nondiscrimination
24	Have ongoing recurrent costs and replacement of technology costs been estimated and entered into forward budgets?	To ensure that there is budgeted financial support for sustainability	Accountability Non-retrogression

Introducing an app that can, for example, diagnose skin cancer or detect a pregnant person's increased risk of pre-term birth, does nothing to fulfill people's right to health entitlements, or universal health coverage, if there are no suitable treatments available for skin cancer or secondary-level obstetric services accessible to those who

need them. Every component of the health system must be functioning well before a service can become equitably available, accessible, acceptable, and of good quality; and if these and other right to health features are not achieved, people's rights cannot be fulfilled. This tool includes questions that not only probe the technocratic aspects of the

health system—even though they are crucially important—but also assess other key right to health principles, including participation, accountability, equality and nondiscrimination, non-retrogression, and international cooperation. It is not enough for developers of a new AI application to claim that their application will address one health service and will therefore “help achieve SDG3 and universal health coverage”; without a right to health impact assessment, there can be no confidence that this is a likely outcome. Similarly, all human rights are interrelated and indivisible, which means that a rights-based app assessment must look beyond the health sector to determine how the technology could also affect other rights, including those related to privacy, confidentiality, and security.

The long-term sustainability of a technology-based business depends not only on states’ and businesses’ fulfillment of their obligations to protect human rights but also on the development of products that service providers find useful, affordable, efficient, and acceptable to rights holders, including men, women, and children. These criteria apply whether the technology is state or nonstate owned and developed.

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VIEWPOINT

Technology, Health, and Human Rights: A Cautionary Tale for the Post-Pandemic World

RAJAT KHOSLA

Technology is widely known for moving fast and breaking things, to paraphrase Mark Zuckerberg. Indeed, technology is fast moving into each and every aspect of our life, especially our health and well-being. The COVID-19 pandemic has shown how technology can and should play an important role in helping stop the spread of the disease, including by disseminating public health messages and increasing access to health care (for instance, through virtual consultations). However, the pandemic has also demonstrated how certain governments—in the name of combatting the disease—have rushed to expand their use of surveillance technologies to track individuals and even entire populations. Without human rights safeguards and meaningful public consultation, digital health technologies threaten privacy, freedom of expression, and freedom of association, thus violating rights and degrading trust, which also undermines the effectiveness of such technologies. At Amnesty Tech (a program of Amnesty International), we are taking stock of all that is broken in the technology and health and human rights nexus, while trying to ensure that critical human rights safeguards are put in place.¹

As we contend with the growing adoption of technology as a tool to address COVID-19, we should learn from past experiences and ensure that health and human rights are protected every step of the way. Within this context, we have identified three growing human rights concerns.

The first is the increasing use of technology to expand surveillance by states, including through access to data collected for public health. Earlier this year, many groups, including Amnesty Tech, raised the alarm about privacy with regard to the rollout of contact tracing apps. Our investigation confirmed that the alarm was well founded, as it discovered major privacy problems in contact tracing apps being used or developed by Qatar, Norway, Bahrain, and Kuwait.²

Among the most concerning was the use of centralized systems, wherein governments retain the data gathered by the apps on a central server, making it harder to protect the data from being shared or misused in ways that could lead to human rights abuses.

Over the past few years, Amnesty Tech has uncovered extensive examples of state authorities and others unlawfully using digital surveillance to spy on, intimidate, threaten, or silence activists or to locate, detain, or imprison them.³ State authorities have increased the surveillance and disempowerment of already disadvantaged communities. Among the lessons we take from this is that function creep—the

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tendency of data collected for one purpose to be repurposed for another, unforeseen purpose—is a fundamental component of the human rights risk posed by state surveillance and, as such, needs to be addressed with adequate safeguards. This means, as our research has shown, that we need strong data protection rules, legal safeguards, and meaningful regulation of the surveillance industry as we enter this new world of massive collection of data within the context of public health concerns.⁴

Unfortunately, we are already seeing rumblings of such government abuse. For example, Israeli authorities attempted to grant the security services access to contact tracing data.⁵ While this proposal appears to have been withdrawn, a look at the United States gives a dire warning of where such data sharing could lead. In the United States, the Immigration and Customs Enforcement Agency uses technologies provided by Palantir, a secretive tech giant, to conduct immigration raids that have led to hundreds of arrests, deportations, and family separations.⁶ In April 2020, Palantir won a contract with the Department of Health and Human Services to build the “Protect Now” platform aggregating over 187 different data sources from the government and private sector. Given previous examples of the Department of Health and Human Services sharing data with Immigration and Customs Enforcement Agency, policies and practices around the use of technology within the context of public health pose serious concerns, especially for groups that are in particularly vulnerable situations.⁷

In response, Amnesty Tech continues to make targeted and mass state surveillance an ongoing focus of our work, both in our investigations via our Digital Security Lab (which leads technical investigations into cyber attacks against civil society and provides critical support when individuals face such attacks) and in our advocacy and legal efforts, while taking account of the new ways in which states’ use of technology to respond to the pandemic may exacerbate these harms globally.

The second cause for concern is the ways in which employers can potentially abuse employee health data. Can an employer be allowed to demand

that employees take COVID tests or to reveal their status? How can an employer use this information, and with whom can it be shared? Furthermore, existing regulations governing the collection and use of health data have not kept pace with a rapidly changing economy, especially in the United States. For instance, a gig worker may have very different legal protections or face other vulnerabilities than a contract employee. The intersection of the right to health and privacy requires more robust data protection standards.

Amnesty Tech is analyzing existing legislation and upcoming efforts that may offer protection in some circumstances across jurisdictions governed by differing data protection frameworks, in order to inform our work to ensure human rights-compliant safeguards in these new contexts.

The third cause for concern is health data taking on a key role in the expansion of the surveillance-based business model that dominates the tech sector, whereby people’s digital data are bought and sold as a commodity. It is crucial to understand that these risks and harms take place against the backdrop not only of this business model but of a generally thinly regulated marketplace in data. As we pointed out in our report *Surveillance Giants*, the internet is dominated by companies whose primary means of earning profit is through advertising sales premised on their ability to collect, analyze, and draw inferences from massive amounts of our personal data.⁸

Consider the issue of gathering and using health data to sell for advertising purposes. While this practice did not start with the pandemic, it has accelerated during this time. Numerous firms have been collecting health data from consumer products for some time now, including from a wearable fitness trackers, genetic test kits, and myriad other products. This valuable data can fuel analytics aimed at predicting consumer habits or choices and can be purchased to increase data companies’ resources and value. In 2019, Fitbit’s CEO stated that “ultimately Fitbit is going to be about the data” rather than its hardware or devices.⁹ In 2020, Google acquired the company for US\$2.1 billion.¹⁰

This massive accumulation of personal data

usually occurs without individual consent (or with “consent” that is far from adequate under most data protection regimes), but the risk of harm is compounded when the data in question can be resold or shared without adequate safeguards. Moreover, the data are often useful insofar as they provide the basis for predictions about our behavior. While the underlying data themselves may be subject to protections in some jurisdictions, the inferences based upon them often are not, creating a particularly complex scenario.¹¹

Inferences that are created based on personal health data—“emergent medical data”—carry tremendous risks for human rights.¹² A health insurer may deny coverage based on a prediction made about a person to which they never consented and may not even know about. Likewise, artificial intelligence can monitor people’s movements to track the spread of infectious disease or purchases to track a person’s pregnancy status. Just as worrying is how frequently these predictions are inaccurate.¹³ Moreover, without proper data subject rights or other avenues via which to claim a remedy, we are left without much recourse.

In response, Amnesty Tech continues to push for a human rights-respecting business model for the internet, as well as safeguards for AI and machine learning systems, such as the Toronto Declaration, which highlights principles for protecting the rights to equality and nondiscrimination in machine learning systems.¹⁴ We will do this while continuing to expose and oppose the harms created by the current business model, as well as any additional harms that may emerge from extensive and invasive analysis of our health data and the uses of the inferences that flow from them.

Our rights to health and privacy are now more interlinked than ever before. Health data pose significant risks at the intersections of state surveillance, a surveillance-based internet, and data protection. All of these lack adequate safeguards to protect the rights at risk. George Orwell once said, “Who controls the past controls the future. Who controls the present controls the past.” Without adequate safeguards and protection of rights in the

digital space, we risk the health and well-being not only of people today but also of future generations.

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VIEWPOINT

From Information to Valuable Asset: The Commercialization of Health Data as a Human Rights Issue

AMY DICKENS

Health data is a valuable source of knowledge that states can use to advance or undermine the right to health. But the sources and use of health data are changing in our emerging global data economy. Novel forms of digitized health information are fueling a booming industry for algorithmic technologies in health care, rendering it a huge source of scientific and commercial value. To date, the tech giants—Google, Apple, Microsoft, Facebook, and Amazon—are way ahead of public health systems in capitalizing on this value. There is an urgent need for states to recognize the value of health data and use it to advance human rights. Failing to do so risks private actors gaining ever more expansive monopoly powers that threaten patients' social and economic rights.

Health data as a valuable asset

Health data—that is, “information related to health conditions, reproductive outcomes, causes of death, and quality of life”—has long been at the core of efforts to improve health through its use in epidemiology, public health, and health informatics.¹ Human rights advocates have also utilized health data as a tool to identify vulnerable populations and monitor states' progress toward the realization of the right to health.² Conversely, repressive states such as China, Venezuela, and Turkmenistan have undermined the right to health through the censorship of public health data.³ These uses of health data point to a longstanding recognition of its value as a source of knowledge and power.

More recently, the increasing production of digitized health data through the widespread use of electronic patient records, new health applications, and wearable technologies—coupled with advancements in computational power—have enabled the development of novel algorithmic and machine learning tools to improve diagnostics, treatment, and administration in health care. Training these algorithmic technologies requires access to huge datasets, resulting in increased demand for health data and fueling the emergence of a burgeoning global health data economy. With the booming AI health care market set to be worth US\$6.6

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billion by 2021, health data is no longer simply a source of information but a valuable asset used to generate intellectual property and economic profit.⁴

The commercialization of health data: A problem for human rights

Today, the scientific and commercial value of health data is captured predominantly by the tech giants, whose first-mover advantage, technical expertise, and wealth of resources enable them to dominate the market for data-driven innovation in health. In recent years, these companies have sought to extract the commercial value of health data by collaborating with health care providers to develop new algorithmic technologies. This business model is exemplified by the controversial partnership between Google's DeepMind and the UK's National Health Service, in which DeepMind was given free access to 1.6 million patient records in exchange for developing a new clinical application to detect acute kidney injury.⁵

The deal raised serious concerns around patient privacy, highlighting how the tech giants' access to health data risks infringing on civil and political rights, such as the right to privacy.⁶ It also granted DeepMind exclusive property rights to any technologies developed through the collaboration, enabling the company to determine the price of such technologies and to control access to their health benefits. Commercial capture of the scientific and financial value of health data through partnerships such as these may restrict equitable access to data-driven technologies and their health benefits, thus infringing on the rights to science and health.

Unlike the tech giants, states are currently ill equipped to realize the value of patient data. Most health systems, particularly those in low- and middle-income states, do not have the financial or technological capacity to develop algorithmic technologies themselves. The private sector thus has an indispensable role to play in facilitating data-driven innovation. Yet the public sector also lacks the necessary commercial expertise to strike up effective deals with the tech giants. This is compounded

by the difficulty of quantifying the true "value" of data, which makes it unclear as to whether states (and patients) are getting a fair return for providing access to patient records.

The commercialization of health data is thus a double-edged sword for human rights: while the development of data-driven technologies that could advance socioeconomic rights depends on the capabilities of tech giants, human rights are also threatened by these companies' involvement.

Realizing the potential of health data resources

State signatories to the International Covenant on Economic, Social and Cultural Rights have an obligation to take steps to progressively realize the rights to science and health to the maximum of their available resources and to protect these rights from violations by third parties.⁷ Furthermore, according to the Committee on Economic, Social and Cultural Rights' General Comment 25, states are required to "promote scientific research ... to create new medical applications and make them accessible and affordable to everyone."⁸

If states are to harness the true value of health data to advance human rights, they must first recognize its potential to deliver scientific and economic benefits. To this end, they should strive to improve the availability of health data while ensuring appropriate protections. This requires that states invest in efforts to develop and maintain high-quality health data systems. Where resource-scarce countries face barriers to digitization, other states should provide international assistance.⁹

States must also ensure that research collaborations with technology companies do not allow commercial actors to infringe on human rights, including the rights to science and health. To do so, they must challenge tech giants' monopoly ownership of algorithmic technologies and demand equitable benefits for the use of rights-holders' data. This requires that states consider alternative means to advance data-driven innovation, such as commercial models like profit- or IP-sharing

agreements or more innovative data governance solutions like data trusts. In order to determine what constitutes a fair return for rights-holders, states should support efforts to develop novel methods of quantifying the value of health data and actively promote the participation of patients in data governance efforts.¹⁰

For the commercialization of health data to advance human rights, states must use patient data to generate new innovations, while pushing back against the encroaching powers of the tech giants by laying claim to rights-holders' legitimate stake in the ownership of algorithmic technologies and protecting patient privacy. This urgent task reinforces the Committee on Economic, Social and Cultural Rights' call for states "to regulate the ownership and control of data according to human rights principles."¹¹

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VIEWPOINT

Participatory Machine Learning Using Community-Based System Dynamics

VINODKUMAR PRABHAKARAN AND DONALD MARTIN JR.

The pervasive digitization of health data, aided with advancements in machine learning (ML) techniques, has triggered an exponential growth in the research and development of ML applications in health, especially in areas such as drug discovery, clinical diagnosis, and public health.¹ A growing body of research has shown evidence that ML techniques, if unchecked, have the potential to propagate and amplify existing forms of discrimination in society, which may undermine people's human rights to health and to be free from discrimination.² We argue for a participatory approach that will enable ML-based interventions to address these risks early in the process and to safeguard the rights of the communities they will affect.

The promise of machine learning is its ability to efficiently comb through data to find valuable patterns and insights that the machine may use to make predictions or to aid humans in making decisions. However, data reflect numerous societal and human biases that shape their generation, availability, collection, synthesis, and analysis. Machines learn insights based on correlations in data; but most current ML algorithms do not have a means to distinguish between correlations that are mere reflections of these societal biases (for example, racial and gender disparities in society) and those that are causal and reliable insights on which to base their decisions. This is especially problematic in high-stakes domains such as health, where propagating and amplifying such societal biases may disproportionately harm those who are already facing discrimination in society.

For instance, a recent study found that an ML-based health care risk-assessment tool used in the United States exhibited racial bias against Black Americans, denying them access to special programs and resources.³ The goal of the risk-assessment tool was to improve care for patients with complex health needs while reducing overall costs by connecting high-risk patients with special programs and resources. During the ML problem formulation, this strategic goal was reduced to identifying patients who had the highest health care costs, relying on the implicit causal theory held by the developers that patients with more complex health needs would have spent more on health care in the past. However, this inference failed to consider the historic disparities in health care access (among other things) that Black individuals face in the US health care system and the dynamically complex ways that such disparities affect their spending on health care.

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Consequently, the algorithm tended to mistakenly construe Black individuals as not being high-risk patients, further denying them access to special programs and resources.

One mistake made in the design of the aforementioned tool was the decision to use health care costs (spending) as a proxy variable for health care needs. Relying on such simplified models of the societal context in which ML-based interventions will be deployed fails to account for the dynamically complex nature of society and the various factors affecting how health care needs may be reflected in data. More importantly, the assumptions that guided this choice emerged from an opaque and iterative process among key internal stakeholders (often limited to product managers, business analysts, computer scientists, and ML practitioners) resulting from their cumulative lived experiences and reflecting their world views and biases. These stakeholders often lack the subject-matter expertise or lived experiences required to comprehensively approximate and account for the various peripheral stakeholders whom their interventions will affect, especially the communities that are already subject to social discrimination. For instance, if the problem-formulation step had facilitated the equitable participation of diverse communities with lived experiences within the US health care system, the developers could have flagged that the above assumption regarding health care spending was flawed. This capability gap is a core issue that contributes to the recurring blind spots of tech interventions in society.

Toward participatory methods in machine-learning fairness

Fairness failures in deployed ML systems may have negative impacts on human rights, such as the right to the highest attainable standard of health and the right to be free from discrimination. However, explicit human rights considerations have largely been absent within the community of technical researchers working to ensure fairness in machine learning. Computer scientists often focus on the biases in their models and attempt to mitigate them

through algorithmic means. Such purely observational and statistical approaches may be inadequate when considering normative, constitutive, process-oriented, and socially constructed concepts such as fairness and equity.

As a solution, we recently proposed a complex adaptive system (CAS)-based model of societal context.⁴ CASes are *complex* in the sense that they are made up of components that are directly or indirectly related in a causal network, and the behavior of the system cannot be predicted based solely on the behavior of its components; and they are *adaptive* in the sense that they adapt to the changes in their environment by mutating or self-organizing their internal structures. The CAS-based model has been successfully applied to model social systems of varying sizes and complexity, from individual organizations to large health care systems. A key component in our model is the causal theories that human agents hold about the cause-to-effect relationships between various factors that cause or lead to specific problems in society. In the health care example above, the assumption that more complex health needs would lead to increased health spending for all groups is analogous to a causal theory in the CAS model. Highlighting causal theories as a key component of societal context emphasizes the importance of more complete causal theories and incentivizes making them explicit for scrutiny, critique, and improvement.

In order to mitigate the negative consequences of incomplete causal theories described above, we recently proposed community-based system dynamics (CBSD) as a practice that could supply diverse sources of causal theories to core decision-making steps during the ML development process.⁵ CBSD is a participatory method that relies on group modeling sessions involving diverse stakeholders, with the goal of developing a shared understanding of a *complex adaptive* problem by making the causal theories held by participants explicit. It relies both on informal maps and diagrams to make everyone's causal theories more explicit and on formal models with computer simulation to uncover the dynamics of complex problems from a feedback perspective. To uncover and understand

feedback processes, CBSD uses a series of graphical tools with varying degrees of formalism, requiring modelers to make their causal theories explicit. This reliance on visual diagramming in CBSD emphasizes transparency and facilitates the engagement of diverse stakeholders to add, revise, and critique causal theories. Moreover, a strength that this methodology shares with other causal modeling approaches is the correspondence between its visualizations and their underlying mathematical representations, which allows stakeholders to develop deep insights about important data for collection and consideration and to simulate the impact of their interventions.

Rather than merely gathering insights through participation, CBSD seeks to co-create solutions in a way that ensures communities' active involvement. The process often results in counterintuitive insights about the problem space and has successfully led to solutions that challenge conventional wisdom in numerous interventions in public health and social work.⁶ Employing CBSD to build fairer technologies means that stakeholders get to define and negotiate together what fairness means in the contexts where these technologies are applied. For instance, an initial CBSD-oriented workshop was held at the Data for Black Lives II conference in January 2019. Attended by about 70 participants, this workshop facilitated group model-building exercises on the topic of the racial wealth gap in the United States. A subset of conference participants continued on for a months-long CBSD effort on the topic of racial bias in artificial intelligence and its implications for health disparities. The modeling process and outcomes were then presented at the 2020 Conference of the System Dynamics Society.⁷ This work demonstrated how employing CBSD to center the discussion of data and health care on people and their experiences helped derive important structural insights into how ML-based interventions in health care may perpetuate or exacerbate racial biases. Specifically, the CBSD process identified collective memory of community trauma (through deaths attributed to poor health care) and negative experiences with health care as endogenous drivers of seeking treatment and ex-

periencing effective care, which in turn affect the availability and quality of data for algorithms.

We believe that a proactive, participatory, rights-based approach to ML fairness will provide the much-needed grounding for a set of globally salient and cross-culturally accepted values and principles and will help orient the conversation toward humans and the risks to their rights rather than machines and the risks of their biases. Businesses have the responsibility to protect and respect human rights, as outlined in the United Nations Guiding Principles on Business and Human Rights.⁸ Effective and scalable participatory methods such as CBSD may help bring forth the perspectives of marginalized communities during the earliest stages of the product development process, enabling the co-creation of solutions by technologists and communities. These efforts could inform companies' approaches to evaluating potential human rights impacts across the product life cycle.

Disclaimer

Any opinions, findings, conclusions, or recommendations expressed in this article are those of the authors and do not necessarily reflect the views of their employer.

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VIEWPOINT

An Invitation to a Feminist Approach to Global Health

Data

SHIRIN HEIDARI AND HEATHER DOYLE

The notable gendered socioeconomic, health, and human rights implications of COVID-19 have sparked a renewed conversation on gender data gaps and the risks of gender-blind responses that ignore structural determinants of health and undermine social justice goals.¹ Higher mortality among men, disproportionate social, economic, and health effects on ethnic and racial minorities, high infection rates among the predominantly female health workforce, the rise in violence against women and people of diverse sexual orientation and gender identities, the heavy burden of unpaid care on women, and diminished access to essential services such as sexual and reproductive health services are some of the factors that bring to the fore the urgency of capturing disparities and delivering a gender transformative and equitable response to the pandemic.²

Delivering accessible, affordable, and equitable health care for all requires policies and strategies that are grounded in high-quality reliable data and are “conscious of the need to address the social determinants of health, including those related to gender, income, education, ability, conflict and ethnicity.”³ An intersectional feminist approach to global health data—for epidemiological surveillance, monitoring and evaluation, or research—has the potential to examine the intersectional nature of power and privilege, whether due to patriarchy, colonialism, capitalism, neoliberalism, or the many other endemic hierarchies, and reveal health disparities and gender-related barriers to health information and quality services. Drawing on feminist thinking, governments and global health actors can productively address the underlying causes of health inequities and deliver on the right to health, including the universal health coverage goal of leaving no one behind.⁴

COVID-19 on the heels of growing data activism

Despite the visibly gendered outcomes of COVID-19, the research and analysis of data on the pandemic continue to be remarkably gender blind.⁵ Countries have been slow in reporting and analyzing COVID-19 infection and mortality data by sex and age, among other dimensions, and gender analyses on testing,

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hospitalization, access to services, and social and economic implications are missing.⁶ The implications of intersecting axes of inequality—such as race and ethnicity, sexual orientation and gender identity, disability, migration status, and socioeconomic status—are even more rarely analyzed, concealing the compounded impact of the pandemic on different populations.⁷

The data activism of the last decade offers a useful critique of the gender biases in the way we produce and use data to respond to the COVID-19 pandemic. Authors including Sara L. M. Davis, Caroline Criado Perez, Angela Saini, Catherine D’Ignazio, Lauren F. Klein, and Alyson J. McGregor eloquently underline the power of data and the harms that biased or incomplete data can inflict on those whose experiences have been ignored.⁸ The biases that have plagued systems are increasingly the focus of international global health and gender equality players—such as Data2X, an entity established by the United Nations Foundation with the sole purpose of improving “the availability, quality, and use of gender data.” At the same time, we are also witnessing a long-overdue momentum to decolonize global health at a time when preexisting “racial, ethnic and financial inequities” are being exacerbated as a result of the COVID-19 pandemic, in a bid to finally reverse the remaining “colonial hangover,” in the words of World Health Organization Director-General Tedros Adhanom Ghebreyesus.⁹ As Clara Affun-Adegbulu and Opemiposi Adegbulu states, “the patterns or matrix of power, born of colonialism, ... [continue to] define and control the economy, culture, knowledge production, body and psyche, and authority, beyond the limits or end of colonialism.”¹⁰ An intersectional feminist lens to data can uncover the multiplying effect of gender, race, ethnicity, poverty, and other dimensions of inequality on the physical, mental, and social health of different populations.

The growing recognition that biased and incomplete data render individuals’ needs invisible and ignored is echoed in the human rights-based approach to data, which focuses on issues of data collection and disaggregation to improve “the quality, relevance and use of data and statistics

consistently with international human rights norms and principles.”¹¹ A report submitted to the 41st session of the United Nations Human Rights Council states that “disaggregation of data that allows a comparison of population groups ... forms part of the human rights obligations of States and has become an element of the human rights-based approach to data.”¹² Fragmented, partial, and gender-biased data that ignore the experiences of, health needs of, and barriers to access services faced by certain populations risks violating the rights of all to equal and nondiscriminatory access to health services, while infringing the right to enjoy the benefits of, and protection from the harmful effects of, scientific and technological development. These rights entail positive obligations on state parties. In the case of the Convention on the Elimination of Discrimination against Women, state parties must take proactive measures to modify or abolish existing laws, regulations, customs, and practices that result in discrimination against women. This includes the obligation to ensure that data collection and use reflect the real-world experiences of women and that any conclusions reached are supportive of equality.

Needless to say, the increasing focus on data surveillance to control and contain community transmission of COVID-19 raises concerns about infringement of the right to privacy and confidentiality, potentially exposing individuals to serious human rights violations. Hence, the need to collect granular data for an effective response must go hand in hand with data protection and respect for human rights. As a result, it is not sufficient to consider the intersection of gender with other dimensions of oppression regarding what data are collected. We also need a critical reflection on the ways in which data are collected and evidence is produced, further emphasizing our call for the adoption of feminist principles to global health data.

A call for a feminist approach to global health data

Feminist approaches to knowledge production are concerned primarily with the issue of power differ-

entials—understanding how people’s lived realities are captured by data processes and how this affects the power structures that help or hinder people from realizing their human rights. Feminist thinking is particularly useful in contemporary global health discourse, as it reaches beyond gender and applies an analytical approach to power hierarchies rooted in colonial and other forms of oppression. By employing a feminist approach to global health data (from developing data collection strategies to analysis, interpretation, and reporting), one can “make visible aspects of ... the world that are unavailable from dominant [white male] perspectives, and in so doing, generate the kinds of questions that will lead to a more complete and true account” of events and our societies.¹³

Most importantly, what distinguishes the feminist stance toward data from traditional practices is its critical reflection on the influence of our biases and subjectivities on the process of data collection and knowledge production. Data are not objective. Decisions about what needs to be measured and how, and the evidence that is constructed based on the analyses and interpretations of large scale data, are inevitably subjective and political.¹⁴ Individuals who already face discrimination or are marginalized are most at risk from policy decisions resulting from gender-biased and partial data, most often collected through bureaucratic and exclusionary processes.

Therefore, feminist principles, similar to the human rights-based approach to data, emphasize the participation of women and other marginalized communities to inform methodological and analytic decisions on which data are to be collected and how, striving for this engagement to be emancipatory and the benefits reciprocal.¹⁵ Participatory processes offer space to these groups to understand the data, interpret the meanings that these findings have for their lives, and guide how this knowledge could inform investments, strategies, and programmatic decisions in a way that is relevant to their needs. Participatory processes can also engage communities in addressing the gender, decolonial, and ethical issues pertaining to data protection, privacy, and confidentiality.

While applying feminist methodologies systematically to big data will undoubtedly generate greater insights into health disparities, we need to caution about an over-reliance on numbers. Unraveling the nuanced and complex causes of health disparities identified through quantitative measures requires complementary qualitative inquiries that can unmask the complexities of lived experiences.¹⁶ As observed in every health crisis—from HIV to COVID-19—an in-depth examination of the intersections of oppression, vulnerabilities, and marginalization can reveal essential insights about the realities of our diverse lives and offer innovative solutions on how to equitably meet the diversity of needs and realities. As an illustration, country-level HIV responses are based on the principle “know your epidemic,” which relies on subnational data disaggregated by sex, age, and other factors (such as wealth quintile and education status) to identify disparities. In many countries in sub-Saharan Africa, quantitative information has revealed disproportionate HIV rates among young women and identified areas with the biggest increases in HIV incidence. The quantitative data were supplemented with consultations with adolescent girls and young women to understand the lives behind the numbers. The consultations were run by organizations led by young women using methodologies to gather and analyze the data to collectively agree on program recommendations on the most effective response. The process brought to the fore ideas on why and how to include economic empowerment programs, and preferences regarding contraceptive and HIV prevention commodity.

Embracing intersectional feminist perspectives—and their inherently decolonizing features—in national and global health data collection methodologies necessitates a transformation of institutions within which data and knowledge are produced and used to guide responses to health crises, such as the COVID-19 pandemic. A reconstruction of the health data and knowledge production system will undoubtedly require international institutions, including donors and global health bodies, that control and shape the global health agenda to reckon with the persistence of pa-

triarchal and colonial ideologies and legacies, and their influences on data systems.

The COVID-19 pandemic presents an opportunity not only to reinvigorate our demands for a gender-transformative, nondiscriminatory, and equitable response but also to transform global health institutions, dispose of our harmful historical legacies, and implement equitable measures to guard against the already insipid regression in the realization and protection of rights. This is not a utopian dream. This is a chance to reshape our thinking and redraw our future. The time to act is now.

Visit www.gendro.org/statements to endorse our call for urgent action: a renewed commitment to gender-responsive research for health equity and human rights in the context of the COVID-19 pandemic.

Disclaimer

The views and opinions expressed in this commentary are those of the authors and do not necessarily reflect the views, decisions, or policies of their respective organizations.

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VIEWPOINT

The Human Rights Challenges of Digital COVID-19 Surveillance

AKARSH VENKATASUBRAMANIAN

Digital technologies offer huge potential to improve the accuracy, breadth, reliability, and speed of contact tracing and other public health surveillance measures. However, in the absence of appropriate global governance frameworks, the usage of digital technologies during health emergencies presents multidimensional challenges. The article by Sharifah Sekalala and colleagues in this issue analyzes the human rights implications of tools used for outbreak surveillance and suggests concrete recommendations to mitigate risks to human rights.

This commentary discusses the technological and governance challenges associated with their recommendations. It incorporates a technological feasibility viewpoint into some of the recommendations and proposes one additional recommendation to strengthen the governance and accountability of technology developers, regulators, and evaluators.

Digital tools for public health surveillance

As Sekalala and colleagues note, several countries now use digital COVID-19 surveillance technologies for symptom tracking and contact tracing to enable rapid case identification and integration into public health databases.¹ Most technologies use location or GPS services (for example, China's Health Code and Ghana's COVID-19 Tracker) or Bluetooth (for example, France's TousAntiCovid and Singapore's TraceTogether). Many use a decentralized exposure notification system that aims to protect privacy, which was jointly created by Google and Apple (for example, Switzerland's SwissCovid and Japan's COCOA), while others use hybrid solutions (for example, Germany's CoronaWarnApp and India's Aarogya Setu).²

As discussed below, recent innovations also support privacy protection during public health surveillance, such as by using the data produced by such tools for disease modeling and epidemic dashboards, informing health decisions through technology-driven disease testing, or using technology to counter health-related discrimination. Each of these innovations comes with technological strengths and limitations, ethical challenges, and even threats to human rights. But there are potential solutions.

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Evidence-based measures

Sekalala and colleagues recommend that countries proactively ensure evidence-based decision-making by utilizing existing legal standards, such as the Siracusa Principles, to assess the necessity and proportionality of digital surveillance technologies.³ The Siracusa Principles provided an important legal basis for the strengthening of the World Health Organization's International Health Regulations in 2005, emphasizing the importance of respect for human rights in an outbreak response.⁴ Digital surveillance technologies can easily be disproportionate vis-à-vis public health needs, and when employing such technologies, countries should not only examine these tools' necessity, legality, and proportionality but also their situational acceptability and their methods of data collection, storage, access, and analysis.

Along these lines, the debate over centralized versus decentralized approaches to digital contact tracing—such as the debate over Europe's PEPP-PT (centralized) versus Switzerland's DP₃T (decentralized)—highlights how technological innovations could help uphold human rights.⁵

Decentralized approaches, with personal data saved only on an individual's device, are less intrusive than centralized approaches, with data stored on a single database. Centralized data creates greater risks and therefore a greater need to consider the legality, necessity, and proportionality of the approach. Leaky data architectures of unregulated centralized approaches may allow the exploitation of sensitive health data to unlawful effect, such as the tracking of individuals' personal movements.⁶ Security, safety, interoperability, and consent concerns also remain, as highlighted by Morocco's experience: a widely used centralized contact tracing app, *Wiqaytna*, developed by the Moroccan Ministry of the Interior interprets national regulations to allow authorities to disproportionately access and process personal data without individuals' informed consent.⁷

In comparison, decentralized approaches generally offer greater privacy, anonymization, confidentiality, and ownership of health data.⁸ An example is the exposure notification system

jointly created by Apple and Google, which allows countries to prioritize privacy-preserving contact tracing.⁹ For this purpose, the tech giants leveraged application programming interfaces (APIs), which are software technology protocols that enable smooth data transmission between multiple interacting applications.¹⁰ This system is more expensive than conventional centralized approaches, meaning that certain countries may not see financial advantages to this public-private partnership. However, this decentralized example offers an added defense against data exploitation and human rights violations.

But at the same time, neither system is foolproof. Mobile-phone-based contact tracing for COVID-19 works provided that the devices are switched on, the phones' Bluetooth or location sensors are turned on, the devices are within 1.5 meters of each other, and they stay that way for at least for 15 minutes. Virus transmission with just one of these conditions unmet can produce false negatives. Equally concerning, two mobile phones may contribute data to contact tracing pools without detecting the fact that people are separated by walls or solid surfaces (assuming no robust proximity sensors), giving false positives.¹¹

While a consideration of the legality, proportionality, and necessity is clearly key in selecting an approach to contact tracing, countries must also factor into their selection the real-world compromises required by technologies that are rapidly evolving.

Integrated public health measures

Sekalala and colleagues encourage countries to ensure that symptom tracking and contact tracing tools are integrated into countries' public health systems. They do not address how health systems may be further strengthened by using data produced by contact tracing to inform population-level digital health tools, such as epidemiological modeling for disease surveillance and remote testing technologies; but these deserve reflection as well.

Outbreak surveillance tools such as the World Health Organization's *Go.Data* do aid the

discovery of disease transmission dynamics and pandemic response.¹² So do epidemiological modeling and disease dashboards like that hosted by Johns Hopkins University.¹³ Digital health technologies such as geospatial maps also show promise in disease surveillance by enabling epidemiologists to understand the community transmission dynamics of malaria and hemorrhagic fevers.¹⁴ Predictive nowcasting, in which models help predict the current value of observable data, can help countries choose policies that uphold and respect human rights, by tailoring their responses to specific needs and current trends.¹⁵ However, to make these models effective and to inform good decision-making requires more cross-sector and interdisciplinary collaborations that bring together policy makers, epidemiologists, engineers, technologists, health professionals, and scientists in trusted spaces to communicate about the models and to understand human aspects of pandemics.

Such decision-making tools could be further enhanced by data produced by remote testing technologies, such as remote cough-audio-based testing.¹⁶ These approaches offer promise in the future, though currently data are not always transferable without loss or manipulation between systems (for example, among older systems such as in France or India).¹⁷ Continuous data integration may also threaten security, as in Norway or in Qatar, whose digital surveillance failed to preempt data leaks.¹⁸ Newer public health systems in Estonia and Rwanda have demonstrated that interoperability can be achieved while building or strengthening public health systems and can result in more effective data sharing to inform national-level outbreak surveillance, ultimately resulting in health policy decisions that improve the accessibility and acceptability of health services.¹⁹

Furthermore, when integrating digital contact tracing and surveillance into health systems, it is crucial to bear in mind that technology can only complement human expertise and experience, not replace it. Training is imperative for community health workers to effectively use tech tools for contact tracing. An example of this is TdH's IeDA project, which offers an integrated e-diagnostic

model to strengthening rural primary health care.²⁰ Its encouraging success underscores the importance of integrating learning for digital health policies from effective HIV/AIDS responses in sub-Saharan Africa and elsewhere.²¹

Nondiscrimination

Sekalala and colleagues rightly note the risk of discrimination linked to the collection and storage of data that do not mask identifying characteristics, and note that excluding populations in areas without mobile phone coverage can heighten health inequalities. This is certainly true, but beyond data *misuse*, incomplete data collection can create *missing* chunks of health data, while deliberate or inadvertent non-usage of important available health data can be a form of *missed* data. Both of these also present direct avenues to discrimination against already marginalized groups.

Poor, adolescent, and elderly populations typically have less access to the mobile phones used for contact tracing. The Global System for Mobile Communications Association estimates only about five billion owners of mobile phones worldwide (~65%), with half that number having smartphones.²² Of these, just over half have internet access, including a mere half of Latin America's population and a quarter of sub-Saharan Africa's population. About two billion mobile phone users cannot use Bluetooth or API-enabled tracing tools. Vulnerable communities often have family mobile phones, owned by the breadwinner and used by all family members.

This lack of access to data can cause discrimination by presenting misleading and inaccurate health data for dissemination and analysis, further widening existing inequalities and resulting in poorly informed decisions that ultimately undermine the right to health.

Stronger governance frameworks

Sekalala and colleagues identify United Nations human rights mechanisms as one way to ensure the transparency and accountability of data man-

agement.²³ While this commentary seconds this recommendation, we may need to go much further to ensure the accountability not just of data holders (such as states) but also of technology developers and evaluators. While the courts may provide oversight based on existing legislation (as the authors observe in Slovakia), we are in the middle of an industrial revolution, and laws may quickly become outdated, as seen in Algeria.²⁴

A rights-based, multisectoral, and geographically equitable global governance structure should set relevant standards to promote accountability for technology developers by monitoring a sectoral cycle of incentivization. Through such a structure, technology developers could incentivize external evaluators (for example, research institutes) to ensure that their products satisfy accepted human rights standards and may in turn be incentivized by governments that regulate the availability of developed products in the market.

Regulating technology developers may require new regulations. The United Nations Guiding Principles on Business and Human Rights guide technology firms to be duty holders, but these principles are nonbinding, and violations may go unsanctioned.²⁵ There is a clear need for global regulation of health data, perhaps through the creation of registers or indices similar to the Access to Medicines Index.²⁶

It is concerning that there are currently no global benchmarks or governance mechanisms that can effectively regulate digital health. COVID-19 offers an opportunity to build and strengthen a global rights-based, equitable, inclusive governance structure, such as an international health data regulation, that is designed with geographical and sectoral representation and that promotes responsible and appropriate digital health surveillance during and beyond emergencies.

Robust data remain the functional life force of all digital surveillance technologies. Hence, new governance mechanisms must build new and strengthen existing global data governance frameworks, and institutionalize innovative, trustworthy, and equitable international health data regulations with, for instance, a POSSICA protocol

(guidelines on privacy, ownership, security, safety, interoperability, consent, and anonymization). Such regulations would engender multisector collaboration that respects human rights advocacy and action and could drive global, regional, and national representations of standards, benchmarks, and transparent regulatory mechanisms for digital contact tracing tools utilizable and evaluable in health emergencies. This would ultimately help build multistakeholder trust, which is essential for all health systems to function.

Further research and literature should amplify this call for building and strengthening stable global health data and technology governance frameworks to assist digital surveillance for COVID-19 responses and overall health systems strengthening. The appropriate institutionalization of such a rights-based framework would enhance trust, longer-term geographical equity, and comprehensive health and care.

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Sekalala et al respond

We welcome Akarsh Venkatasubramanian's helpful commentary, which locates the different digital technologies that operate within public health surveillance systems, supporting our argument that countries should employ the technology that is least restrictive of human rights.

We have two comments:

First, it is correct that we do not specifically acknowledge how health systems might be strengthened by using data produced by contact tracing to inform population-level digital health tools, and instead we focus on data for health uses, such as enforcing quarantines or isolation. However, we argue that data for outbreak surveillance tools are no different from other data for health uses. We think that the tests of necessity and proportionality should be used to gauge whether the data being collected are really necessary for the health objective,

and the risk to individuals is proportionate.

Secondly, Venkatasubramanian's commentary challenges us to think about accountability beyond the United Nations system. Soft-law standard setting can be useful in complex and specialized issues where we need actors to respond quickly, which is ideal for rapidly changing health technologies.¹ However, we are unsure whether this would entail shifting the governance of technological health surveillance outside the United Nations and the World Health Organization system of global governance. If that is the proposition, we would be concerned that this could further fragment human rights in global health governance. We need to ensure that any efforts to create new accountability measures are consonant with existing human rights mechanisms. As the current COVID-19 crisis has shown, there is an imperative for coordinated efforts in

managing global health crises, and we must ensure that the World Health Organization retains its legitimate mandate under the International Health Regulations (2005) to coordinate global health efforts in this area.

Final comment

I thank the authors for their clear and concise comments. In response to their second comment, I believe cross-sectoral accountability in health technology innovation for outbreak surveillance and beyond is essential, through trusted multi-stakeholder platforms such as WHO, and that global governance must not shift out of WHO's (or the UN's) mandate. Instead, I recommend that governments (tech regulators), for-profits (tech developers), research/academia (tech evaluators) and civil society must proactively and appropriately collaborate to ensure global governance frameworks and instruments within WHO (both existing, such as the International Health Regulations and new, such as potential international health data regulations) are strengthened and stabilised. As the authors say, we must maintain the overarching legitimacy of WHO.

A. Venkatasubramanian

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Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action

NAOMI BRAINE

Abstract

This paper proposes the concept of autonomous health movements, drawing on an analysis of harm reduction in the United States and self-managed abortion globally. Harm reduction and self-managed abortion appear in the professional literature largely as evidenced-based public health strategies, more than as social movements. However, each began at the margins of the law as a form of direct action developed by activists anchored in social justice movements and working in community contexts independent of both state and institutional control according to a human rights perspective of bodily integrity and autonomy. An analysis of the history and dynamics of harm reduction and self-managed abortion as social movements underlies the proposed framework of autonomous health movements, and additional potential examples of such movements are identified. The framework of autonomous health movements opens up new pathways for thinking about the development of autonomous, community-based health strategies under conditions of marginalization and criminalization.

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Health and health care have increasingly been a locus of social movement action in the late 20th and early 21st centuries, often mobilizing a language of human rights. The health social movements that have been most visible since the 1980s have organized around particular disease constituencies and access to care, and have forced significant changes in institutional practices.¹ However, during this same time period, activists working in domains not generally considered “health social movements” have engaged in direct action to create de-medicalized, community-based practices with sufficient reach and effectiveness to visibly affect health statistics and receive scientific validation.² This is particularly noteworthy since this work has been done in highly stigmatized, often criminalized, contexts—locations where autonomous movements, based outside political parties and other institutional systems, may be more comfortable than service providers.³ While these movements demand policy change, their core practices enable autonomy and self-determination for marginalized populations regardless of state or institutional action. These movements challenge us to recognize the role of social movements and direct action in the creation of autonomous community-based practices that have transformed health risks in highly marginalized contexts.

This paper will analyze harm reduction (HR) in the United States and self-managed medication abortion (SMA), primarily in Latin America, as forms of collective action that emerge from larger social justice movements to respond to particular health issues in marginalized, criminalized contexts. Organized action around SMA is clearly anchored within feminist movements, and there is a globally evolving set of shared practices to assist women with the use of medication for abortion in contexts of limited access.⁴ HR in the United States, specifically syringe exchange and overdose prevention, initially emerged from within social movements that were not primarily concerned with drug use, and went on to develop multiple practices anchored in drug user autonomy and critical analyses of medical institutions and criminalization.⁵ In both cases, activists developed practices that were

simultaneously radical and pragmatic to empower people to autonomously manage their health in contexts where the primary risks result from stigma and law. The work of these movements has entered the literature as evidence-based public health, often with little attention to the processes through which activists developed community-centered practices anchored in the right to bodily autonomy and self-determination. I will use the common elements of these two movements to propose the concept of autonomous health movements as a framework for thinking about certain forms of collective action at the intersection of criminalization, health, and human rights. I believe that this theoretical framework has the potential to shift our thinking about forms of direct action within social movements and the development of human rights-centered, evidenced-based public health in criminalized contexts.

It is important to note that the phrase “harm reduction” has been adapted and used across a range of locations, including by medical providers who support women with SMA under highly restrictive conditions.⁶ While this reflects the power of the ideas and practices of activists globally who coined the term to describe street-based work with illicit drug users—activists whose work is central to this paper—the use of the term within more institutional settings creates linguistic ambiguities. For the purposes of this paper, HR (capitalized) will be used to refer to the US movement that emerged in the late 1980s and early 1990s with regard to users of illicit drugs. In some countries, drug-related harm reduction was supported by the state as a public health measure, which would affect the dynamics discussed here. For that reason, the analysis in this paper will focus on HR in the United States.

Overview of the literature on HR and SMA

The majority of the research done with HR and SMA has focused on evaluating the effectiveness of the practices as health interventions, rather than on the social organization of the work. This research has been done largely by scientists allied with or actively involved in the movement who collaborate

with (other) activists to validate movement practices, understand the needs and experiences of people who access the practice, or otherwise answer questions of shared interest. The largely epidemiological focus of this work examines the experiences of people who engage with the practice, whether drug users at syringe exchanges or people who contact an abortion hotline, and leaves implicit how these practices were developed by activists under conditions that range from provisional legality to outright clandestinity.⁷ I have participated in this at times; a paper describing the drug user networks that distributed sterile needles from an underground syringe exchange addressed an issue of core interest to the collective running the exchange as well as to me as a sociologist funded by the National Institutes of Health, without substantive discussion of the exchange itself as a long-term activist collective engaged in clandestine action.⁸ The underlying disciplinary and methodological structures of research tend to direct attention to *either* the work of activists *or* the experience of persons who engage with the movement practice.⁹ The predominant focus on the latter creates valuable literatures that scientifically validate social movement-generated practices and enable both political and medical discourses about evidenced-based medicine, yet the work of creating and maintaining these practices remains understudied. While disciplinary and methodological explanations may seem limited, the public health literature recognizes the role of movement organizations, and activists make no efforts to hide their work. It is worth noting that the one report I am aware of that directly connects the experiences of both SMA activists and women seeking abortions was self-published by an activist collective (<https://womenhelp.org/en/page/1103/el-aborto-con-medicamentos-en-el-segundo-trimestre-de-embarazo>).

The relative lack of research on HR and SMA as social movements is particularly noticeable given the identities and self-representations of activists and collectives themselves. Organizations providing education and assistance with SMA unambiguously represent themselves as feminist, including lesbian-feminist, on websites

(for example, <https://socorristasenred.org>) and in printed materials, and are referenced as such in the public health literature.¹⁰ In Latin America, SMA collectives integrate feminist political education within workshops and materials about the safe use of medication for abortion.¹¹ In the United States, syringe exchange emerged largely as an outgrowth of AIDS activist and anarchist formations, and a visible social movement identity continues today among some HR workers and organizations despite an overall shift to nongovernmental service organizations.¹² The US-based National Harm Reduction Coalition's description of the principles of harm reduction states, "Harm reduction is a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use. Harm Reduction is also a movement for social justice built on a belief in, and respect for, the rights of people who use drugs."¹³ This statement brings together the dual nature of both HR and SMA as movements rooted in struggles for justice that develop pragmatic, autonomous practices that enhance self-determination and address stigmatized, often criminalized, health issues.

For this analysis, I will draw on the existing literature on HR and SMA, supplemented by my own observations and experiences from decades of both activism and research in street-based HR. The social movement literature on HR is even more limited than that on SMA, and my analysis is based in part on my own engagement with the movement. My involvement in HR ranges from membership in an unauthorized needle exchange collective to overseeing research funded by the National Institutes of Health, and includes attendance at the majority of US harm reduction conferences and syringe exchange conventions over the past 30 years. My activist and professional history does not constitute research data, but I draw on it to construct the analytical arguments made in this paper. The organizational structure of HR in the United States has largely evolved into a system of nongovernmental service organizations in ways that expand access but limit the potential for social movement-focused research.

This paper presents an analysis that emerges from thinking across movements; a detailed de-

scription of either HR or SMA is beyond the scope of this paper. However, I will provide a brief overview of each movement as a basis for an analysis of their commonalities and to develop the concept of autonomous health movements. In the final sections of the paper, I will briefly suggest some other examples of autonomous health movements as part of a discussion of the utility of the framework for thinking about social movements, public health, marginalization, and human rights.

Harm reduction

While HR is often understood in terms of particular forms of outreach to and services for people who use drugs, as a movement it is anchored in an analysis of the social and political marginalization of people who use drugs and their communities. HR emerged as a community-centered response to HIV among people who inject drugs, initially focused on providing sterile injection equipment as a way to prevent the spread of HIV. The first documented needle exchanges were created by the *junkiebonden*, or drug user unions, in the Netherlands in the early 1980s in response to hepatitis B, and the strategy spread globally in response to the AIDS epidemic.¹⁴ In the United States, needle exchanges were created largely by HIV/AIDS activists who had a wide range of personal drug use histories and practices but were not, for the most part, organizing around identities as people who use drugs.¹⁵ While explicit human rights language is rare among US activists, a commitment to self-determination was central to evolving HR practices, at times framed as “nothing about us without us” (a phrase shared with disability rights activists).

The second HR practice to emerge on a wide scale was overdose prevention, which began in the late 1990s and quickly became more broadly accepted in the United States than syringe exchange. Naloxone is a medication—long used by emergency medical services—that interrupts the action of opiate drugs and thereby reverses an overdose. Overdose prevention involves distributing naloxone to people who use drugs and community members, along with a brief training on how to

recognize an overdose and use the medication to interrupt it.¹⁶ The practice began when a Chicago syringe exchange program started to hand out naloxone to program participants and teach them how to use it; this practice then spread to other cities.¹⁷ Initially, providing naloxone in this manner was a violation of prescription laws, although this may not have been widely known outside core activist networks.

The emergence and spread of HIV coincided with the escalation of the United States’ War on Drugs, creating a context of extreme criminalization within which activists created the first syringe exchanges.¹⁸ It is important to note that the War on Drugs—and US drug policy overall—functions primarily as a policy tool for racialized criminalization, targeting African American and other racially marginalized communities more than drug users per se.¹⁹ This entrenched political context for drug law amplified the stigma of HIV/AIDS and the centrality of criminalization over public health, drawing on long-standing representations of drug users as dangerous residents of urban ghettos. In US cities, the presence of a syringe exchange in the 1990s was more strongly associated with AIDS activism and the prevalence of HIV in LGBT communities than with measures of drug use or HIV prevalence among people who inject drugs.²⁰ This highlights the role of larger movements in the genesis of syringe exchange and HR, as the severity of the local epidemic among people who use drugs does not appear to be the driving factor. It also draws attention to the invisibility of HR as a social movement, despite its connection to forms of HIV/AIDS activism that have been central to the study of health social movements.

It is difficult to overstate the radical nature of HR in the United States in the late 1980s and the 1990s. A relatively objective measure of this can be seen in the extended restrictions on federal funding for syringe exchange programs despite a near endless succession of studies demonstrating their effectiveness as a public health strategy.²¹ The radical stance of HR as an emerging social movement was to develop a community practice centered on people who use drugs as active agents of public

health, independent of state control or institutional supervision. Syringe exchange positions injection drug users as people who can and will organize their use of (illicit) drugs in ways that effectively limit the spread of blood-borne disease. Overdose prevention again situates people who use drugs and members of their communities as valued actors who can recognize and effectively intervene in a health crisis through the autonomous use of a medication previously controlled by credentialed health professionals. This disrupted dominant cultural, medical, and political understandings of people who use illicit drugs as primarily criminal or, at best, severely dysfunctional. The creation of a set of community-based, autonomous practices that locate stigmatized persons as key actors in relation to their own health and self-determination is also central to the movement for self-managed abortion.

Self-managed abortion

While the contemporary movement for SMA emerged in the 21st century, abortion itself has long been an area of autonomous health action and self-determination among women. To choose some well-documented examples, the feminist health movement of the 1960s and 70s taught women how to perform “menstrual extraction” and other de-medicalized approaches to abortion in the first trimester, and the Jane Collective in Chicago may be the most direct predecessor to contemporary activism.²² As a movement, SMA combines online feminist telemedicine services and activist-driven community-based strategies to assist women with the use of widely available medication.

The standard medical abortion protocol uses two medications—mifepristone and misoprostol—but misoprostol alone is effective and more readily available.²³ Misoprostol is a medication for gastric ulcers that has obstetric uses, including abortion and treatment for postpartum hemorrhage; the label warns against use by pregnant women and lists miscarriage as a side effect.²⁴ Women in Brazil began to use misoprostol to induce abortion in meaningful numbers in the 1990s, leading to a measurable decrease in complications from unsafe

abortion.²⁵ The practice spread in contexts with limited legal access to abortion, despite difficulty in obtaining accurate instructions for use.²⁶ Starting in the 2000s, feminist websites, hotlines, and other education and support strategies began to provide women with accessible and trusted information on how to use the medication, which has increased women’s acceptance of SMA.²⁷ As with HR, the practices developed by SMA activists are used by women who may not themselves identify with the movement.

Feminist activism for SMA began at the margins of the medical system and has since developed fully de-medicalized practices that have spread globally. In 1999, Women on Waves began to offer abortions on board a ship that would anchor in international waters near countries with highly restrictive laws.²⁸ In the early 2000s, Women on Waves initiated a telemedicine service, Women on Web, that provides online consultations and sends medication by mail. Women on Waves and Women on Web were founded by a doctor and both operate technically within, although at the margins of, institutional systems of medical practice. Additional online telemedicine platforms have emerged since, all of which medically prescribe and then mail standard abortion medications.

Since then, a series of more autonomous initiatives developed outside institutional medical systems. In 2008, a collective in Ecuador launched the first autonomous safe abortion hotline, providing information on how to use medication for first-trimester abortions, and hotlines soon appeared in other Latin American countries.²⁹ Around the same time, a practice of *acompañamiento*, or accompanying women through the abortion process, developed in Mexico in both Guanajuato and Mexico City and subsequently spread in Latin America.³⁰ In some African contexts, community health workers teach the use of misoprostol for the management of both postpartum hemorrhage and first-trimester abortion, using the legitimacy of the former to obscure the centrality of the latter.³¹ Variations on the strategy of a hotline have been implemented globally, including in Indonesia, Poland, Thailand, and multiple sub-Saharan African

countries; by 2018, at least 20 community-based projects operated globally.³²

HR and SMA reflect different, though related, circumstances and dynamics of marginalization and collective action. Both movements advocate for systemic institutional change (for example, full access to abortion on demand and fundamental changes in drug policy) but the primary focus of their work is the development of autonomous health practices that enhance self-determination. In each case, activists faced a health crisis created by stigma and criminalization and responded with community-level direct action that brought professionally controlled knowledge and technology into lay use. Syringe exchange programs combine community education about disease transmission and injection hygiene with the distribution of a medical technology (syringes) that was already in use but difficult to access. Overdose prevention and SMA both have community education components that centrally involve the de-medicalization of pharmaceuticals as a technology for use by ordinary persons with no professional training. Both movements developed practices that enable people to engage in autonomous health action (for example, safe injection, overdose prevention, and SMA) without any requirement to identify with or join the movement itself, thus separating questions of access from those of identity or political commitment. Syringe exchange and overdose prevention have had widely varying levels of government involvement and legal status in different parts of the world, although in the United States they emerged from social movement networks working at the margins of the law. At this writing, abortion globally is almost universally regulated through criminal law, and SMA has not been legalized (or decriminalized); the organizations that provide education and support have clear roots in feminist organizing.³³

Autonomous health movements

Contexts for emergence

Based on these two examples, I argue that autonomous health movements may emerge within societal contexts that share four important charac-

teristics. First, there is a highly stigmatized health issue or population. HIV/AIDS in the United States demonstrates this clearly in the emergence of a new, initially fatal, disease that spread in stigmatized ways and largely among marginalized, often criminalized, populations. In contrast, abortion is a common and longstanding practice that has been criminalized in many countries, thereby creating socially marginalized contexts that carry stigma even for women of otherwise dominant status. Second, the government responds to the situation with criminalization and marginalization rather than health care. In the United States, HIV among people who use drugs was met with escalating criminalization through the War on Drugs, in the context of medical and social services systems that largely required abstinence as a precondition to care. Abortion continues to be restricted and criminalized in much of the world, and it is only under these conditions that hotlines and other SMA practices have emerged. The United States under the Trump administration offers a dynamic example of this, as interest in SMA has spread among feminist activists as the probable demise of *Roe v. Wade* becomes more proximate. Third, the criminalization primarily affects marginalized populations, as those with resources can often access privatized solutions. This has long been true for abortion, as women with resources obtain assistance from private providers or travel to locations where abortion has been broadly legalized. Similarly, drug users with socioeconomic resources are often able to obtain sterile syringes or to access various forms of care without first becoming abstinent, despite the overall criminalization of drug use and users.

Fourth, the health issue is of concern to an existing social movement, which then provides the context within which activists develop a de-medicalized, community-based response anchored in the principles of bodily autonomy and self-determination. This last element appears to be crucial, as a variety of health issues meet the first three criteria but autonomous health movements do not appear to develop unless a larger social movement provides the initial context and resources for the emergent autonomous health movement. The first

HR programs in the United States were created within the context of a militant response to the AIDS epidemic, although both criminalization and drug-related health issues were common and long-standing among drug users. As noted previously, syringe exchange programs initially had a stronger statistical association with the level of HIV among gay men, and associated AIDS activism, than with the level of HIV among drug users, highlighting the importance of the context and resources provided by a larger social movement. Abortion outside the medical system is hardly a new phenomenon, but the reemergence of feminist movements enabled a shift toward organized, publicly accessible, movement-based assistance (for example, 1970s feminist self-help, the Jane Collective, and, more recently, SMA). In each of these cases, activists working within a larger movement began to develop direct action practices to address a criminalized health issue, leading to the formation of independent organizations and movements. Attention to the centrality of the role of a larger social movement in the emergence of autonomous health movements leads to consideration of autonomous health movements themselves as both practices and movements.

Characteristics of autonomous health movements

Autonomous health movements share certain characteristics that are connected to, but somewhat independent of, their conditions of emergence. Three characteristics appear to be conceptually central, particularly in relation to the “autonomous” element of autonomous health movements; I will first list these characteristics and then develop them in subsequent paragraphs. One, the health practice involves de-medicalization through community use and control of medical knowledge and technology. Two, this process of de-medicalization results in significant shifts in power relationships between marginalized, often criminalized, contexts and populations and mainstream medical institutions in ways that enhance the autonomy and self-determination of the marginalized. And three, activists within autonomous health movements demonstrate a willingness to work at the edges of

or outside the law when necessary.

The de-medicalization of medications, technologies, and knowledge sits at the heart of autonomous health movements, enabling their autonomy from medical systems and development of effective community-based practices. The clearest illustration of this may be various forms of autonomous abortion, whether contemporary use of medication or earlier community-based feminist practices. Safe abortion outside the medical system brings together the different elements of de-medicalization in a straightforward way; women take control of knowledge and technologies that enable safe abortions, which directly empowers them in relation to medical institutions and enhances their autonomy and self-determination. Perhaps less obviously, HR de-medicalizes important technologies (such as sterile syringes and naloxone) that people who inject drugs need to autonomously manage their own health and bodily self-determination while using drugs, reducing their vulnerability to medical (and other) institutions that typically stigmatize and marginalize users of illicit drugs. More radically, HR positions active users of illicit drugs as valued members of their communities, fully capable of health-sustaining action on their own and another’s behalf. Similarly, SMA positions women as persons with the knowledge and authority to make decisions about their own bodies, sexuality, and reproduction, which continues to be a contested claim even in contexts where abortion is legal.

The combination of criminalization and stigma, on the one hand, with strategies of de-medicalization, on the other, can locate the work of autonomous health movements at the borders of the law. Again, abortion outside the medical system provides clear examples of this in the work of earlier feminists and in contemporary SMA, which has been criminalized in much of the world. In the early days of syringe exchange in the United States, many programs were of, at best, ambiguous legal status, and many were outright illegal, sometimes for years. New Jersey did not legalize syringe exchange programs until 2007, despite relatively high rates of injection-related HIV. Syringe exchange programs in New York State were “legalized” in

1992 when the state health commissioner declared a state of emergency; the declaration had to be reissued annually until the early 2000s, when the state legislature legalized possession of up to 10 syringes for personal use. Similarly, naloxone distribution for overdose prevention began in at least technical violation of prescription laws.

Through their willingness to work at the edges of the law, autonomous health movements challenge mainstream cultural and public health assumptions that medical safety lies within institutional systems. These movements take medications and other technologies out of institutional settings and train ordinary people to safely use them in ways that had previously been exclusively the purview of professionals. SMA and overdose prevention are obvious examples of this, but the idea that people who inject drugs could consistently inject safely—reducing bacterial infection and viral transmission—was largely unimaginable to medical and public health officials prior to the work of syringe exchanges. The collaborative work between autonomous health movements and affiliated or allied scientists to prove the efficacy of their community-based practices provides traditional scientific evidence that medical safety can exist within de-medicalized, community-controlled practices and contexts. This scientific validation of social movement practices then enables a discourse of evidence-based medicine and public health. However, it must be emphasized that these practices are developed and sustained as autonomous community action, not as “second best” or provisional pending integration into institutional systems.

The legal risks taken by activists in autonomous health movements elicit obvious questions about the social and political commitments underlying the willingness to engage in what, in certain locations, could be considered routinized, ongoing civil disobedience. It is not possible to understand the risks taken by SMA or early HR activists without attention to the larger social movements that provided the contexts within which these autonomous health movements emerged. The Ecuadorian activists who created the first abortion hotline were committed feminists and members of a youth-run

nongovernmental organization focused on issues of gender and sexuality.³⁴ The safe abortion hotlines and *acompañamiento* collectives that subsequently formed in other Latin American countries also emerged from networks of feminist, often lesbian, activists.³⁵ Early syringe exchange programs in the United States were often linked with AIDS activist organizations or anarchist networks, and the HR movement that emerged through the 1990s has been consistently driven by a strong social justice analysis that provides the framework within which risks are assessed and taken.³⁶ Based on these examples, I argue—or at least hypothesize—that autonomous health movements emerge from within larger social movements that provide the initial analytical frameworks for the development of autonomous practices (for example, hotlines and street-corner syringe exchange), as well as the motivation to accept legal risk.

Autonomous health movements and human rights

The practices of these movements lie within a human rights framework of bodily autonomy and self-determination, although, to paraphrase Alicia Yamin, they may use civil disobedience as a strategy for the epistemic disobedience necessary to address health problems created by law and policy.³⁷ Autonomous health movements refuse to remain within a state- or institution-focused paradigm, using de-medicalization and direct action to create effective health practices outside of institutional control. HR and SMA offer immediate strategies for action without waiting for state policies to change, challenging marginalization and isolation as well as criminalization, and recognizing that bodily autonomy and self-determination for marginalized communities require engagement and resources. SMA activists do more than hand out pills and instructions; they create pathways for communication and support around the management of unwanted pregnancy as a moment within the lives and communities of pregnant persons. Similarly, HR activists do more than hand out syringes and naloxone, instead creating spaces within which socially stigmatized drug users are

valued community members and health educators. These movements prioritize autonomous forms of direct action rather than battles over state policy and obligation, which may render them less visible as movements engaged in a struggle for human rights. In practice, autonomous health movements step outside state- and institution-centered debates around policy change, political pragmatism, and technocratic development goals.³⁸

High-profile confrontation is often key to the visibility of a social movement, and I believe that part of why autonomous health movements have been largely overlooked as movements comes from the dynamics of low-profile direct action rather than visible challenge. In some US cities, the activists who *intentionally* provoked an arrest for handing out syringes, in order to argue in court that their actions were “necessary to preserve life,” were AIDS activists who supported HR but were not engaged in ongoing outreach, and those arrests did not occur at syringe exchange sites. Arguably, they were part of the larger movement that “birthed” the autonomous health movement but not part of the autonomous health movement itself, as they were not involved in ongoing HR work. Within SMA, an abortion hotline is unlikely to formally lead a campaign to change the legal status of abortion, but hotline activists may well be involved through other feminist organizations. The dynamics of deliberate, visible confrontation are, in reality, not conducive to developing trust and accessibility among marginalized people in a criminalized context in which encounters with authority are to be avoided as much as possible. The collective action frameworks and community-oriented strategies central to the work of both SMA and HR go beyond questions of state repression or obligation and embrace an understanding of autonomy anchored in shared connection and support.

Autonomous health movements in a broader perspective

While I have developed the concept of autonomous health movements around the examples of HR and SMA, these are clearly not the only potential cases. The practice of safer sex among gay men and

MSM was created and initially circulated by gay male activists as an act of liberation and communal self-determination at a time when sodomy was still criminalized in parts of the United States and when there were credible fears about the escalating marginalization of populations identified with AIDS.³⁹ While the condom is not a medical technology, there is a profound de-medicalization in the direct action of creating practices to control the spread of a new, terrifying disease. Much of the health organizing done by sex worker activists, including but not limited to HIV, falls within the general frameworks described here and is anchored in decriminalization, bodily autonomy, and self-determination within the framework of collective action. Moving beyond HIV, the work of *No Más Muertes* (No More Deaths) in the US-Mexico border region emerged as a response to the public health crisis created by the escalating criminalization of migration, which forced migrants into the most dangerous deserts of Arizona. Activism surrounding transgender identity and bodily autonomy may well function as an autonomous health movement in contexts where trans identities and access to medical care are restricted or criminalized.

I am reluctant to set hard boundaries around autonomous health movements at this stage of conceptual development, but the characteristics outlined previously set some criteria for what does and does not lie within the framework. Health social movements organized around illness identities that demand inclusion and change in institutional systems are not autonomous health movements. Some potential ambiguities arise in relation to self-help and consumer movements, and here a return to the defining characteristics and the earlier discussions of HR and SMA offer some guidance. Autonomous health movements develop a practice that addresses a health issue, and they make the practice accessible to others without any requirement to identify as part of the movement. For example, feminist self-help groups of the 1970s may have assisted one another with menstrual extractions in the first trimester of pregnancy, but the requirement to be an ongoing group member creates an internal practice, which is very different than the explicitly open

work of the Jane Collective during the same time period. Many contemporary consumer movements would not fit well within the autonomous health movement framework, as they focus primarily or exclusively on institutional change rather than on autonomous practices and do not operate in a criminalized context. Marijuana buyers' clubs, however, are much closer to autonomous health movements, since they provide access to an often criminalized substance on the basis of a medicinal use and may have wide peripheries of "membership."⁴⁰ Autonomous health movements as conceptualized in this paper occupy a particular location within the larger domain of health and social justice movements, one characterized by autonomous health work as a form of direct action.

Locating certain practices as autonomous health movements expands and reorients our understanding of work that has largely been positioned as innovative and controversial public health measures, not as direct action by social movements. This is particularly true for HR but also to some extent for SMA, both of which appear in a public health literature that at least partially decontextualizes the experiences and processes being studied. In both cases, the effectiveness of a practice cannot accurately be understood independent of the work of the activists and movements that create contexts through which individuals realize the practices studied and validated by epidemiologists. The role of activists is visible within much of the epidemiological data, although primarily as sources of information (for women, drug users, and principal investigators) or locations for data collection, but this does not in itself enable an understanding of how these projects and practices were developed and how they are sustained. These absences are particularly notable given the self-representation of the organizations and the multiple, movement-connected social locations of many of the scientists and contributors to the published literature. However, from the perspective of activists, collaboration with epidemiologists directly advances the work of the movement, while research on social movements may be less obviously beneficial.

The conceptual framework of autonomous health movements has the potential to elicit new questions and directions for research in health, human rights, and social movements, particularly in relation to innovation and strategies to move beyond existing models.⁴¹ It challenges us to look for ways that social movements can sidestep the state or large institutions and how work may be divided within a field of related activity, with some elements specializing in policy while others engage with low-profile direct action. An understanding of direct action as a potential health strategy opens up questions about the contexts and processes that lead to significant innovations at the intersections of human rights, health, and criminalization. The role of larger movements in fostering the emergence of autonomous health movements directs attention to how social movements can initiate, or incubate, health practices that break with previous assumptions and move beyond established models for human rights-based approaches to health. In addition, the collaboration among activists and scientists that leads to scientific validation of direct action practices may encourage new ways of thinking about relationships between marginal communities and public health (or human rights) professionals.

Conclusion

As I finish this paper, in New York City in June 2020, the United States is immersed in simultaneous insurrection and pandemic, as protests against racist police systems erupt in cities still under quarantine from COVID-19. In this moment, activists are intrinsically working at the intersections of public health and collective action, adapting health guidelines to the ever-emergent processes of street protest. Some practices reflect creative innovation, such as the use of rhythmic clapping in place of chanting to allow collective expression without the widespread expulsion of potentially virus-laden droplets from hundreds or thousands of people chanting. Marches with evolving routes reduce the health risks of both COVID-19 and

encounters with the police, as highly mobile and low-density protests wind through the streets in unpredictable patterns. It is a powerful reminder that social movements not infrequently work in contexts where health risks must be managed as an intrinsic contextual element of organizing and action, troubling the theoretical boundaries around “health movements” and the relationship between health and human rights.

The coming decades are likely to bring sociopolitical turbulence and emergent health risks as climate patterns shift, populations of humans and other life forms migrate, and social systems scramble to respond in ways that range from authoritarian to liberatory. Environmental changes and associated migrations alone have the potential to create multiple, shifting contexts in which criminalization, health, medical technologies, and social movements interact. It is unsurprising that the examples of autonomous health movements in this paper involve intersections among gender, sexuality, and drug use, as these have long been domains where repression and social control use the language of health. Looking ahead, the anti-immigrant rhetoric that has gained power throughout Euro-American societies in the 21st century situates migrants as a threat to societal health broadly speaking and could easily be mobilized in more targeted ways, as signaled by the rise in anti-Asian prejudice with COVID-19. The criminalization of marginal contexts and populations has been a central tool of neoliberalism under centrist and right-wing governments alike and can lead to health crises under a range of circumstances and configurations.

The conceptual framework of autonomous health movements expands our thinking and the direction of our attention in relation to contexts where stigma and criminalization create or significantly amplify health risks and the role of social movements in forging new pathways in health and human rights. While policy change and destigmatization are vital, they are generally long term projects that do not immediately reduce health risks or enhance autonomy. The movements analyzed in this paper demand that we recognize and work

to understand the role of social movement-driven direct action in transforming health practices in contexts of extreme marginalization.

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Toward Human Rights-Consistent Responses to Health Emergencies: What Is the Overlap between Core Right to Health Obligations and Core International Health Regulation Capacities?

BRIGIT TOEBES, LISA FORMAN, AND GIULIO BARTOLINI

Abstract

COVID-19 has highlighted the responsibilities of states under the International Health Regulations (IHR), as well as state accountability in case of a breach. These approaches and dimensions are valuable, as many COVID responses have breached human rights. We should also look beyond this crisis and address country preparedness for effective and equitable responses to future infectious disease outbreaks. This paper assesses countries' international legal obligations to be prepared to respond to this and future public health emergencies. It does so from the perspective of the right to health, in interaction with the IHR. We analyze the functional relationship between the right to health and the IHR, focusing in particular on "core obligations" under the right to health and "core capacities" under the IHR. We find considerable parallels between the two regimes and argue in favor of more cross-fertilization between them. This regime interaction may enrich both frameworks from a normative perspective while also enhancing accountability and public health and human rights outcomes.

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Introduction

COVID-19 has put a spotlight on the responsibilities of states under the International Health Regulations (IHR) and on state accountability in case of a breach.¹ In addition, there has been much debate about how measures to protect against COVID-19 infringe on the enjoyment of civil and political rights, in particular the rights to privacy and freedom of movement.² It is important to evaluate these matters carefully given the current crisis. While these approaches and dimensions are valuable, we should also look beyond this crisis and address country preparedness to respond to future infectious disease outbreaks.

To this end, this paper assesses countries' international legal obligation to be prepared to respond to this and future public health emergencies. It does so from the perspective of the right to health as a fundamental economic and social right, in interaction with the IHR. This contribution is grounded in the understanding that COVID-19 reflects, in essence, a crisis of the right to health: because countries do not deliver the right to health in its own right or as reflected by the IHR, many other problems, including violations of international law, arise. We contend that better integration of human rights into the IHR will not simply boost social justice and health equity in IHR-related pandemic responses but could also boost the public health efficacy of such measures.³ We analyze the functional relationship between the right to health and the IHR, focusing in particular on core obligations under the right to health and core capacities under the IHR. We consider the overlaps between these two international law regimes insofar as they prescribe prioritized state duties within both regimes, and the extent to which their respective duties may assist in defining or implementing each other. We argue that this kind of systemic integration is supported within international law's accepted rules for treaty interpretation in the Vienna Convention on the Law of Treaties, which provides that "international standards may be interpreted in the light of any relevant rules of international law applicable in the relations between the parties."⁴ We argue further that doing so helps resolve the problem of fragmen-

tation within international law, as demonstrated by interpretations of the IHR that are not compliant with human rights. It also helps advance a more human rights-consistent implementation of the IHR. Legal analysis of this nature offers important guidance to states implementing the IHR during the COVID-19 pandemic, as well as for future disease outbreaks. It is also relevant to potential reforms of the IHR that seek to boost adherence to human rights during pandemic outbreaks.⁵

Historical emergence of the right to health and the IHR

The right to health

To understand the interaction between the right to health and the IHR, one must go back to the period right after World War II. It was a period of optimism and belief in a better and healthier world, a time where the idea was voiced that "medicine is one of the pillars of peace."⁶ In 1946, states adopted the Constitution of the World Health Organization (WHO), the founding document that led to WHO's establishment in 1948. It is a remarkable and groundbreaking document in many ways. The preamble to the WHO Constitution defines health as a "state of complete physical, mental and social well-being, and not merely the absence of disease." This definition has often been criticized for being too absolute, yet it should be seen in the light of postwar idealism and can be appreciated for its reference to mental and social well-being as important dimensions of health.⁷

The preamble was also pioneering for its recognition of health as a right: "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition." This wording informed the right to health provisions in the United Nations (UN) human rights treaties that were adopted in the decades thereafter. The most authoritative provision is arguably article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which stipulates the "right to the highest attainable standard of health." Other key provi-

sions include article 12 of the Convention on the Elimination of All Forms of Discrimination against Women; article 24 of the Convention on the Rights of the Child; and article 25 of the Convention on the Rights of Persons with Disabilities. Since the beginning of this century, article 12 of the ICESCR and article 24 of the Convention on the Rights of the Child have begun to be complemented with “general comments,” explanatory documents that carry the status of soft law but are nonetheless seen as authoritative.⁸

These treaties are widely ratified—171 countries have ratified the ICESCR, 182 countries have ratified the Convention on the Rights of Persons with Disabilities, 189 countries have ratified the Convention on the Elimination of All Forms of Discrimination against Women, and 196 countries have ratified the Convention on the Rights of the Child.⁹ Thus, in contrast to the universality of ratifications of the Convention on the Rights of the Child, approximately 25 of 196 states globally have not ratified the ICESCR and are not legally bound by this treaty’s right to health. On the one hand, this shortfall underscores that our analysis is relevant for the majority of states. On the other, the fact that nonratifying states include the United States points to the larger political challenge of advancing a right to health lens for the IHR given the United States’ long-standing objections to the legal status of economic, social, and cultural rights in general and the right to health in particular.

As indicated above, WHO was the first international organization to recognize health as a human right. However, over the past 73 years of its existence, WHO has not manifested itself as a human rights organization. Yet the organization has gradually embraced the human rights framework owing to the way that it has been developed by UN human rights mechanisms.

The International Health Regulations

The WHO Constitution grants considerable legislative powers to the World Health Assembly. Based on articles 19–23 of the Constitution, the assembly may adopt conventions, (binding) regulations, and (nonbinding) recommendations. The results have

been very disappointing so far: since its establishment in 1948, WHO has adopted only one treaty (the Framework Convention on Tobacco Control) and two regulations (the Nomenclature Regulations and the IHR). While the results are scant, the Framework Convention on Tobacco Control and the IHR are highly authoritative instruments. Central to this paper is the IHR.

International collaboration in the field of infectious disease control started in the second half of the 19th century. In 1851, the first international sanitary conference took place. Many similar meetings followed, and subsequent sets of international sanitary regulations were gradually adopted. The IHR, adopted in 2005 and entered into force 2007, is the most recent set of regulations. Given its status as regulations, the IHR is binding on all 194 WHO member states without their consent (although members may notify the director-general of rejection or reservations).

The new IHR is innovative because of its “all hazards” approach: it covers risks arising from numerous sources, not just a limited list of diseases.¹⁰ Thus, even a terrorist attack with anthrax or a chemical spill could fall within the remit of this instrument if it is established that the threat constitutes a “public health emergency of international concern.”¹¹ Such emergencies have been declared six times since the IHR’s adoption: influenza in Mexico (2009); Ebola in West Africa (2014); polio in Pakistan, Afghanistan, and Nigeria (2014); Zika in South America (2016); Ebola in Congo (2018); and COVID-19 in China (2020).

The IHR refers to human rights in various provisions (articles 3, 23, 32, and 45). Article 3, which outlines general principles of the regulations, states that the IHR shall be implemented with “full respect for the dignity, human rights and fundamental freedoms of persons” and “guided by the Charter of the United Nations and the Constitution of the WHO.”¹² Despite this reference to the WHO Constitution, these references are, in essence, linked to respect for civil and political rights, including the rights to privacy, physical integrity, and freedom of movement (for example, medical consent in article 23 and respect for travelers in article 32). Contrary

to the WHO Constitution and the Framework Convention on Tobacco Control, the IHR does not mention the right to health.¹¹ This is an important omission, given that—as we will demonstrate below—states’ obligation to prepare and respond to infectious disease outbreaks is an essential component of the right to health. This overlap is apparent in the stated goal of the IHR—“universal application for the protection of all people of the world from the international spread of disease”—which is functionally similar to the ICESCR’s duty to prevent, treat, and control epidemic, endemic, and other diseases, even though the former has a more explicitly universal focus than the largely domestically oriented duties of the ICESCR.¹³

Another important shortcoming of the IHR is its lack of sanctions: states refusing to collaborate with WHO in case of an outbreak can go without any warning or punishment. As we argue below, the UN human rights monitoring system and domestic courts may offer complementary mechanisms for holding states accountable under the IHR.

Comparing and contrasting core obligations and core capacities: Connecting the dots

Our main point is that the core obligations under the right to health are closely intertwined with the core capacities under the IHR. Starting with the UN human rights framework, we will now briefly discuss both regimes and discuss their interaction with each other.

The right to health’s prioritized obligations: Essential elements and core and comparable priority obligations

Article 12 of the ICESCR stipulates that states should take steps necessary for “the prevention, treatment and control of epidemic, endemic, occupational and other diseases.” Hence, there is a clear human rights obligation on the part of states to take measures to combat epidemic diseases. An explanation of the meaning and scope of the right to health is provided in General Comment 14, issued by the Committee on Economic, Social and

Cultural Rights. Although this instrument is not legally binding, it is seen as highly authoritative. Three components of this general comment are important for infectious disease control because they identify and define essential, core, and otherwise prioritized aspects of this right:

AAAQ. According to General Comment 14, the right to health contains a set of interrelated and essential elements, which are considered to provide guidance to the actions by states: availability, accessibility, acceptability, and quality. This so-called AAAQ is an authoritative set of standards that is increasingly applied across international and domestic health settings. While it certainly lacks precision, it helps identify weak spots in health decision-making. Given that these (and similar) principles are applied frequently in health settings and because their importance is underscored by governments and health authorities, we suggest that this framework is emerging as a norm of customary international (health) law.

The AAAQ is also very informative in the context of COVID-19, as it pinpoints the weak spots in states’ responses to this crisis. First, key problems stem from a lack of *availability* of health personnel, intensive care beds, drugs, masks, and gloves. Second, many problems occur in the context of *accessibility*—for example, inequalities in access to health care by vulnerable persons (such as older persons, persons with low socioeconomic status, and persons with underlying health conditions) and a lack of geographically accessible, affordable, and good-quality health care. Third, in terms of *acceptability*, COVID-19 creates many health care settings where medical ethics are under threat, such as care homes where older and disabled persons are denied contact with the outside world. Lastly, in terms of *quality*, due to a scarcity of properly trained personnel and suitable medical equipment, many people are deprived from accessing good-quality health care. Again, while this framework lacks precision and may not be used to identify concrete human rights violations, it helps frame the analysis and debate about how the right to health is guaranteed in the context of COVID-19, and it shows the extent to which countries are prepared to address future crises.

Core obligations. The second concept in the right to health framework that is of key importance to infectious disease control is the recognition of “core obligations” under the right to health. General Comment 14 refers to General Comment 3, which notes that states have “a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights enunciated in the Covenant, including essential primary health care.” For the identification of the specific core obligations under the right to health, General Comment 14 makes reference to the Programme of Action of the International Conference on Population and Development (1994) and WHO’s Alma-Ata Declaration (1978), stating that these programs provide “compelling guidance” on the core obligations arising from article 12.¹⁴ The committee identifies a set of core obligations, four of which are particularly relevant to the COVID-19 crisis: (1) ensure nondiscriminatory access to health facilities, goods, and services on a nondiscriminatory basis, especially for vulnerable or marginalized groups; (2) provide essential drugs as defined by WHO; (3) ensure equitable distribution of all health facilities, goods, and services; and (4) adopt and implement a national public health strategy and plan of action addressing population health concerns. General Comment 14 reinforces the importance of core obligations, indicating that they are non-derogable and that states cannot justify noncompliance under any circumstances.

The meaning of the concept of core obligations has been discussed extensively in human rights discourse, and interpretations regarding its scope and force differ.¹⁵ For example, there are debates about the omission of essential health care as a core obligation, and confusion as to whether the core obligations of the right to health are non-derogable or whether resource scarcity may be an excuse for governments not to fulfill these obligations.¹⁶ In addition, there has been controversy over the legitimacy of this concept in toto, as well as discussion about whether the Committee on Economic, Social and Cultural Rights was justified in importing into the ICESCR a set of obligations without obvious textual basis in the covenant itself.¹⁷ In its

subsequent general comments, the committee has moved away from its controversial articulation of core obligations as non-derogable, focusing instead on whether implementation is reasonable or proportionate.¹⁸ This shift is potentially reflective of the committee’s response to wide-standing criticisms of the unfeasibility of a non-derogable standard for core obligations, particularly for low- and middle-income countries.¹⁹ It also reflects the committee’s broader adoption of a contextual “reasonableness” analysis as a standard for adjudicating violations of economic, social, and cultural rights under the Optional Protocol to the ICESCR, adopted in 2013.²⁰ The committee’s defined criteria for assessing reasonableness include whether states have taken deliberate, concrete, and targeted steps to fulfill rights; have acted in a nondiscriminatory manner; and have taken into account the precarious situation of disadvantaged and marginalized individuals and groups and prioritized grave situations or situations of risk.²¹ Core obligations are cited explicitly insofar as they are affected by retrogressive resource constraints.²² This interpretation implies that the committee sees the minimum core acting as a bar to regression, and an important consideration in assessing the legitimacy of resource constraints.²³ The suggestion is that states hold core obligations under the right to health as specified in General Comment 14, with a duty to take reasonable steps toward fulfilling them.

Thus, the *idea* of a core content—and the notion that there is a basic subsistence line below which no government should fall—is informative in a crisis setting, where resources are limited and there are surging needs for urgent health care.

Comparable priority obligations. Core obligations are buttressed by obligations of comparable priority, which also hold validity in relation to COVID-19. These duties include providing immunization against major infectious diseases occurring in the community; taking measures to prevent, treat, and control epidemic and endemic diseases; providing education and access to information concerning the main health problems in the community; and providing appropriate training for health person-

nel, including education on health and human rights.²⁴

In essence, all the principles and obligations set out in Table 1 are related to states' duty to build resilient health systems.

Core capacities under the IHR

Alongside the core content of the right to health outlined above, the IHR include a series of obligations related to structural and capacity-building measures that are expected to contribute to the overall goal “to prevent, protect against, control and provide a public health response to the international spread of disease.”²⁵ Articles 5 and 13 require states to develop within fixed deadlines the capacities to detect, assess, notify, and report public health risks and public health emergencies and respond promptly and effectively to such events. Core capacities to be implemented at the local, intermediate, and national level are detailed in annex 1 of the IHR and further specified in subsequent technical documents.²⁶ Currently, according to the IHR monitoring process, states are requested

to self-assess the implementation of 13 core capacities spelled out in 24 indicators related to different issues, including health infrastructure, legal and financial frameworks, staff, decision-making, and information capacities (Table 2).²⁷

The parallels and overlaps between the core right to health obligations under the ICESCR and the core capacities under the IHR are striking. For instance, as set out in Table 1, the right to health framework requires states to “adopt a national public health strategy and plan of action, on the basis of epidemiological evidence.” This element has several commonalities in the IHR, where, for example, core capacity 1 addresses the need to have “an adequate legal framework in all relevant sectors to support and facilitate the effective and efficient implementation of all of their obligations and rights under the IHR”; core capacity 8 “focuses on the overall national health emergency framework and system for enabling countries to be prepared and operationally ready for response to any public health event, including emergencies, as per the requirement of IHR”; and indicator C9.3 refers to “access

TABLE 1. Right to health obligations under the ICESCR

Right to health principles relevant to infectious disease control (General Comment 14, para. 12)	Right to health core obligations relevant to infectious disease control (General Comment 14, para. 43)	Right to health comparable priority obligations relevant to infectious disease control (General Comment 14, para. 44)
<ul style="list-style-type: none"> • Availability of health-related services • Accessibility <ul style="list-style-type: none"> • nondiscrimination • physical accessibility • economic accessibility (affordability) • information accessibility • Acceptability • Quality 	<ul style="list-style-type: none"> • Ensure the right of access to health facilities, goods, and services on a nondiscriminatory basis, especially for vulnerable and marginalized groups • Provide essential drugs as defined under the WHO Action Programme on Essential Drugs and Vaccines • Ensure equitable distribution of all health facilities, goods, and services • Adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods (such as right to health indicators and benchmarks) by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to vulnerable and marginalized groups 	<ul style="list-style-type: none"> • Provide immunization against major infectious diseases occurring in the community • Take measures to prevent, treat, and control epidemic and endemic diseases • Provide education and access to information concerning the main health problems in the community • Provide appropriate training for health personnel, including education on health and human rights

to essential health services” aimed to guarantee “resilient national health systems.”²⁸ Core capacities provided by the IHR, as further detailed in WHO practice, might thus give more substance to the less detailed wording under the right to health through the identification of minimum requirements provided by the IHR, regardless of the structural and

economic differences among states.

However, while core capacities are a cornerstone of the IHR system, evidence suggests that their implementation and monitoring remain a challenge. Even if states were required to comply with them by 2016, based on self-assessments provided by states in 2018, about two-thirds of states

TABLE 2. Core capacities under the IHR

<p>Core capacity 1: Legislation and financing Indicator C.1.1: Legislation, laws, regulations, policies, administrative requirements, or other government instruments to implement the IHR Indicator C1.2: Financing for the implementation of IHR capacities Indicator C1.3: Financing mechanism and funds for timely response to public health emergencies</p> <p>Core capacity 2: IHR coordination and national IHR focal point functions Indicator C2.1 National IHR focal point functions under IHR Indicator C2.2 Multisectoral IHR coordination mechanisms</p> <p>Core capacity 3: Zoonotic events and the human-animal interface Indicator C3.1. Collaborative effort on activities to address zoonoses</p> <p>Core capacity 4: Food safety Indicator C4.1 Multisectoral collaboration mechanism for food safety events</p> <p>Core capacity 5: Laboratory Indicator C5.1. Specimen referral and transport system Indicator C5.2 Implementation of a laboratory biosafety and biosecurity regime Indicator C5.3 Access to laboratory testing capacity for priority diseases</p> <p>Core capacity 6: Surveillance Indicator C6.1 Early warning function: indicator- and event-based surveillance Indicator C6.2 Mechanism for event management (verification, risk assessment, analysis investigation)</p> <p>Core capacity 7: Human resources Indicator C7.1 Human resources for the implementation of IHR capacities</p> <p>Core capacity 8: National health emergency framework Indicator C8.1 Planning for emergency preparedness and response mechanism Indicator C8.2 Management of health emergency response operations Indicator C8.3 Emergency resource mobilization</p> <p>Core capacity 9: Health service provision Indicator C9.1 Case management capacity for IHR-relevant hazards Indicator C9.2 Capacity for infection prevention and control and chemical and radiation decontamination Indicator C9.3: Access to essential health services</p> <p>Core capacity 10: Risk communication Indicator C10.1 Capacity for emergency risk communications</p> <p>Core capacity 11: Points of entry Indicator C11.1 Core capacity requirements at all times for designated airports, ports, and ground crossings Indicator C11.2 Effective public health response at points of entry</p> <p>Core capacity 12: Chemical events Indicator C12.1 Resources for detection and alert</p> <p>Core capacity 13: Radiation emergencies Indicator C13.1 Capacity and resources</p>

Source: World Health Organization, *International Health Regulations (2005): State party self-assessment annual reporting tool* (Geneva: World Health Organization, 2018)

have poor or modest levels of preparedness, with overall scores ranging from 1 to 3 out of 5.²⁹ According to Lawrence Gostin and Rebecca Katz, many countries lack the financial resources to meet the core capacities, while high-income countries have offered little financial support; further, Amitabh Suthar et al. suggest that there is limited knowledge on how countries should achieve the core capacities domestically.³⁰

In addition, the IHR is not accompanied by an effective monitoring system able to push states toward the implementation of core capacities: mandatory annual reports to be provided by states on their implementation are not subjected to any review mechanism or follow-up, as is common in other areas of international law. Only in 2016, based on the recommendation “to move from exclusive self-evaluation to approaches that combine self-evaluation, peer review and voluntary external evaluations,” did WHO’s director-general launch some new technical tools aimed at supporting states in the implementation of core capacities.³¹ These instruments, reflected in the current *IHR Monitoring and Evaluation Framework*, include guidance on simulation exercises and after-action reviews, as well as a joint external evaluation tool aimed at independently assessing states’ capacities to prevent, detect, and respond to public health risks. This latter tool has resulted in the preparation of detailed reports reviewing the strengths and weaknesses of countries under scrutiny. Thus far, around 110 countries have been evaluated through this process: however, no follow-up on reports is expected, and the above-mentioned tools are voluntary ones.³² While these processes are worthwhile and may strengthen the implementation of the IHR, a series of additional concerns are still present. For instance, states that have failed to implement the core capacities are no longer required to develop national implementation plans as originally required under articles 5 and 13. Additionally, the dispute settlement mechanism provided by article 56 of the IHR might be qualified as a weak one: indeed, the review committee established in relation to the H1N1 pandemic underlined how “the lack of

enforceable sanctions” was “the most important structural shortcoming of the IHR.”³³

Toward an integrated interpretation of the right to health and the IHR

As Table 3 illustrates, there are considerable parallels between states’ obligations to have core capacities under the IHR and their “minimum core” and other obligations under the right to health. We argue in favor of more cross-fertilization between these two regimes. This regime interaction may enrich both frameworks from a normative perspective while also enhancing accountability, social justice, and public health outcomes.

Normative interaction may arise through a systemic interpretation of the IHR, whereby, according to article 31(3)(c) of the Vienna Convention on the Law of Treaties, “international standards may be interpreted in the light of any relevant rules of international law applicable in the relations between the parties.” The right to health clearly can be considered a relevant rule of international law that can assist in the interpretation of the IHR, particularly insofar as it underscores the importance of IHR duties from a human rights perspective. Table 3 offers a non-exhaustive illustration of obvious overlaps and synergies between right to health duties and IHR core capacities. For example, implementing the core obligation to ensure nondiscriminatory access to health care facilities, goods, and services would require explicit legal protection against discriminatory applications of pandemic-response legislation, such as emergency orders and lock-downs (core capacity C.1). It would also require explicit protection against discrimination in access to testing (core capacity C.5), surveillance (core capacity C.6), emergency resource mobilization (core capacity C.8), access to essential health services (core capacity C.9), and public health responses at points of entry, such as airports and border crossings (core capacity C.11).

The pressing need for strong human rights protections in these areas has been reinforced by the discriminatory applications of COVID-19 laws

TABLE 3. Comparison of IHR core capacities and ICESCR right to health obligations

Core capacities (IHR)	Core right to health obligations (ICESCR)	Other aspects of the right to health (ICESCR)
Core capacity 1: Legislation and financing <ul style="list-style-type: none"> Indicator C.1.1 Legislation, laws, regulations, policies, administrative requirements, or other government instruments to implement the IHR Indicator C1.2 Financing for the implementation of the HR capacities Indicator C1.3 Financing mechanism and funds for timely response to public health emergencies 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to implement legislation Duty to progressively realize the right to health within maximum available resources Duty to take measures to prevent, treat, and control epidemic and endemic disease
Core capacity 2: IHR coordination and national IHR focal point functions <ul style="list-style-type: none"> Indicator C2.1 National IHR focal point functions under IHR Indicator C2.2 Multisectoral IHR coordination mechanisms 		Duty to provide access to information concerning the main health problems in the community, including methods of preventing and controlling them
Core capacity 3: Zoonotic events and the human-animal interface <ul style="list-style-type: none"> Indicator C3.1 Collaborative effort on activities to address zoonoses 	Duty to adopt national public health strategy and plan of action to address population's health concerns	Duty to prevent, treat, and control epidemic and endemic disease
Core capacity 4: Food safety <ul style="list-style-type: none"> Indicator C4.1 Multisectoral collaboration mechanism for food safety events 	Duty to adopt national public health strategy and plan of action to address population's health concerns	Duty to prevent, treat, and control epidemic and endemic disease
Core capacity 5: Laboratory <ul style="list-style-type: none"> Indicator C5.1 Specimen referral and transport system Indicator C5.2 Implementation of a laboratory biosafety and biosecurity regime Indicator C5.3 Access to laboratory testing capacity for priority diseases 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Realization of the AAAQ
Core capacity 6: Surveillance <ul style="list-style-type: none"> Indicator C6.1 Early warning function: indicator- and event-based surveillance Indicator C6.2 Mechanism for event management (verification, risk assessment, analysis investigation) 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to prevent, treat, and control epidemic and endemic disease
Core capacity 7: Human resources <ul style="list-style-type: none"> Indicator C7.1 Human resources for the implementation of IHR capacities 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to prevent, treat, and control epidemic and endemic disease Duty to provide appropriate training for health personnel Realization of the AAAQ

Sources: World Health Organization, International Health Regulations (2005): State party self-assessment annual reporting tool (Geneva: World Health Organization, 2018); Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. E/C.12/2000/4 (2000)

and policies in all of these core IHR domains, including disproportionate force in the enforcement of COVID-19 emergency orders against racial and ethnic minorities and the poor; unaffordable and unavailable testing and health care services; discriminatory enforcement of border restrictions; and failures to adequately consider nondiscrimination on the basis of disability or race in policies to address essential critical care during COVID-19 surges.³⁴ The core obligation to ensure the equitable distribution of health care facilities, goods, and services holds similar cross-cutting relevance for many of these same parts of the IHR, including legislative frameworks and financing mechanisms (core capacity C.1), access to laboratory testing

(core capacity C.5), human resources for implementation of IHR capacities (core capacity C.7), and emergency resource mobilization (core capacity C.8). Taking serious account of core right to health duties in the implementation of such IHR capacities would significantly enhance the fairness and efficacy of pandemic responses, with concrete benefits for public trust, social justice, and population health.³⁵

At the same time, the comprehensive IHR framework gives more detail to the open-ended wording under the right to health framework and provides considerable clarification of states' duty to prevent, treat, and control epidemic disease. For example, the core capacity requirement regarding

TABLE 3. *Continued*

Core capacities (IHR)	Core right to health obligations (ICESCR)	Other aspects of the right to health (ICESCR)
Core capacity 8: National health emergency framework <ul style="list-style-type: none"> Indicator C8.1 Planning for emergency preparedness and response mechanism Indicator C8.2 Management of health emergency response operations Indicator C8.3 Emergency resource mobilization 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to prevent, treat, and control epidemic and endemic disease Realization of the AAAQ
Core capacity 9: Health service provision <ul style="list-style-type: none"> Indicator C9.1 Case management capacity for IHR-relevant hazards Indicator C9.2 Capacity for infection prevention and control and chemical and radiation decontamination Indicator C9.3 Access to essential health services 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to provide essential medicines Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to prevent, treat, and control epidemic and endemic disease Duty to provide appropriate training for health personnel Realization of the AAAQ
Core capacity 10: Risk communication <ul style="list-style-type: none"> Indicator C10.1 Capacity for emergency risk communications 	Duty to adopt national public health strategy and plan of action to address population's health concerns	Duty to prevent, treat, and control epidemic and endemic disease Duty to provide access to information concerning the main health problems in the community
Core capacity 11: Points of entry <ul style="list-style-type: none"> Indicator C11.1 Core capacity requirements at all times for designated airports, ports, and ground crossings Indicator C11.2 Effective public health response at points of entry 	Duty to adopt national public health strategy and plan of action to address population's health concerns Duty to ensure nondiscriminatory access to health facilities, goods, and services Duty to ensure equitable distribution of health facilities, goods, and services	Duty to prevent, treat, and control epidemic and endemic disease
Core capacity 12: Chemical events <ul style="list-style-type: none"> Indicator C12.1 Resources for detection and alert 	Duty to adopt national public health strategy and plan of action to address population's health concerns	
Core capacity 13: Radiation emergencies <ul style="list-style-type: none"> Indicator C13.1 Capacity and resources 	Duty to adopt national public health strategy and plan of action to address population's health concerns	

access to essential health services during a disease outbreak (C.9) fills a key gap in core obligations under the right to health, which do not speak explicitly to this imperative.

Subsequently, recognition that the IHR core capacities might inform the content of the human right to health suggests that if states fail to comply with the IHR, they may be held accountable under the UN human rights regime (for example, the reporting procedures and individual complaint mechanisms of the CESCR, Convention on the Rights of the Child, CEDAW, and Convention on the Rights of Persons with Disabilities, as well as the UN Special Procedures). They may also be held accountable in domestic courts, as illustrated by successful human rights-based challenges to disproportionately forceful and restrictive COVID-19 lockdowns in Kenya and Malawi.³⁶

More generally, there is an urgent need to perceive public health emergencies as a matter of international human rights obligations and accountability. The right to health means that governments should evaluate their preparedness for the next global public health emergency, whether it comes from within their own borders or from abroad. Governments should do so in close consultation with WHO, the most authoritative organization globally when it comes to infectious disease outbreaks, which has generated a wealth of expertise over the course of its existence. Given that WHO is unable to sanction, the ultimate consequence when states fail to comply with their obligations should be accountability under the UN human rights regime, in addition to domestic litigation.

Conclusion

The COVID-19 pandemic underscores the importance of more effective and more equitable disease control initiatives within and across borders. It also illustrates the challenges posed by the fragmented areas of international law relating to health and disease control. We suggest that the right to health offers principles and binding duties capable of achieving some extent of the systemic integration called for in

2006 by the International Law Commission.³⁷ This idea finds support in international human rights law scholarship, with suggestions that the right to health could act as “a core, unifying standard” and “pillar” in international law related to health.³⁸ As this paper indicates, taking the right to health seriously in the IHR could concretely improve the fairness and efficacy of the IHR and associated pandemic responses in ways that the COVID-19 pandemic has underscored are critically required.³⁹ At the same time, the greater specificity of IHR duties gives more detail to the open-ended wording of the right to health, including by clarifying the state duty to prevent, treat, and control epidemic disease and suggesting that access to essential health services should appropriately be construed as a core obligation under the right to health. In particular, we hope that this analysis supports greater regime interactions in which human rights law is more seriously taken into account in the potential redesign of the IHR and in which responses to COVID-19 and future disease threats more concretely consider the right to health. This proposal is not simply legalistic: this time of significant upheaval underscores the imperative for pandemic responses to be rooted in socially just, humane, and cooperative domestic and global state actions. We believe that advancing a more integrated interpretation of the IHR and the right to health offers practical and policy-relevant pathways to achieve this outcome. This paper offers a preliminary sketch of some conceptual and institutional overlaps between these two regimes. The imperative for global health and human rights researchers is to advance this research to ensure that both the IHR and international human rights law are further developed to achieve these goals.

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Beyond Reproduction: The “First 1,000 Days” Approach to Nutrition through a Gendered Rights-Based Lens

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Abstract

The First 1,000 Days approach highlights the importance of adequate nutrition in early life—from conception to a child’s second birthday—for good development and growth throughout the child’s life and potentially onto their own offspring. The approach has been highly influential in mobilizing policy attention and resources to improve maternal and infant nutrition in global health and development. This paper undertakes a critical review of this approach from a gendered human rights lens, finding that the theoretical underpinnings implicitly reflect and reproduce gender biases by conceptualizing women within a limited scope of reproduction and child care. We explore the processes of systemic neglect through Pierre Bourdieu’s theories on how social structures are reproduced. Understanding theory is important to the governance of global health, how we frame priorities, and how we act on them. Revisiting influential theories is a means of accountability to ensure inclusiveness and to reduce gender and health inequities in research. We argue that a greater focus on women could increase the potential impact of nutrition interventions.

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Introduction

The First 1,000 Days approach to nutrition highlights the importance of adequate nutrition between conception and a child's second birthday as the most critical period of growth and development in a child's life, with far-reaching effects on capacities to work and learn and intergenerational effects on their own children.¹ While the emphasis on pregnancy and early life nutrition is not new, the First 1,000 Days movement represents a convergence of international development and health sectors, including nutrition, food security, maternal and child health, primary education, and poverty alleviation.² A powerful draw of the findings from the *Lancet's* 2008 series on maternal and child undernutrition was the idea that childhood malnutrition was knowledgeable and actionable, an idea that was taken up by the First 1,000 Days movement.³ It provided systematic evidence of the problem of early-life undernutrition and its largely irreversible long-term effects, as well as the availability of high-impact and feasible interventions.⁴ A study demonstrated that a package of 13 known interventions—including appropriate breastfeeding and infant feeding practices, the provision of micronutrients for young children and their mothers, salt iodization and iron fortification, and therapeutic feeding of malnourished children—could eliminate a million child deaths a year.⁵ Beyond mortality reduction, adequate early nutrition could break the intergenerational cycle of malnutrition where stunted girls grow up to be stunted mothers who have a higher likelihood of giving birth to low-birthweight babies.⁶ Additionally, with growing evidence that good nutrition in early life is essential for normal development and the prevention of life course health risks, including obesity, hypertension, and diabetes, reducing stunting in children was highlighted as foundational for poverty reduction and key in the development toolkit.⁷

Improved nutrition in the first 1,000 days of life is consequently seen as a discourse of hope, as a way to help break the intergenerational cycle of malnutrition and poverty in low- and middle-income countries (LMICs).⁸ Though primary education attendance has long been a key

development indicator, the findings of the 2008 *Lancet* series posited that good nutrition in early life was a fundamental prerequisite for individual human development and that early childhood malnutrition hindered a child's capacity to learn.⁹ The subsequent 2013 *Lancet* series on maternal and child nutrition further highlighted the implications of early undernutrition for adult chronic diseases.¹⁰ Framing the first 1,000 days as a “critical window of opportunity” highlights the urgency and temporal aspect of the approach, which has been described as a powerful anticipatory narrative that compresses the potential of global futures into a very specific time frame focused on the mother-child dyad, often exclusionary to those outside this window, such as men, adolescents, and women beyond childbirth.¹¹

While the approach is powerful for building momentum and partnership between diverse collaborators—including national governments, private donors, and international development organizations—researchers have previously argued that it may be oversimplified, paying inadequate attention to the complexity of social and ecological interaction and focusing narrowly on mothers as primary caregivers.¹² Additionally, the anticipatory narrative may take away from the position of the human right to health and food. “A primary challenge for nutrition policy in low-income settings is to position nutrition as an investment,” nutritionist and economist Harold Alderman argues, “rather than simply as a form of social spending that governments grant poor people to the degree that governments prioritize equity.”¹³ Though the approach is effective in mobilizing donors and international support, what becomes lost in the messaging? By framing early nutrition as a key investment for developing nations, what does the approach mean for the agency and personhood of mothers and women more generally? This paper explores the First 1,000 Days approach through a human rights-based lens. Specifically, we evaluate the approach's gender responsiveness using the World Health Organization's (WHO) Gender Responsive Assessment Scale and understand the processes of systematic neglect using Pierre Bourdieu's theories on how social structures are

reproduced. Understanding the theoretical framework is important to the governance of global health because how we think about global health problems frames priorities and defines how we act on them. Critically examining influential theories is a means of accountability to ensure inclusiveness and reduce replications of gender and health inequities in evidence-based research.

Human-rights based approaches to health and gender-transformative health interventions

Background on rights-based approaches to health

Under a rights-based approach, health is a human right, and at the core of human rights is equal dignity for all, which means that each person is considered an “ends” in themselves, and not treated as a “means” to further another goal.¹⁴ Global health human rights lawyer and advocate Alicia Ely Yamin writes that “[o]ne principal way in which women’s ethical and legal subjectivity is diminished is through laws and practices that reduce them to mere means for reproduction and childrearing.”¹⁵ Conventional health programming often targets mothers in “efforts to reshape knowledge, attitudes and practices ..., not asking them about their needs but treating them as primarily instrumental, as caretakers for their children.”¹⁶ However, within the rights-based framework’s conceptualization of the equal dignity of all human beings, to diminish a person to a tool to advance any other goals is to dehumanize them.¹⁷ While there has been a proliferation of human rights-based approaches in international development and global health in recent decades, Yamin argues that not all of them are genuinely transformative:

[A]pplying a transformative human rights framework to health calls on us to rethink the underlying causes of substantive inequalities among different people ... It also causes us to rethink the nature of power ... [I]t causes us to rethink what it means to be human, in a world where people are too often reduced to consumers or targets of programs.¹⁸

A genuine transformative human rights framework to health critically evaluates structures of power, how social inequalities may manifest as health disparities, and how people are conceptualized in programming.

WHO’s Gender Responsive Assessment Scale

One approach to evaluating programming is WHO’s Gender Responsive Assessment Scale, which describes a continuum of five categories: gender unequal, gender blind, gender sensitive, gender specific, and gender transformative.¹⁹ Gender-unequal approaches exploit existing gender biases and roles, consequently perpetuating and reinforcing gender inequalities. Gender-blind approaches move from exploitative to accommodating, as they often ignore gender norms and differences in opportunities and resource capacities for men and women. Gender-blindness may seek to treat everyone the same on a principle of fairness but actually result in reinforcing gender-based and other forms of social and political discrimination.²⁰ Gender-sensitive approaches acknowledge and accommodate gender norms but do not address the inequalities generated. Meanwhile, gender-specific approaches acknowledge and consider women’s and men’s specific needs and may intentionally target a specific group of women or men to achieve certain goals or needs, often to make it easier for them to fulfill responsibilities and duties associated with their gender roles. Finally, gender-transformative approaches consider gender norms and their impact on access to services and resources, consider the specific needs of men and women, and work to address the causes of gender-based inequities. Within health promotion activities, this means “approaches that avoid reproducing harmful gender norms or stereotypes and instead empower women and men to reach their health potential.”²¹

Gender- and nutrition-sensitive programs

Gender discrimination and malnutrition

Gender discrimination across the lifespan contributes to mortality and morbidity in women and girls. According to a recent estimate, up to 126

million women are demographically “missing” across LMICs.²² Though women tend to live longer than men when given similar economic and health resources, places where men’s life expectancy is longer than that of women reveal systemic gender inequities that contribute to the concentration of adverse health outcomes.²³ Gender discrimination is acknowledged to play an important role in the undernutrition of women and girls, which leads to higher rates of both acute and chronic illnesses, as well as increased risk of adverse pregnancy outcomes for mothers and infants.²⁴ Women are doubly burdened with higher nutritional requirements during pregnancy and lactation, as well as gender inequalities in poverty.²⁵ A review using a human rights approach to health implications of food and nutritional insecurity found that women’s access to food is significantly hindered by gender discrimination, despite women being key players in food production.²⁶ Women are found to lack control of and access to agricultural resources, land, credit, and educational resources.²⁷ This is reflected in a report by the Food and Agricultural Organization that found that in sub-Saharan Africa, twice as many women suffer from malnutrition than men, even though women constitute up to 80% of the agricultural workforce.²⁸

Women’s empowerment through a limiting lens

Nutrition programs include nutrition-specific interventions—such as supplementation—that directly affect nutritional status, while nutrition-sensitive interventions work with underlying factors that indirectly affect maternal and child nutrition and include agriculture and food security, water and sanitation, family planning, and gender empowerment.²⁹ Though women’s empowerment is considered a part of nutrition-sensitive interventions, discussions on empowering women are often expressed as helping women better care for their children.³⁰ This underlying sentiment is found even in literature highlighting the need to mitigate gender inequality. Before the 2008 *Lancet* series, economists Siddiq Osmani and Amartya Sen reported that maternal deprivation adversely affects

the health of the fetus. Like the 2008 *Lancet* series, they highlighted that high maternal undernutrition is associated with low-birthweight infants, which increases rates of child undernutrition and adult ailments.³¹ While they start the causal chain with gender bias and strongly recommend eliminating gender inequalities, the authors still see women within the scope of reproduction:

[W]omen’s deprivation in terms of nutrition and healthcare rebounds on the society in the form of ill-health of their offspring—males and females alike. Given the uniquely critical role of women in the reproductive process, it would be hard to imagine that the deprivation to which women are subjected would not have some adverse impact on the lives of all—children as well as adults—who are “born of a woman.”³²

In the wake of the two *Lancet* series, the literature focused on the first 1,000 days embraces a strong awareness that gender inequalities are both a cause and an effect of malnutrition and that the empowerment of women and girls is needed in efforts to improve nutrition. Additionally, a Scaling Up Nutrition report, *Empowering Women and Girls to Improve Nutrition: Building a Sisterhood of Success*, states that “[n]utrition justice will only be achieved when women are empowered and when policies and programmes are gender responsive.”³³ However, as evident in the following statement from the same report, women’s empowerment is expressed in limiting terms as fulfilling better outcomes for their children: “Higher female earnings and bargaining power translate into greater investment in children’s education, health and nutrition, which leads to economic growth in the long term.”³⁴ Though nutrition-sensitive programming often highlights the need to empower women, its underpinnings implicitly reflect and reproduce gender biases by conceptualizing women within a limited scope of reproduction and child care.

Motherhood as a site of intervention

Underlying gender assumptions

According to the Gender Responsive Assessment

Scale, the First 1,000 Days approach involves a continuation of the assumption that mothers are the primary caregivers and are subsequently the natural facilitators of health care interventions for their families.³⁵ Consequently, though the primary objective of the First 1,000 Days approach to nutrition is the reduction of childhood malnutrition, the primary target of intervention is the mother. This includes health education and counseling for mothers that promotes the value of exclusive and complementary breastfeeding practices, as well as the importance of maternal nutrition during pregnancy and early infancy. Such educational efforts acknowledge that within the first half of the thousand days, “the infant is entirely dependent for its nutrition on the mother: via the placenta and then ideally via exclusive breastfeeding.”³⁶ Additionally, they note that maternal undernutrition can cause intrauterine growth restriction in infants and affect a mother’s lactation, which may compromise the ability to exclusively breastfeed.³⁷

Others within the First 1,000 Days literature have also argued that adequate nutrition is important for women not only during pregnancy and lactation but also during adolescence. Girls will become future mothers; thus, ensuring that they enter their reproductive years with adequate nutrition is essential.³⁸ The need to reach adolescents—and the preconception period more generally—was introduced in the 2013 *Lancet* series by Zulfiqar Bhutta and colleagues, who argued that this was especially important in countries with high rates of undernutrition and teenage pregnancies.³⁹ Rates of adolescent pregnancy remain high in many LMICs, and adverse pregnancy outcomes are seen when adolescent girls are unable to meet the nutritional needs for their own growth and the growth of their unborn infants.⁴⁰ Using the case of Guatemala, where almost one in every five seventeen-year-olds had given birth or was pregnant, David Flood and colleagues highlight that targeting mothers in general for nutrition programs based on the First 1,000 Days neglects the unique situation of adolescent pregnancies and the need to address adolescent sexual and reproductive rights.⁴¹ However, while

Flood and colleagues critique that teenage mothers give up their own rights as children themselves, subsumed under the rights of their infants, this speaks to a larger issue in First 1,000 Days policies in which women are seen through a maternal lens as current or future mothers.

A means but not an ends

While highlighting the importance of women and girls during pregnancy, lactation, and pre-conception expands the focus of the First 1,000 Days approach, it does not yet escape the encompassing categorization of what anthropologists Michelle Pentecost and Fiona Ross term “the *maternal*.” Drawing on ethnographic research on the implementation of a First 1,000 Days policy in the Western Cape, South Africa, the authors conceptualize “the *maternal*” as a key time frame for a wide range of health interventions.⁴² They note that the policy’s focus on categories of persons means that there is a lack of adequate consideration of women themselves and their social conditions. Conceptualizing women in nutrition programs as mothers or mothers-to-be reduces motherhood to a site of intervention that in turn reduces women’s personhood to their bodies, seen as an environment to strengthen future health.⁴³

In another example from South Africa, a study found that the narrow time frame of the First 1,000 Days approach limits the support that women receive. While women may be well supported during pregnancy, their access to food and other support is withdrawn after birth, when the focus is transferred to infants.⁴⁴ In this way, the approach conceptualizes maternal nutrition as a means to affect child health outcomes, while overlooking the value of women’s own well-being.

Consequently, while the First 1,000 Days approach has been critiqued as “mother centric,” an important caveat is that motherhood is expressed as a site of intervention rather than personhood. The *maternal* is a time frame of opportunity, a category of persons, a target of programming, and a resource to support the scaling of nutrition interventions—but not necessarily a person with her

own intrinsic worth. Thus, on the Gender Responsive Assessment Scale's continuum of approaches that exploit, accommodate, and transform gender norms, roles, and relations, nutritional initiatives that target mothers primarily to measure child health outcomes are arguably gender exploitative since their involvement is primarily instrumental.

Reproducing social inequalities

A priority gap

Challenges standing in the way of the development of genuinely gender-transformative nutrition interventions and research stem in part from processes of systemic neglect and the naturalness of conceptualizing the mother-infant dyad in global health and development. This neglect is systematic rather than necessarily intentional. Within a vicious cycle of the research-advocacy gap, the current emphasis on evidence-based medicine and interventions means that an area with limited evidence regarding maternal outcomes leads to a lower prioritization of that area within the field of international development and global health, and subsequently less funding for and less research on that area.⁴⁵ Though its explicit application to global nutrition agendas is recent, the concept of the measurement trap dates back to the early 1990s as part of the Safe Motherhood Initiative.⁴⁶ Based on an observation that maternal health priorities were often subsumed under child health within primary health care programs, the measurement trap describes how poor tracking of maternal deaths compromised the capacity to develop and evaluate maternal interventions and contributed to the neglect of maternal health as a priority topic.⁴⁷ As explained by obstetrician Mahmoud Fathalla:

Failure to address the preventable causes of maternal death is a violation of women's human rights ... Women are not dying during pregnancy and childbirth because of conditions that are difficult to manage. They are dying because the societies in which they live did not see fit to invest what is needed to save their lives. It is a question of how much the life of a woman is considered to be worth ... Even with the tragedy of maternal mortality, a

justification sometimes put forward for investment in keeping mothers alive is that their survival is critical for the survival of the children. Resources allocated for maternal health are generally grouped together with resources for child health in a "mother and child health (MCH)" package. The "M" in MCH has often been seen as a means and not an end, as a means for child health.⁴⁸

Arguing that safe motherhood is a human right, Safe Motherhood Initiative proponents highlighted maternal survival as intrinsically valuable beyond its associations with child health.⁴⁹ Within the global nutrition agenda described by the First 1,000 Days approach, there is likewise a similar concern that maternal nutrition interventions are seen as investments in child health, but women's health outcomes tend to be systematically neglected and remain invisible in assessments and prioritization.

Deconstructing "naturalness" as doxa

The process of systematic neglect can be further understood through theories of Bourdieu and others on relationships of power and how actors reproduce social structures through their daily interactions. French sociologist Bourdieu described how social structures are constantly being reproduced by people's actions, beliefs, and feelings.⁵⁰ The concept of "the field" is the space of social interaction where "habitus" refers to our internalized norms and values for interacting in a certain social space. Habitus is both structured by the norms, values, and expectations of a given community and also structuring in that it reproduces the community's norms through practice.⁵¹ "Doxa" is when the established order becomes entrenched and subsequently viewed as self-evident and natural.⁵² The global health and international development community may be considered a field where actors advocate for their specific area of interest while competing for resources and the legitimacy of their priority areas.

Toril Moi's critical feminist revisiting of Bourdieu highlights the social significance of what is prioritized and what becomes devaluated and notes that priority setting is a distinctly political practice.⁵³ The naturalness of targeting pregnant

and lactating mothers for nutrition interventions to help their children grow appeals to the biology of reproduction, which masks the arbitrary social constructions of gender divisions of care, individualizes maternal nutrition as a woman's concern, and hides socially produced power relations that reduce women's bodies to fertile environments for cultivating healthy children, grandchildren, and societies in LMICs at large. The role of motherhood for women is emphasized in development programs with a significance that is not seen with fatherhood for men.⁵⁴ It seems to make sense to policy makers, researchers, program implementers, and even the women themselves because it reproduces the same habitus in which the naturalness of women as the primary caretakers of children is unquestioned. What mother would not want her children to be healthy, successful in life, and part of developing a modern nation? The rhetorical question allows for only one legitimate response and reveals the naturalness of conceptualizing women only in relationship to their offspring. In order to remain relevant to the discussion, expansions to promote women's health within maternal health often claim legitimacy by connecting their arguments to motherhood. This can be seen, for example, in efforts to highlight the importance of maternal nutrition during pregnancy and exclusive breastfeeding, the need to work with adolescent girls as future mothers, and the importance of reducing maternal mortality to ensure child health and survival.⁵⁵ As Moi writes, "In a wholly doxic society, women as social agents will freely choose the social destiny which they cannot in any case expect to escape."⁵⁶

Moi's feminist appropriation of Bourdiean theory speaks to Yamin's argument that human rights-based approaches to health must question the naturalness of disease disparities, explore the power relations that exacerbate risk, and understand how health systems reflect and reproduce power inequalities in a given society.⁵⁷ It thus makes sense that bodies of research likewise reflect and reproduce power inequities. Research and implementation projects often reflect the implicit priorities of our society and reproduce value in the selected topics.

Challenging doxa: Knowledge production and reproduction for change

Expanding the scope

In challenging doxa, the perceived naturalness of the established social order, and asking "What, then, does it take for critique—and thus for change—to enter the social space?" Moi quotes Bourdieu to highlight the need to "bring the undiscussed into discussion," which opens up the possibility for critical discourse to challenge the naturalness of power relations and assumptions of practice.⁵⁸ This provides insight into the power of critically informed research on marginalized topics to disrupt implicit gender inequities in health. As medical anthropologist Paul Farmer describes in his book *Pathologies of Power*, research has the value of "bearing witness" to injustices of health and human rights and bringing the two together.⁵⁹ Research as witness helps break the silence and consequently creates spaces to challenge doxa. As evident in the widely influential 2008 *Lancet* series on maternal and child undernutrition, research has an important role in shifting the field of prioritizations.

Currently, only one of the six global nutrition targets in the World Health Organization's *Comprehensive Implementation Plan on Maternal, Infant and Young Child Nutrition*, which has been incorporated into the Sustainable Development Goals, relates to outcomes among women.⁶⁰ This target aims to reduce anemia among women of reproductive age, as there is evidence that severe anemia increases the risk of maternal hemorrhage, the leading cause of maternal mortality.⁶¹ To strengthen the focus on maternal nutrition and health indicators, additional risk factors (such as low maternal stature and other nutritional deficiencies in association with obstetric complications) could be further explored in research. Sustainable Development Goal 2.2 (end all forms of malnutrition) is currently child focused, using the prevalence of stunting and the prevalence of wasting and overweight in children under five as the key indicators. The policy implications of these global targets are important, for in LMICs whose national health budgets depend significantly on do-

nor contributions, the key targets and indicators of the Millennium Development Goals “quickly came to be used by donors and national governments as national planning targets, displacing any other priorities [national governments] may have had previously.”⁶² Further research should explore the implications of the First 1,000 Days movement for political landscapes and health systems, with their subsequent impacts on women’s health.

While successful in building momentum for nutrition interventions to improve child growth, the First 1,000 Days approach frames nutritional policies as a high-impact development investment for LMICs rather than an issue of accountability that states have toward the health and well-being of their citizens. It speaks to an undervaluing of social, economic, and cultural rights as “programmic,” where the rights to work, health, and education are aspirational but not necessarily legally actionable.⁶³ Consequently, health and gender research has an important role in shedding light on disparities, expanding the scope of neglected topics, and record keeping in order to strengthen the accountability of states and other actors involved. For the First 1,000 Days movement and the Scaling Up Nutrition movement, this means accountability toward the empowerment of women and girls in a genuinely gender transformative way.

Conducting women-centered research to inform nutrition-sensitive programs

To conduct women-centered research that is gender transformative and that reaches marginalized women in LMICs, we can learn from Ann Pederson and colleagues’ discussion of gender-transformative health promotion for women.⁶⁴ They highlight the importance of explicitly women-centered interventions that acknowledge women’s rights to control their own lives and that consider women’s everyday lives and the multiple roles and identities they may hold.⁶⁵ Gender-transformative health promotion programming is strength based, which considers women’s everyday lives and the social conditions in which they live.⁶⁶ This means being trauma informed and embracing harm reduction approaches that meet women where they are.⁶⁷ The agency of

women involved is consequently expanded beyond adherence to healthy behavioral change recommendations and understood within the context of their lives, including existing constraints and their hopes and desires. These are valuable lessons to incorporate into global maternal and child health and nutrition research and interventions.

As part of the aim to conceptualize women not simply in terms of reproduction, there is also a need to reflect on why we should focus on maternal nutrition specifically rather than on women’s nutrition in general. On the one hand, maternal nutrition is an important topic because women face higher nutritional requirements during pregnancy and lactation at the same time that they face gender inequalities in accessing health and economic resources.⁶⁸ However, we must acknowledge that such an emphasis is also influenced in part by convenience, as pregnancy may be a time when women are more engaged with medical systems.⁶⁹ Efforts to expand beyond the narrow time frame of pregnancy and postpartum can help reduce the withdrawal of support to women outside the maternity window and acknowledge the lifelong gender discrimination and disparities they may face in food and nutritional security and other dimensions of their lives.⁷⁰

Conclusion

Though researchers, policy makers, and implementers following the First 1,000 Days approach advocate for women’s empowerment and are sensitive to the ways that gender discrimination can affect women’s ability to access food, limiting women’s involvement to ensuring the well-being of her child perpetuates underlying gender stereotypes. Under the First 1,000 Days approach, the scope of women is both *limited* to their roles in reproduction and child care and also *limiting* in that it seems natural to all parties involved that women and women alone are found within this sphere. Mothers as targets of interventions rather than partners and beneficiaries dehumanizes women’s bodies. To work with maternal and child nutrition in a genuinely gender-transformative

way, we have to acknowledge the delicate balance of working with maternal health as a unique area of vulnerability, priority, and celebration of women while also not limiting our conceptualization of women to the process of motherhood. Building on the works of Bourdieu and others regarding how social structures are constantly being reproduced through people's beliefs and practices, we find that there is potential for critically informed research on neglected topics as a part of modifying priorities and mobilizing for social justice. The 2008 *Lancet* series on maternal and child undernutrition was groundbreaking as an extremely influential piece of public scholarship that pushed the agenda for maternal and child nutrition forward. With the First 1,000 Days approach to nutrition revealing its systemic neglect of women's health beyond that of their children, it is time to push further. Without minimizing the importance of child health—since health is not a zero-sum game within human rights frameworks to health—there is a need to ground the future-looking narrative of hope to the present, to the life of the mother as a woman whose health and well-being has its own intrinsic worth.

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A Right-to-Health Lens on Perinatal Mental Health Care in South Africa

SHELLEY BROWN, GILLIAN MACNAUGHTON, AND COURTENAY SPRAGUE

Abstract

South African women experience some of the highest rates of depression and anxiety globally. Despite South Africa's laudable human rights commitments to mental health in law, perinatal women are at high risk of common mental disorders due to socioeconomic factors, and they may lack access to mental health services. We used a right to mental health framework, paired with qualitative methods, to investigate barriers to accessing perinatal mental health care. Based on in-depth interviews with 14 key informants in South Africa, we found that (1) physical health was prioritized over mental health at the clinic level; (2) there were insufficient numbers of antenatal and mental health providers to ensure minimum essential levels of perinatal mental health services; (3) the implementation of human rights-based mental health policy has been inadequate; (4) the social determinants were absent from the clinic-level approach to mental health; and (5) a lack of context-specific provider training and support has undermined the quality of mental health promotion and care. We offer recommendations to address these barriers and improve approaches to perinatal mental health screening and care, guided by the following elements of the right to mental health: progressive realization; availability and accessibility; and acceptability and quality.

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The Sustainable Development Goals (SDGs), adopted by the United Nations General Assembly in 2015, included the promotion of mental health on the global development agenda for the first time, signaling the rise of mental health as a policy priority for the global community.¹ Mental health remains a significant human rights concern that negatively affects a large number of women globally. Depression, for example, is a leading cause of disability worldwide; approximately 264 million people live with depression, and more women than men are affected.²

Common perinatal mental disorders, including depression and anxiety, during and after pregnancy affect an estimated 10%–13% of women in high-income countries and 15.6%–19.8% of women in low- and middle-income countries.³ Prevalence estimates vary greatly across contexts, in part because they depend on how researchers define the perinatal period and whether they use screening or diagnostic data to estimate prevalence.⁴ Mental illness, especially in perinatal women, affects women's capacity to work, interact with family, fulfill social and community roles, and achieve overall well-being, with detrimental effects for women and their families.⁵ Poor mental health in pregnancy, if untreated, also undermines the health of infants, in part through higher risk of prematurity and low birth weight; and, exposure to maternal depression in utero can have lasting negative effects on the developing brain.⁶ Postpartum depression has been linked to poorer emotional regulation in children through less responsive and attuned relationships between mother and child.⁷ There is less attention in the literature to the impacts of maternal anxiety on the child, but research suggests that maternal depression, anxiety, and stress during pregnancy have potential long-term impacts on the baby and mother.⁸

Effectively addressing mental health requires a multisectoral approach that includes attention to the social determinants and lived experience of mental health. In his 2019 report, Danius Pūras, United Nations Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health (right to health), high-

lights the critical role of the social determinants of mental health—especially relationships and social connection—to realizing the right to mental health.⁹ In addition, the World Health Organization launched QualityRights training and guidance in 2019, which promotes the active engagement of and support for civil society to build capacity among all stakeholders to improve mental health systems and services.¹⁰ Both the Special Rapporteur's report and the QualityRights initiative emphasize that transforming mental health requires person-centered, human rights-based approaches within and outside the health care sector. For many people, quality mental health care is not available or accessible; and mental disorders, when left untreated, can have significant consequences for one's quality of life, physical health, and even risk of suicide.

South Africa is a highly relevant context for an investigation of perinatal mental health and human rights because South African women experience some of the world's highest rates of common perinatal mental disorders. Relative to women in high-income countries, they are almost three times as likely to experience mood and anxiety disorders during the perinatal period. The prevalence of women living with or at high risk of depression in South Africa is an estimated 21%–39%, and the prevalence of postnatal depression is an estimated 16%–32%.¹¹ And, according to one recent study, the prevalence of anxiety disorders among South African pregnant women is 23%.¹² Complex biological and social determinants position South African women uniquely for risks of adverse mental health during the perinatal period. The post-apartheid socioeconomic and cultural context, combined with 30% HIV prevalence in pregnant women, high prevalence of food insecurity, and an increasing non-communicable disease burden, increase the risk of poor mental health.¹³ Importantly, the prevalence of intimate partner violence during pregnancy ranges from 15% to 38%. Research in South Africa shows an association between such violence and an increased risk of antenatal anxiety and depression; and an increase in the severity of intimate partner violence is associated with increased depression symptom severity for pregnant

and postpartum women.¹⁴ These and other risk factors combine to substantially increase the risk of perinatal mental illness—especially in the absence of rights-based, holistic mental health promotion and access to mental health services.

The traditional, still dominant, model for understanding mental disorders is biomedical in orientation, viewing mental disorders as diseases of the brain and rooted in biology, which largely ignores the underlying social determinants of mental health.¹⁵ There is growing evidence, however, to explain the ways in which social determinants shape mental health and how action to promote population mental health, using a rights-based approach at all stages of the life course, could significantly improve physical and mental health.¹⁶ Audrey Chapman stresses the need for more attention to the social determinants of health when focusing on the right to health:

If the human rights community wants to improve the health status and health outcomes throughout the society, as well as to protect the interests of vulnerable and disadvantaged groups, it will need to pay more attention to differences in social, economic, and political status and their underlying causes and mechanisms.¹⁷

South Africa has embraced a human rights approach to mental health in law and established a mental health policy framework, yet struggles to build a “culture of human rights.”¹⁸ Antenatal care attendance in South Africa is high, serving as an entry point to connect women to an array of supports within and outside the health sector, with a focus on comprehensively addressing mental health and well-being.¹⁹ The National Department of Health periodically issues a manual that provides guidance on maternity care in South Africa; the most recent version provides for routine postnatal care, including postnatal visits at 3–6 days and 6 weeks postpartum to assess women’s mood and general well-being.²⁰ Despite these advances, a complex set of mental health determinants persists, contributing to perinatal mental illness among South African women. To address perinatal mental health

as a health and human rights concern, we identify the core obligations of the South African government concerning the right to mental health, with a focus on the perinatal period (Table 1). Guided by these core obligations, we then present findings concerning the obstacles to accessing perinatal mental health care based on in-depth interviews with 14 key informants with expertise in perinatal mental health in South Africa. To address the obstacles identified, we recommend a shift toward a more holistic, human rights-based approach that would better realize the right to mental health for perinatal women in South Africa. To that end, we present brief recommendations, communicated by key informants, to advance this shift (Table 2).

The right to mental health in South Africa

In 2015, South Africa ratified the International Covenant on Economic, Social and Cultural Rights, which enshrines the right to the highest attainable standard of physical and mental health. The covenant recognizes that in many countries it is not possible to fully realize the right to health for all immediately. Consequently, it provides for state parties to take steps, to the maximum of available resources, to progressively realize the right to health over time.²¹ In 2000, the Committee on Economic, Social and Cultural Rights, responsible for monitoring implementation of the ICESCR, published General Comment 14 to elaborate the normative content of the right to health, thus guiding states on the implementation of their treaty obligations concerning the right to health.²² General Comment 14 states that the right to health is an inclusive right to timely and appropriate health care and the underlying determinants of health.²³ It also specifies that “progressive realization” means that “States have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of article 12,” and that each state must take “deliberate, concrete and targeted” steps to the maximum of available resources.²⁴ Further, the general comment provides that health care and the underlying determinants of health must

be available, accessible, acceptable, and of good quality.²⁵ Along with progressive realization and maximum available resources, these traits—commonly known as AAAQ—are the key elements of the right to health. Table 1 describes these elements.

South Africa's 1996 Constitution includes provisions on the right to health care services, which reflect the international right to health. Article 27(1) states, "Everyone has the right to have access to health care services," and article 27(2) provides, "The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights."²⁶ Additionally, South Africa adopted the Mental Health Care Act in 2002, which has a patient-centered and human rights orientation.²⁷ This law requires that any person needing mental health care services receive appropriate treatment or receive a referral to a health establishment that provides the appropriate mental health care.²⁸ Furthermore, South Africa's National Mental Health Policy Framework and Strategic Plan 2013–2020 promises, "The human rights of people living with mental illness will be promoted and protected through the active implementation of the Mental Health Care Act (2002)."²⁹ Full implementation of

the plan was to be realized by 2020; however, delivering on this promise in practice has been hindered for many reasons, particularly a lack of funding.³⁰

Integration of mental health into primary health care and antenatal care in South Africa

The prioritization of mental health globally has included the integration of mental health into primary health care and community-based settings, as outlined in the World Health Organization's *Comprehensive Mental Health Plan 2013–2020*.³¹ Due to limited resources dedicated to mental health, South Africa largely relies on task-shifting (or task-sharing), whereby nonspecialist providers address mental health in primary care settings.³² While task-shifting benefits include the reduction of stigma and disparities and more routine access to mental health services, a multicountry study highlighted the need for more mental health training for nonspecialist providers, in addition to resources, to mitigate the risks of overburdening nurses and other health professionals.³³ Another study conducted in 40 rural and urban maternal-child health clinics across four districts in South Africa

TABLE 1. Elements of the right to mental health

Progressive realization and maximum available resources	<i>Progressive realization</i> means that states must take deliberate, concrete, and targeted action, to the maximum of available resources, with a view to achieving the right to mental health.
	<i>Maximum available resources</i> means that states must prioritize revenue raising and the allocation of necessary resources toward fully realizing the right to mental health.
Availability and accessibility	<i>Availability</i> means that states must ensure the existence of sufficient health care services and the underlying determinants essential to mental health promotion. Health care must include integrated and coordinated services for promotion, prevention, treatment, rehabilitation, care, and recovery. That includes mental health services integrated into primary and general health care, which support early identification and intervention and are designed to support a diverse community.
	<i>Accessibility</i> means that states must ensure that mental health services and the underlying determinants of mental health are accessible to all, with particular attention to nondiscrimination, economic accessibility (affordability), geographic accessibility, and physical accessibility. Accurate information on mental health must be made accessible to the public.
Acceptability and quality	<i>Acceptability</i> means that states must ensure that mental health services and the underlying determinants of mental health are acceptable to affected individuals and communities (including by being sensitive to cultural, gender, and life-cycle requirements) and designed to empower individuals to make informed decisions about their health and well-being.
	<i>Quality</i> means that states must ensure that goods and services provided to realize the right to mental health are of good quality. This requires the use of evidence-based practices to support prevention, promotion, treatment, and recovery. Effective collaboration between service providers and people using the services, as well as families and partners, ensure enhanced quality of care.

similarly revealed that a lack of provider training for mental health undermined the integration of mental health into primary care.³⁴ Long-term and locally delivered mental health training in South African primary care settings has shown promise to improve the quality of care in practice, but shorter-term training remains more typical, despite evidence demonstrating that it is less likely to translate into changes in clinical practice.³⁵

In 2019, a study conducted in all nine provinces and at all levels of the South African public health system found that inpatient and outpatient mental health services represented only 4.6% of the total health budget, with inpatient care accounting for 86% of this budget.³⁶ The study also found insufficient numbers of mental health professionals, infrastructure, medication, and supplies, all constraining realization of the right to mental health guaranteed by law. Crucially, the National Mental Health Policy Framework and Strategic Plan does not explicitly require reporting on progress, which means that the true burden of mental illness and effectiveness of mental health care are unknown.

The literature has also documented the powerful role that nurses can play as agents of change in health care settings, while serving as health care providers to patients from similar communities.³⁷ Critical contextual factors associated with maternal health care delivery in South Africa, however, also include the mistreatment of patients by nurses.³⁸ Factors explaining this abuse are complex and can include nurses' own experiences of trauma and intimate partner violence.³⁹ South Africa's Perinatal Mental Health Project, which provides training designed to engender an ethos of care and compassion in maternity settings, has observed that "a complex mix of power and marginalization ... plays out at the micro-level of nurse-patient relationships."⁴⁰ The provider-patient relationship in South Africa is crucial to understanding how to improve the quality of perinatal mental health care through a patient-centered and human rights-based approach.⁴¹

Despite the importance of incorporating the right to mental health into policies and practice in

South African clinical settings, the literature examining mental health and human rights in practice is slender. In one study, based on 11 semi-structured interviews with health professionals and administrators, researchers in the Eastern Cape Province used the AAAQ framework to understand the integration of mental health into primary care and identified 11 barriers to realization of the right to health for people living with mental disabilities, including a dearth of staff training, a lack of organizational capacity, and an insufficient number of providers.⁴²

Our research is located in this mental health and human rights opening. South Africa's National Mental Health Policy Framework and Strategic Plan 2013–2020, which guides mental health policy implementation for the provinces through 2020, is due to expire this year. This juncture therefore presents a timely window of opportunity to revisit the promise of the plan and to reevaluate policies governing clinical practice to promote mental health for perinatal women, particularly in antenatal care settings.

Approach and methods

We used a right to mental health framework to investigate barriers to accessing perinatal mental health care. Our study received ethical approval from the University of Massachusetts Boston's Institutional Review Board. Data collection included a document review and in-depth interviews with 14 key informants using a semi-structured guide. Our document review included international legal instruments, South Africa's Constitution, and laws and policies on mental health. This laid the groundwork for interviews. We developed the interview guide using the right to mental health framework outlined in Table 1. We obtained verbal informed consent from participants prior to conducting and recording interviews. The interviews were conducted via Skype and Zoom from September 2019 to March 2020 with key informants with expertise in perinatal women's health. The 14 key informants included three medical doctors; three

birth and postpartum doulas; two psychologists specializing in maternal health; two mental health academics; two nurse-midwives; a certified mental health counselor; and a government maternal health professional. Digital recordings were stored and encrypted in a password-protected location requiring authentication. Recordings were transcribed verbatim, and we coded and analyzed data based on preliminary themes emerging in accordance with selected elements of the right to mental health.⁴³ We used a code-recode strategy to capture the dominant themes and to arrive at our final set of analytical findings.

Findings and discussion

Below, we categorize the findings from key informant interviews across the interconnected elements of the right to health as (1) progressive realization and maximum available resources, (2) availability and accessibility, and (3) acceptability and quality. At the conclusion of each of these three subsections of findings, we discuss the contribution to knowledge and highlight key implications for policy and practice.

Progressive realization and maximum available resources

Three analytical themes emerged related to progressive realization and maximum available resources: first, clinicians view mental health care and screening as less important than physical health care and screening; second, the allocation of resources to mental health is inadequate to ensure minimum essential levels of mental health screening and care; and third, the implementation of mental health policies in clinical practice has been inadequate.

Most respondents remarked on the lack of equivalence between mental and physical health. Participant 3 questioned, “Why are we exceptionalizing physical health care above mental health care?” This lack of parity between mental and physical health was described as most pronounced in screening for mental health during antenatal care visits. Mental health screening is recommended but was viewed as separate and not as important

as physical health screening. One participant explained:

We’ve got high rates of rheumatic fever, diabetes, obesity, hypertension. There’s going to be concentration on issues like that, and that mental health screen is probably going to be left behind for the last minute or so of the visit. (participant 4)

Notably, informants mentioned that mental health is relegated to a lower status, receiving fewer resources and attention because it is less tangible than physical health concerns. This hierarchy of importance is evident, according to several respondents, in the lack of resources devoted to promote mental health and address the rise in maternal suicides. One participant remarked:

The number of deaths due to suicide are increasing. Because the other deaths overshadow the suicide deaths, we tend to concentrate more on other conditions such as HIV, hypertension and hemorrhage. I think the reason for this is resources and then also priorities. Although mental health is a priority, we’ve got other big issues as well. (participant 4)

A second challenge identified was the health system’s lack of resources for the prevention of mental illness and the promotion of mental health. On this subject, one interviewee, who works closely with midwife obstetric units and district hospitals, referred to the World Health Organization’s health system building blocks when discussing systems issues. She explained:

[T]he other thing ... that you must bring into the equation is the functioning of the system, where clinical governance is one, but the supplies and the documentation that needs to take place, and enough staffing. So it’s the human resources, the drugs, the supplies, the physical environment and so on. Those all play a big role in how this woman that is arriving with a problem will be screened. (participant 10)

A third barrier identified by respondents was the weak implementation of the National Mental Health Policy and Strategic Framework despite the

strong human rights commitment in South Africa's mental health law. One key informant recounted:

I do despair, and I get absolutely furious and angry. It's disgusting and shocking, and a human rights violation that we have a mental health policy in this country, which was signed off in 2013, which hasn't been implemented. There's all sorts of fabulous provisions, and it took millions ... of rands to get various stakeholders to develop this policy and to ratify it and discuss it and have meetings and, as with many of the policies in South Africa, it looks fabulous on paper. (participant 3)

Related to policy implementation in clinical practice, interviewees noted that it is difficult to make substantial progress because habitual behaviors of health professionals are deeply embedded. Three respondents referred to a well-known study that found it can take, on average, 17 years to translate evidence-based findings into clinical practice and that it is understandable to expect progress to be slow.⁴⁴ As one respondent recalled:

A lot of issues are culturally ingrained in South Africa, combined with poor facilities and lack of resources. How do you then accelerate progress and change? It is difficult and research has shown it takes 20 years to adopt new practices. (participant 7)

Translating policies into practice takes time and is understandably challenging. One key informant with extensive experience in policy implementation in district hospitals explained the need for champions of mental health in maternal health clinics to role model how mental health care policies should be implemented in practice.

Discussion: Knowledge contributions and implications. States must take deliberate, concrete, and targeted action, to the maximum of available resources, and must prioritize the allocation of resources toward full realization of the right to mental health. South Africa's National Mental Health Policy Framework and Strategic Plan 2013–2020 affirms that “the human rights of people living with mental illness will be promoted and protected, through the

active implementation of the Mental Health Care Act” by 2014. We found, however, that this was not the case for perinatal mental health. The low allocation of resources to mental health overall, also found in previous studies, reduces the availability of staffing and supplies necessary for policy implementation.⁴⁵ Our findings substantiate that mental health lacks commensurate status relative to physical health in clinical practice in South Africa, despite recognition in law and policy that the right to health includes both physical and mental health. This lack of parity is apparent in the allocation of resources, including funding, supplies, and staffing, and in health provider decision-making in clinical practice, which is rooted in norms and deep-seated cultural practices. These norms and practices, according to respondents, result in physical health frequently taking precedence over mental health during antenatal visits.

The recommendations that emerged from the interviews included the need for increased mental health leadership at the district and subdistrict levels. Informants proposed that meaningful change be made by identifying leaders who are passionate about mental health care, willing to serve as role models, eager to champion efforts to promote perinatal mental health, and prepared to train others. This approach could be implemented within existing resources, while longer-term efforts should be focused on ensuring mental health parity with physical health, identifying additional resources for mental health promotion and mental health care, and developing a stronger system of accountability, including indicators and targets with specific deadlines and reporting on obligations.

Availability and accessibility

Two major themes related to the availability and accessibility of mental health care emerged from the data. First, there are insufficient numbers of antenatal health care providers in the public health system, which reduces opportunities to identify mental illness in women. Second, there are insufficient numbers of mental health care providers to whom women can be referred and an uneven distribution of providers across provinces, making

mental health care even less accessible to women in some provinces.

The absence of sufficient numbers of health care providers for women was apparent to respondents. Women in need of antenatal care often wait hours in long queues before seeing a nurse. Although women have access to health information through MomConnect, a mobile health app for pregnancy launched in collaboration with the National Department of Health, and access to a national counseling hotline called LifeLine, one respondent noted:

[W]ith respect to actually being able to meet with a clinician, physically, that is much harder ... We just don't have the coverage that we need. There's not enough people in the right places. (participant 6)

When women access providers for their first antenatal care visit, they should have a comprehensive examination and history taken. However, according to respondents, due to high patient volume, the high demand for services, and many required components of the visit, there are insufficient numbers of providers. Consequently, this places a burden on nurses providing care, who have to choose between providing the full protocol to only some patients, or reducing the care provided to see all patients. One respondent explained:

[I]f it's one nurse and she has 30 or 50 new first visit ladies ... announcing their pregnancy for the first time, and because of our HIV burden, the first visit should take you an hour. But now, there's one nurse, and there's 50 patients outside. But that's not the only burden, there's another 60 that's coming for their second and third visits. (participant 10)

Increased mental health screening during antenatal visits would, however, increase the need for referral resources. Almost every key informant mentioned the need for more referral resources to specialist providers and social support services, including in postnatal care, along with improved capacity building to deliver mental health services. As one respondent highlighted:

[T]here is a lot more we can do in terms of mental health screening, upscaling our care and treatment and also then the referral system ... There's a lot more that we should be doing in terms of maternal mental health and caring for these women. We're going to have to increase the resources out there, the other support services, social workers, psychiatric, psychological services, and that hasn't been done yet. If we're screening more, we're going to have to treat more and increase the other support services and structures. (participant 4)

Additionally, several respondents noted that it is important to support women by facilitating the connections to the referral resources rather than simply handing women a piece of paper with referral information. One informant advocated:

It's not good enough for us to tell them, "I do actually know someone who [can help]. I'll give you her number, she can call you." We need to help make these connections for them. I think that's how we are going to get people the help they need after trauma. (participant 13)

Respondents indicated that if a woman did receive a referral, it would likely be to a junior medical officer or psychiatric nurse who would typically prescribe medication but not counseling, aligning with a narrow biomedical approach to mental illness.

Another impediment to accessing care through referrals was the variation across provinces. Patients in better-resourced provinces are more likely to gain access to care than those in provinces with less robust health systems. Respondents found such inequalities concerning:

In South Africa, there's actually quite a big discrepancy in resources and health worker distribution among different provinces. For example, if you look at the Western Cape, there are quite well-resourced structures in place, and there's a system and a referral route where the patient will be able to go to. But if you go to a province such as the Eastern Cape, Mpumalanga or Limpopo, where the health system is not as well organized, women are going to fall through the cracks, even if they are screened, [they] may not get the treatment or care that is desired. (participant 4)

Discussion: Knowledge contribution and implications. Availability and accessibility mean that states must ensure that sufficient health services and the underlying determinants of mental health are accessible to all with attention to nondiscrimination, economic accessibility (affordability), geographic accessibility, and physical accessibility. Our study confirms existing research that insufficient numbers of providers in South Africa are a barrier to accessing mental health care.⁴⁶ Moreover, we found that the understaffing of nurses and their resultant heavy workload, especially (but not only) in antenatal care, resulted in insufficient time for nurses to focus on the mental health of women in their care. Similarly, respondents emphasized the urgent need for more specialist mental health providers, the development of stronger referral networks, and a focus on the support of nonspecialist providers who can promote mental health during antenatal care visits.

Screening for perinatal mood and anxiety disorders is being integrated into primary and antenatal care in South Africa through a locally validated and tested ultra-short screening tool, which provides an opportunity to identify those who might need referral for additional assessment or services.⁴⁷ However, according to respondents, if providers do not have functional referral networks, they might be less likely to screen. The decision not to screen due to poor referral networks discriminates against those in lower-resource locations with few options for referrals. It also distorts the evidence base, as without screening there is no record of the need for mental health services—data that could be used to advocate for further funding and additional providers. Additionally, we found that providing referrals to perinatal women may be insufficient to ensure that they connect to essential resources. Therefore, efforts should focus on building strong networks and directly linking women to further support.

Acceptability and quality

Two key themes emerged related to the acceptability and quality of mental health care. First, there is a need to address the social determinants of health

underlying perinatal mental health, in addition to physical health. Second, training is needed in at least two key areas: integrating mental health into clinical practice and ensuring that the provider's mental health issues do not diminish the quality of care.

Several respondents urged a more holistic approach to engaging women in quality mental health promotion by attending to the social determinants of health. One common theme that emerged was that better integration of the social determinants into clinical practice was essential for improved mental health care. A mental health provider confirmed this need, stating:

Addressing perinatal depression needs to include social determinants of health and well-being. Engaging social determinants of health needs to be integrated into [the] workload, and at a practice level, this needs to be prioritized. For example, if someone doesn't have housing, and they tell their provider, the provider needs something tangible to be able to refer the patient to. Social determinants of health is equally impactful, but providers do not know what to do. (participant 1)

A nurse educator shared similar thoughts on the necessity of integrating the social determinants of health both into workload and clinical practice. She also highlighted the importance of contextualizing what patients' lives are like and empowering nurses to think of ways they can support the whole person, with special attention to the role of the social determinants of health:

A lot of people present with conditions where there [are] a lot of underlying social determinants ... [S]ometimes it is a bit difficult to try and conceptualize what they can do as a nurse. You can't work in an environment where these issues are prominent and not acknowledge and recognize the influence of them. (participant 9)

However, respondents communicated a lack of emphasis on the interconnection among determinants such as gender-based violence, food insecurity, lack of basic resources, and mental health issues:

Challenges which are enormous, like gender-based violence, and corruption, and food insecurity, and

a lack of access to basic resources ... Mental health is the Cinderella among ... these big problems. I don't get a sense there is that appreciation of the vicious cycle of these colliding epidemics, nor the potential for the virtuous cycle. (participant 3)

Providing acceptable quality care includes attention to gender and life cycle requirements, and interviewees suggested working more holistically to provide better support systems for mental health in the perinatal period. One respondent suggested a possible solution: "If each doctor's office had someone to walk your journey with you, touch base with and ask those questions that you want to ask, mental health would improve" (participant 7).

Many informants emphasized the need to focus on the whole person in clinical settings and believed there was a need for more provider training on the importance of moving away from a disease-oriented focus on the most visible issues, such as high blood pressure, to a more holistic approach. One informant recounted:

There is a need for some training that will make it meaningful for health professionals to link up and to understand that one works with a full person, not only with the mother's blood pressure and a baby that's growing inside her. And that she has a mind of her own that's maybe not doing very well. And how do you then make sure that this woman receives some extra care? Not only physical care, but mental health care. (participant 10)

Other respondents voiced concerns about a lack of training on how to address mental health in pregnancy and postpartum, especially in light of the extensive training and protocols that doctors and nurses receive to address obstetric emergencies. One informant explained:

Our training is not specifically for mental health screening. We do detailed training for obstetric emergencies, and unfortunately, the mental health screen is not in that. It would be great if we can include the mental health screen as part of this. Provinces are rolling out training on how to explain the maternity case record and how it should be filled in and to give clarity on the changes. I think we're probably lacking in the

training and we're not doing detailed and specific mental health screening. (participant 4)

Another barrier identified was the impact that the provider's mental health and potential burnout might have on the quality of mental health care provided to patients. Respondents pointed to health providers' often unresolved mental health needs as critical in how they carry out mental health care. One informant commented on the lack of attention paid to provider mental health and the impacts that this might have on patients: "Why should we worry about somebody else's mental health when nobody worries about ours?" (participant 5).

Providers' mental health was seen as a barrier to integrating evidence-based practices for mental health. As one key informant explained:

I think a lot of the barriers I'm hearing about, ... integrating this kind of evidence base into their thinking and decision-making, may well have to do with their own mental health issues. So when you come to them and you speak about mental health, it evokes a kind of defensive shutdown response ... This happens at ... coalface when you are speaking to midwives or nursing sisters who are providing services, but ... it equally applies to high-level decision makers. (participant 3)

One respondent with 16 years of experience supporting women during pregnancy and childbirth in government hospitals described providers' mental health as a multilayered concern warranting further attention. Over the years, she witnessed many perinatal care providers using coercive tactics, which undermines the quality of care that women receive and can result in trauma for patients. She suggested that those who resort to such tactics have unresolved issues, which results in pain and self-protection and might manifest in their patient interactions.

Discussion: Knowledge contribution and implications. The acceptability of mental health services is a subjective assessment by individuals and communities concerning the extent to which services provided are culturally acceptable and sensitive to

gender and life stage. Quality mental health services require adequate supplies; providers with necessary skills and training; acceptable standards of care; and treating patients with respect before, during, and after the provision of care. Our study found that there is a lack of attention to the drivers underpinning patients' and providers' mental health. Respondents recommended a shift in practice to provide better support systems for women's mental health promotion across pregnancy, childbirth, and postpartum. General consensus converged on the need for a more holistic approach to engaging women in quality mental health promotion through attention to the social determinants of health. Additionally, this research highlights the importance of addressing the mental health needs of health providers both as rights-holders themselves and to mitigate the impacts that their mental health care needs have on the quality of care they provide to perinatal women. It is necessary to work toward an ethos of care to better support all women.

One recommendation actionable in the short-term was to identify patient-centered mental health supports during the perinatal period, including doulas, peer counseling, and support groups. Doulas focus more broadly on the well-being of women, while peer counselors draw on their own experienc-

es of mental illness and recovery to provide support to individuals facing similar experiences. Both offer a relationship of care and social connection, which is a key underlying determinant of the right to mental health. Individuals in these roles work collaboratively with nurses, midwives, doctors, and mental health professionals.

Study limitations

The main strength of this study is its application of a right to mental health framework to empirical research conducted among perinatal mental health experts, which advances our understanding of real-world challenges to accessing perinatal mental health care and realizing human rights in practice in the South African social context. Further, the findings highlight significant opportunities to address existing gaps, with concrete guidance on ways to strengthen the implementation of mental health care and promotion in clinical settings. Study limitations encompass the following: (1) due in part, to the COVID-19 pandemic, we were able to conduct only a small number of interviews; (2) the majority of respondents were based in urban areas rather than less-resourced rural areas; (3) the views of other mental health professionals (such

TABLE 2. Key recommendations for advancing perinatal mental health

Progressive realization and maximum available resources	<ul style="list-style-type: none"> • Move toward a culture of parity for mental and physical health care • Increase resources for mental health • Establish champions of mental health in antenatal clinics who role model how mental health care policies are implemented in practice
Availability and accessibility	<ul style="list-style-type: none"> • Increase the number of mental health providers, develop stronger referral networks, and focus on training and supporting nonspecialist providers who can promote mental health during antenatal care visits • Ensure equitable access to referral resources across provinces • Integrate screening for perinatal mood and anxiety disorders into antenatal care through a locally validated and tested ultra-short screening tool • Provide mental health screening even in the absence of referral resources to build evidence of the need for further mental health services
Acceptability and quality	<ul style="list-style-type: none"> • Integrate opportunities for identification of and screening for social determinants of health in clinical practice • Work more holistically to provide better support systems for mental health throughout the perinatal period • Improve mental health education and training for all health professionals, including capacity-building to improve attitudes and practices to address mental health-related stigma and discrimination • Provide detailed guidance on engaging women in conversations about their mental health and delivering mental health screening as part of antenatal visits • Provide training and a system of support to address the mental health needs of health care providers, and to improve an ethos of care • Include mental health courses in nursing school and midwifery curricula, and provide opportunities for critical thinking and empowerment of nurses to address mental health

as psychiatrists, psychologists, and social workers involved in the routine implementation of mental health care) and perinatal women were not included in this study. Future research should capture the views of health providers implementing mental health care and, especially, the views of perinatal women receiving care to deepen the understanding of women's experiences and challenges to the realization of their right to mental health.

Conclusion

South Africa has taken significant strides to address women's perinatal mental health, including increasing the number of recommended antenatal visits and encouraging universal antenatal screening for common perinatal mental disorders. These are important steps for improving perinatal mental health in South Africa. Now is a crucial window of opportunity to revisit the National Mental Health Policy Framework and Strategic Plan 2013–2020, to provide stronger guidance on the implementation of policies and training for providers, and to increase the resources available for promoting perinatal mental health. The right to mental health can provide guidance to inform policy and practice, grounded in human rights-based approaches, to improve perinatal mental health promotion and mental health care in South Africa.

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Establishing Good Practice for Human Rights-Based Approaches to Mental Health Care and Psychosocial Support in Kenya

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Abstract

A human rights-based approach (HRBA) to health has long been seen as an important way in which to address public health needs in a manner that is equitable and conducive to social justice. Yet the actual content of an HRBA to health remains unspecific, and therefore implementation remains heterogeneous. This situation is even more challenging in the field of mental health, where human rights considerations are particularly complex and have emerged out of a history of myriad violations. Even when research has been conducted into mental health, it has focused predominantly on the Global North, raising questions of contextual and cultural relevance. Accordingly, this study examined the issue from the perspectives of stakeholders in Kenya who consider their work or the services they use to be rights based. It explored the key principles and interventions deemed to constitute an HRBA to mental health care and psychosocial support, the perceived benefits of such approaches, and the main barriers and supports relevant for implementation. The results produced seven key principles and corresponding interventions. Among other things, it highlighted the importance of economic well-being and self-efficacy, as well as the reduction of barriers to implementation, such as stigma and lack of adequate resourcing. Two key tensions were apparent—namely, the un/acceptability of coercion and the role of traditional and faith-based modalities in an HRBA to mental health care and psychosocial support.

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Introduction

For over 60 years, the health rights community has advanced the idea of an HRBA to attain health outcomes. Article 12(1) of the International Covenant on Economic, Social and Cultural Rights, a treaty that has been ratified by 171 countries, asserts the right of all people to the highest attainable standard of physical and mental health.¹ Scholars have subsequently noted that

the public health community has come to a largely shared perspective that a human rights lens on health helps shape understandings of who is disadvantaged and who is not; who is included and who is ignored; and whether a given disparity is merely a difference or an actual injustice.²

Despite this “largely shared perspective,” a common and universally accepted definition of what constitutes an HRBA has not been articulated. General Comment 14 by the Committee on Economic, Social and Cultural Rights provides interpretive guidance on the content of the right and establishes a now commonly utilized “AAAQ” framework, referring to standards of availability, accessibility, acceptability, and quality.³ Drawing on this and other instruments, the World Health Organization and the Office of the United Nations High Commissioner for Human Rights have adopted an HRBA consisting of the following elements: availability, accessibility, acceptability, quality, nondiscrimination, participation, and accountability.⁴

While these principles provide some guidance, it has been noted that such instruments adopt a “lowest common denominator approach, privileging consensus over specificity ... [Their] general nature has made it difficult to operationalize.”⁵ Content and specificity are required to actualize HRBAs via a focus on interventions as well as principles. Moreover, while HRBAs to health services have been a central preoccupation of public health approaches, it has been suggested that an HRBA to health may extend beyond the health system to broader questions of inequity, policy, and social exclusion:

*Human rights-based approaches, by their nature, cut across sectors and draw from multiple strategies. They might require legal or policy reform to create “enabling” environments; the identification and capacity-building of “rights holders”; comprehensive programs for education, health, and human rights literacy, advocacy, and empowerment; or the elaboration of more participatory accountability and oversight mechanisms.*⁶

Efforts to address health concerns from a rights perspective, therefore, may approach these challenges through avenues that address inequality, promote inclusion, and foster accountability, at times outside the realm of the health system. Officials in health and other associated systems should also pay due attention to the right to benefit from scientific endeavor on an equal basis.⁷ This is especially true in the present day, as the COVID-19 pandemic lays bare the many ways in which health rights are affected by issues of equity, inclusion, and accountability, and as activists, advocates, and scholars grapple with the question of how to imagine a more just world, including but not limited to the realm of health.

Mental health and human rights

Considerable human rights violations have been perpetrated within mental health systems.⁸ These have ranged from widespread neglect of people with lived experience of mental health challenges (also referred to as psychosocial disabilities) to incarceration and coercive treatments, often without any clinical validity.⁹ Problematic beliefs about mental health have been cited as some of the main drivers behind these erroneous and counterproductive ways of “caring” for people with psychosocial disabilities. These beliefs have ranged from supernatural attributions responsible for mental health conditions (that is, the belief that an individual is possessed or has been a victim of witchcraft) to conceptions of such conditions as manifestations of “feeble-mindedness.”¹⁰ Our everyday mental health vernacular is largely derived from the *Diagnostic and Statistical Manual of Mental Disorders*, now

in its fifth edition (*DSM-5*). It classifies the range of “mental disorders” and is utilized widely as a basis for providing services and for justifying insurance coverage.¹¹ These practices and tools have been criticized as overemphasizing the biomedical basis of mental health and offering little insight or support to address the psychological, social, cultural, spiritual, economic, and political determinants of mental health.¹²

Calls for a “human rights model” of mental health have become more vocal in recent years.¹³ Against this backdrop, in 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), the first comprehensive treaty on disability rights.¹⁴ One hundred eighty-one states have ratified the CRPD, reflecting near-universal adoption.¹⁵ In 2017, the United Nations Special Rapporteur on the rights of persons with disabilities reported that at least 32 countries were undertaking reforms to their mental health laws and policies to incorporate the paradigm advanced by the CRPD.¹⁶

Nevertheless, despite the emergence of rights-based mental health laws, compliance with them remains poor, particularly in low-income countries.¹⁷ Hence “the paradigm shift to the human rights model has yet to be reflected in implementation.”¹⁸ A review of the literature on the applied practice of HRBAs to mental health care and psychosocial support services (MHCPS) yielded just 10 studies in 2016, demonstrating the lack of a substantial body of research.¹⁹ Strikingly, this paucity is even more glaring in low- and middle-income country contexts and contexts where sociocultural factors may be different from the Western developed world, with just two studies referring to HRBAs to mental health in these settings appearing in this review.²⁰ Ensuring the cultural and contextual relevance of MHCPS services can also be an issue of health quality and health acceptability in terms of the AAAQ framework referred to above. For this reason, any attempt at articulating an HRBA requires contextual specificity and sensitivity to cultural and social norms.

Bearing in mind the need for specificity of context and a clear focus on implementation,

our study identified good practices in HRBAs to MHCPS services for people with psychosocial disabilities in Kenya. Recognizing that the HRBA is itself an amorphous, contextually bound concept subject to interpretation, the study’s aim was to elicit from respondents their own understanding of what an HRBA means. Using key informant interviews, we aimed to identify what, in the opinion of key stakeholders—and, prominently, people with psychosocial disabilities as mental health service users themselves—constituted the key features of rights-based MHCPS services. Similarly, we sought to identify key interventions of such an approach, along with practical barriers to and supports for implementing these interventions in the Kenyan context, where the mental health system is undergoing a transition to CRPD-aligned legislation but where mental health services remain underfunded despite their inclusion in universal health coverage provisions.²¹

Methodology

Study sites

We chose two organizations—the Kamili Mental Health Organization and the Home of Brains—as sites for this study based on their explicit orientation toward HRBAs to mental health in community-based settings. Due to space constraints, it is not possible to elaborate on the work of these organizations here, but more information is available on their respective websites and in the first author’s doctoral dissertation.²²

Interviews

We conducted 10 interviews as part of this study. These interviews emphasized the participation of mental health service users while also considering the experiences of other key stakeholders, including implementers, clinicians, and advocates. Our sampling of key informants was purposive, utilizing the assistance of the organizations. Key informants were chosen based on three main criteria:

- *Familiarity with the practices of the organization*
- *Diversity among interviewees (in terms*

of gender, educational attainment, and professional orientation or identity as a mental health service user or member of the organization's executive leadership)

- *Balance between sites (five interviews at each site)*

When we approached participants, we provided them with an introduction to our study, indicating that it was an interpretivist study concerned with stakeholder perceptions of what constitutes an HRBA to mental health. We sought their verbal consent prior to the interview. Eight interviewees were fluent in English, meaning that an interpreter was not necessary. For two interviews (one at each site), the aid of an interpreter was employed, including for the consent process. We developed a semi-structured interview schedule (available from the authors) to examine the nature of interventions and the values included in an HRBA and the perceived benefits of such an approach, and we used this as a guide for the interviews. Additional probing questions included those related to issues such as the barriers faced by implementers and the resource and capacity needs for implementation of an HRBA to MHCPS services. Interviews were between 30 and 60 minutes in length and were recorded and transcribed for analysis. We then undertook a process of interpretive data analysis following Robert Elliot and Ladislav Timulak's five-step method.²³

The Harvard School of Public Health granted an Institutional Review Board exemption for this study (IRB18-0839).

Results

We organized the interview data into three main categories: stakeholder perspectives regarding key components of an HRBA to MHCPS (sub-categorized into seven key principles and eight key interventions as outlined below); stakeholder opinions regarding the contribution and efficacy (that is, the impact) of an HRBA to MHCPS; and statements related to the barriers and supports to implementing such an approach (further subcategorized into supports and barriers).

Key principles

Mental health as a human right and the right to access mental health care. A common perception was that the experience of mental health and well-being is itself a fundamental human right (in other words, that no one, on any basis, should be faced with societal barriers to well-being). One participant noted:

The purpose is the guiding factor ... we want to ensure that people are healthy and we want to meet public health goals, [but] we want also to fulfill the right to mental health itself.

An HRBA to mental health and well-being must begin from a position that mental health itself is a right and that barriers to this right (including discrimination, violence, poverty, and unemployment) must be seen as rights violations. Similarly, the factors that contribute to its realization or lack

TABLE 1. Study participants

Site	Participant's identity	Gender	Level of education	Age
Kamili	Executive leadership	F	University	56
	Mental health service user	M	Two years of secondary school	28
	Mental health service user	F	Primary school	40
	Mental health service user and peer educator	F	Completed secondary school	32
	Psychiatric nurse	M	Nursing college	25
Home of Brains	Executive leadership	M	Doctoral degree	39
	Mental health service user and lay counselor	M	One year of university	21
	Mental health service user	F	Completed secondary school	60
	Psychiatrist	M	Completed medical training	36
	Mental health service user and lay counselor	F	Completed secondary school	30

thereof are key determinants not only of well-being but also of rights realization, reflecting the importance of the indivisibility of rights.²⁴ One such factor mentioned several times was the cost of accessing mental health services in Kenya.

A focus on dignity and autonomy. Participants conceived of dignity in several ways, ranging from the ability to participate freely in society to the way in which an individual is perceived by others. Similarly, autonomy was a key theme in the interviews, with respondents highlighting the value of this principle for the realization of mental health and well-being and as an inalienable right.

Despite the CRPD's assertion of equal recognition before the law (amounting to a prohibition of coercion), tensions remain in the realm of autonomy and decision making.²⁵ One respondent noted that she sometimes experiences difficulty in operationalizing autonomy as part of the organization's model:

Of course autonomy and decision making are important. We are here because too many people have been locked up, but sometimes we have to ... when someone is going to get hurt ... we have to.

This is illustrative of the fact that tensions continue to play themselves out in the realm of autonomy and decision making. Evidently, even when organizations are purporting to implement an HRBA, they may qualify or limit a right when they feel they "have to" because of the potential risk to the mental health service user or others, despite provisions in international human rights law that prohibit limitation of the right.²⁶

Access to information. Knowledge regarding human rights and mental health can significantly alter the way in which people with psychosocial disabilities are able to self-advocate or pursue their rights. This is in keeping with the principle of access to services and access to the benefits of scientific progress as part of the AAAQ framework.²⁷ One participant noted:

It starts with information. An [HRBA] requires that people know enough about their own rights and about their condition. Otherwise, they will not be

able to make informed choices.

Another participant echoed this point:

I cannot [access] my rights if I do not know about them, and I cannot understand my mental health if I don't know about it ... The truth is that people do not know enough, and I think this is a problem, especially in the hospitals.

A user-centered and -directed approach. "User-centricity" and "user-directedness" are closely linked with the ideas of dignity and autonomy, but they also appear to manifest as a more personalized and individualized idea. As one respondent noted:

Our model is about asking the person where they are ... and then finding ways to meet them there.

Another highlighted the following:

I am not getting all the same [support] that my friend is getting, and she is not getting some of the [support] that I am getting, because we need different things.

This illustrates that there is an emphasis on individualized support among respondents, aiming to "meet" mental health service users where they are and to recognize and accommodate difference. In essence, this is in keeping with the principle of acceptability as part of the AAAQ framework.²⁸

Right to family life and life in the community. Speakers believed community-oriented care and support to be especially important philosophical elements of an HRBA to MHCPs. For example, one individual remarked:

Why should we be separate? We are not animals [to be kept] in a zoo ... I want to be with others [in the community] ... and I can take my treatment [at the organization] and still live [among them].

Respondents also noted the key role that families play in promoting, preserving, and restoring mental health. One individual noted that

the family is the first source of community. Without

my family knowing and understanding my condition, I would be in a much worse position.

Prevention and the need to focus on social, economic, cultural, spiritual, and political determinants of well-being. According to participants, a focus on prevention is an important means through which to fulfill the right to mental health. When barriers to well-being are addressed, distress can be averted. One participant noted:

This is what makes a [HRBA] different ... We aren't only thinking about circumstances in treatment, we're thinking about the right to be healthy so that treatment isn't really necessitated.

An emphasis on the economic determinants of health in supportive interventions has, according to some respondents, a direct relationship with autonomy, as the following quotation suggests:

I am better because I have a way to feed myself and my family. I don't have that stress anymore, it has made me feel like the person I used to be.

Similarly, another important component of an HRBA to MHCSP is the way in which societies respond to mental health conditions, with the problems of stigma and discrimination being a significant source of distress and a significant human rights violation.

Accountability. Respondents highlighted that over and above a need to ensure that laws and policies accurately reflect an HRBA, they must be implemented and invested in by officials, and the commitments made by these duty bearers must be fulfilled. Referring to impediments to accessing services because of failures in laws and policies, one participant stated:

How can we be well if there is no one that cares enough about this? [The government] doesn't care.

In a similar vein, respondents noted that the health system, too, has a duty to be accountable to mental health service users, catering to their needs in ways

that are respectful and transparent. One individual stated:

I am the beneficiary, but sometimes [doctors and nurses] don't think they have any [duty] to me.

This is indicative of the apparent lack of accountability in traditional mental health systems, countered to some extent by more transparent approaches, expanded on as follows:

Our aim is to build the model and the care as a collective ... We try to do this periodically through participatory means ... It's still a work in progress, but our aim is to be accountable and responsive.

Interventions embodying the rights-based approach to MHCSP

Quality, affordable MHCPS. In a context where financial resources are limited and the ability to access care and support is determined by economic factors, the right to health is significantly compromised. As one individual noted:

How can I pay ten thousand [Kenyan shillings] each time I come for counseling? I would not have money for food. Without [the organization], I would not be able to see a counselor.

Fundamentally, and in keeping with the principle of quality in the AAAQ framework, respondents noted that an HRBA means that service quality is not sacrificed for the sake of affordability, as demonstrated by this statement:

We appreciate the fact that we need to work within our resources, so we try to be creative and actively look for ways to be more efficient ... but to change the level of attention a beneficiary receives or to deny them the same level of care that a [wealthier] person would get ... that would be discrimination.

The act of being “creative” with resources in this instance means finding ways to use the facilities of the government or other agencies or to promote peer support activities that emphasize the participation and efficacy of mental health service users themselves as a viable and possibly even preferable

alternative to over-reliance on specialist staff. Peer support activities can take multiple forms and reflect different models, but they share the same common factor of providing support from the perspective of someone with similar lived experience.²⁹ In terms of gauging the quality of services provided, one respondent stated the following:

We promote quality care in a number of ways, using our networks to continuously train staff, providing beneficiaries with the opportunity to change their treatment plans if they feel they are not effective.

A key part of the work is therefore continuous refinement of the HRBA to ensure quality service provision and democratic decision making concerning treatment and support options. This sentiment comports with the right to benefit from scientific endeavor, as noted above.³⁰

Community, peer, and family supports. Community-based mental health models eschew the possibility that people with psychosocial disabilities might be institutionalized or otherwise removed from their communities. This, according to one respondent, is a direct manifestation of an HRBA:

We aren't taking people away from [their communities]. We are coming to them because they have a right to live with their people.

Community-based interventions, however, are also about actually reaching the wider community, providing education that can help combat stigma, mobilizing resources to ensure service delivery, and addressing living conditions that might contribute to distress. Similarly, respondents spoke about the role of family supports, because often the family is the most direct determinant of an individual's well-being, a sentiment that is also reflected in the literature.³¹ As one participant said:

The family have a right to mental health too, and they can benefit from therapies or education. This has direct benefit to our beneficiary too. It's a sort of virtuous cycle.

Peer support was also mentioned as a key inter-

vention, because people living with psychosocial disabilities might utilize these activities to develop self-efficacy or might find that there are less paternalistic forms of support than traditional approaches. Peer support initiatives include group counseling, the formation of sports teams, and a collective to build autonomy and foster self-advocacy through the development of a user-led radio show produced and hosted by mental health service users. Additionally, a storytelling collaborative in the community was mentioned as one means through which mental health service users can build community. Peer supporters are volunteers in both organizations where the study was conducted.

Medical treatment as a support to psychosocial care. HRBAs, in the organizations visited, did not emphasize psychotropic medication as a preference over psychosocial supports. Instead, the organizations viewed medical treatment as one of several interrelated components of care and as a supportive mechanism for conducting other interventions. One participant noted:

We know that medicine can be an important thing ... but we also know that it doesn't really [achieve the objectives] of helping a person live a whole, happy, healthy life ... For those things, there's a lot more that needs to happen.

The assertion that “there's a lot more that needs to happen” is also borne out in the following quote:

When you go to the clinic, they give you your tablets and they send you away. How is that going to help me [realize] my rights? I need [the medication] but I also need to be able to work.

Education. Initiatives to operationalize the right to access to information include educating people with psychosocial disabilities as well as educating communities. One participant described the nature and purpose of these interventions as follows:

Our organization sees the provision of education around mental health and the rights of service users as an avenue to foster dignity ... We do this through publications, through radio shows and through

direct engagement, sometimes even door-to-door engagement.

The use of peer educators is also a useful model because it ensures that people with psychosocial disabilities become self-advocates and agents of change in their communities. One peer educator stated:

As a peer educator, I can offer something that others can't. I can speak about the experience from a perspective that a doctor can't. The doctors don't know how alone you feel.

Another key aspect is the incorporation of these models into formal mental health training. Supporting mental health training in universities and medical colleges can ensure that a human rights orientation is embedded in clinical practice.

Advocating for legal and policy change. Because Kenya's mental health system is in the process of transition, there is significant interest among the organizations in question to mobilize beneficiaries to claim their rights and to develop advocacy strategies to support reforms. One respondent stated:

Our [HRBA] is a bit of a mishmash because we think that being involved in the political space is as important as being involved in service provision. Our goal is to support our clients to become involved in these processes themselves.

This suggests that mental health organizations providing care and support also naturally advocate for the incorporation of HRBAs into broader systems through, for example, advocacy to promote improved resourcing for mental health or to promote community-based services in the new mental health legislation in Kenya.

Building livelihoods and meeting basic needs. Respondents were unanimous that supporting mental health requires an emphasis on economic well-being. One individual noted:

You can't claim that you care about rights and then not pay attention to people's right to work, or their

right to learn and become self-sufficient, or their right to food. How can anyone be mentally well if they have no source of income to feed themselves and their families?

Efforts to provide support for receiving an education, to provide work opportunities or other sources of income, and to promote food security can all be important and useful ways in which to promote well-being. Another speaker, applauding the cultivation of a community vegetable garden tended by mental health service users, noted:

The thing that I used to worry about the most, and that made me sick was how am I going to feed my children?

Access to justice and fostering accountability. Interventions to assist people denied access to their property and subjected to exploitation to seek redress are seen as part of an HRBA to MHCPS in the eyes of some of the interviewees. These interventions are closely aligned with objectives to educate people with psychosocial disabilities about their rights and to educate judicial officers and other officials about the rights of this population. In this sense, there is both a service provision and an advocacy component to an HRBA to MHCPS. A respondent noted:

Our mobilization is about participatory approaches to holding government to account ... We use various means to do so ... but our primary goal is to work with beneficiaries to claim their own rights.

Internally, efforts to foster accountability are equally relevant and require critical engagement with mental health service users and communities. As one respondent noted:

We actively seek out feedback and we use methods like informal and anonymous complaints-handling ... it can be a challenge to implement because people aren't really accustomed to participating in these kinds of mechanisms ... we are trying to plant the seeds.

Providing care and support that is sensitive and receptive to diversity and accommodating of difference.

The provision of gender-, culture-, and language-appropriate services is an important way in which MHCPS can be rights-based. Participants highlighted the specific needs of particular populations and the potential benefit that a more sensitive or diversity-inclusive approach can have. As one individual stated:

In the clinic, no one cares whether you are male or female, or whether you are Masai or Kikuyu. What if I need something [specific] because I am a woman or because I am Kikuyu? [The service provider] has to be [sensitive] to this.

The way in which organizations go about encouraging or implementing diversity-sensitive practices is multifaceted, focusing on training of staff to offer appropriate supports and to respond to varying needs, on building capacity in the organization that is diverse itself (including recruiting people with psychosocial disabilities), on ensuring access to interpreters, and on emphasizing the user-centered perspective as a means of individualizing the supports provided.

Some participants acknowledged the importance of culturally appropriate care and support but viewed traditional approaches to mental health with suspicion, arguing that these interventions may actually violate human rights. The following quote exemplifies this stance:

Sure, there are traditional services but they are problematic to be honest. You hear about people being chained and beaten or about their bodies being mutilated by these so-called healers.

Faith-based mental health interventions were the subject of some disagreement among respondents. One participant said:

It's really difficult to say. I think that churches and mosques are essential sources of community, so we want to connect with them as much as possible, but some of the things you hear that come out of them about mental health are really chilling.

The fact that “churches and mosques are essential sources of community” is clearly an important

point and an indication of the ways in which religious institutions might be partnered with when seeking to ensure a holistic approach to MHCPS provision. However, the “chilling” occurrences in some of these settings lead to the adoption of a cautious stance and, at times, to avoidance of faith-based models of MHCPS despite the need for sensitivity to diversity. This therefore represents a considerable dilemma for the implementation of HRBAs to MHCPS.

Stakeholder opinions regarding the contribution and efficacy of a rights-based approach to mental health

Dignity and self-esteem. Participants highlighted the effect of an HRBA on dignity and self-esteem. For example, one stated:

The primary purpose and idea behind an [HRBA] is this idea of dignity. I know it's difficult to operationalize or quantify, but you see it in the way that people live their lives, going back to work or advocating in civic spaces or becoming part of the organization as peer educators or lay counselors. I think you have to apply a bit of a subjective lens and say “I know it when I see it.”

Another participant stated:

When I was just going to the clinic, I would get sent home with medication and left alone for another month. I don't think they understand that I want to [participate in society]. They think that I can't or maybe they think that I don't want to.

Importantly, this individual is one of the participants who has since become a lay counselor and who views this as a testament to the validity of an HRBA.

The importance of a focus on social and economic determinants. Reducing stigma through community awareness-raising and education has been shown to contribute to improved mental health outcomes.³² This is borne out by the statements of participants. One participant stated:

It used to be so depressing hearing people call

me mad ... I think that [itself] used to make me unhappy and then I used to isolate myself more, and that used to make me more depressed. Now [with the public education campaign], I don't hear those names and I don't feel so isolated.

Addressing social circumstances can therefore contribute substantially to well-being. The same is true, according to numerous interviewees, of initiatives to address the economic determinants of mental health and well-being. In the words of one respondent:

I can honestly say that it has changed everything ... When we started doing these livelihoods programs, we found that people participated more and that they were becoming well faster and staying well longer ... it makes sense, because it is actually a core [component] of social justice.

Preventive benefits and the benefits (and possible limits) of autonomy. Participants also raised the contribution of an HRBA as a preventive measure, stating that it has the capacity to produce better mental health outcomes. This is exemplified by the following quote:

I don't use these five medications anymore. I don't get sick all the time the way I used to. When I was going to the hospital, I would get sick all the time...Now, I know when I am getting sick, and I can [take the necessary steps] to stop it [from getting worse].

The effect of the HRBA in this case has therefore, been relapse prevention, but it was also highlighted that the provision of appropriate information and the practice of care in the community may have equally beneficial implications.

Participants noted the substantial benefit to users of an autonomous model, based on information sharing and self-monitored care, although a key unresolved question relates to the subject of coercion, as demonstrated by the following quote:

Sometimes you need it, unfortunately...sometimes it can't be avoided...for people who are dangerous or who need protection, surely they have a right to be protected, and their health is better served that way.

The health effects of coercion are the subject of continuous debate, not unlike the situation described by researchers.³³ Even so, as the following quote suggests, the benefits of an HRBA can be realized even when these contentious questions remain without an axiomatic answer:

It's absurd to say that a rights-based approach isn't being operated because of some very real unanswered questions. We do what we know for sure, and the things we don't know, we try to engage with.

This also reflects a need for further documentation and elaboration of the clinical effectiveness of HRBAs and for further engagement with some of the complexities of applying this approach in prevailing systems.

The benefits to mental health service users and their families of peer and family supports. HRBAs to MHCPS incorporating a peer and family support component can aid in the development of self-efficacy among participants. This is highlighted as follows:

Now I am healthy myself but I also can help others ... I wouldn't know how to help them if it were not for [the organization] ... I would still be going to the hospital and getting told what to do like I am a child.

Peer education can be a meaningful way in which to foster self-esteem, while contributing to the mental health and well-being of others, as illustrated by the following quote:

[The peer groups] help me to share my feelings and make me think in a way that the clinic never did. I think that because of this my mind is more clear and I feel more supported.

Similarly, family support systems and services can have a direct impact on mental health service users while also contributing to more harmonized and supportive family systems. This can be a vital way to cater to family needs, using interventions such as family education, counseling, and caregiver training.

Empowering mental health service users to be self-advocates and to participate in society, including civic spaces. Respondents highlighted the fact that the ability to participate in society can be an indication of agency, which in turn contributes to well-being. The following quote illustrates this point:

It makes me feel better that I can use my own voice rather than asking the doctor or the nurse [to speak for me].

Beyond this direct benefit to users, speakers also highlighted that policies and laws benefit significantly from the input of the people most directly affected by them, in keeping with the right to participation in instruments such as the CRPD.³⁴ Therefore, the benefit of an HRBA is also its contribution to better lawmaking, in the process strengthening mental health systems.

Factors that impede the implementation of HRBAs to mental health care and support services

Stigma on the basis of psychosocial disability. Stigma on the basis of psychosocial disability continues to be a pervasive challenge, and it has the effect of causing mental health to be a neglected issue. One participant stated the following:

I don't think [the government] cares about [mental health]. I don't think it means anything to them because it's seen as a condition of the feeble-minded or the bewitched. Even among government officials, you hear these beliefs being repeated.

This indicates that stigma contributes significantly to the under-prioritization of mental health. With respect to HRBAs specifically, these appear even more marginalized because there remain segments of society who do not believe people with mental health conditions should possess the same rights as others. This is exemplified by the following quote:

You are talking about human rights and the [HRBA], but what happens if my neighbor does not think of me as a human being? What happens if my doctor does not think of me as a human being?

Lack of resources. Mental health is clearly a neglected priority, suffering from low levels of investment and social and political barriers that can at times render it difficult to meet the needs of people with psychosocial disabilities. Participants highlighted this as a major impediment to the advancement of HRBAs to mental health, noting, for example, that

we are talking about decades, perhaps centuries of neglect, and about needs that go well beyond the rollout of drugs. I don't think governments and funders are willing to admit that.

This speaker suggested that the biomedical approach was seen as a more cost-effective way to address mental health needs because it requires a more finite allocation of resources. An HRBA is, in the opinion of some, a more substantial ask because of the social supports that characterize it. This, however, was not a view shared by all participants, with one interviewee stating:

Actually I think these community-oriented models are actually cheaper to implement. They don't require new investment in hospitals or a lot of salaries for highly specialized staff and they aren't asking people to travel for miles and miles to access services.

It seems that further clarification is needed to consider what the actual resource allocation needs are for HRBAs to MHCPs, and whether allocating resources in this way is in fact more efficient than allocating for large-scale biomedical interventions that rely heavily on clinicians trained in models developed in the Global North, who may have a contribution to make but need not be the only human resource for health. This speaker also stated:

Even if they are more expensive, that is not the point ... The point is what is the right thing to do? What will create more cohesive and healthier societies in the long term?

Lack of research to support HRBAs. Research to establish standards in HRBAs and to build an evidence base to support the implementation of these approaches is sorely needed. This is a considerable

impediment to the rollout of HRBAs. As one interviewee noted, this problem is particularly acute in low- and middle-income countries:

There is very little [documented evidence] to show that HRBAs work in settings like Kenya ... Even if you can show that [HRBAs] are effective, people will say it's because they have all these resources in Sweden and Canada that we don't have here.

Further research to support the implementation of HRBAs to MHCPS in the Global South is needed. On the subject of monitoring and evaluation specifically, another individual stated:

We want to monitor effectiveness, and we want also to improve delivery, but this is costly and technical ... It's something we know we need to work on.

Organizational challenges. A number of inter-related challenges within organizations can have the effect of making it difficult to implement and further develop HRBAs to MHCPS. These include lack of technical capacity and the short lifespans of some of these organizations due to funding constraints. Additionally, resistance within organizations to certain aspects of an HRBA might be an impediment, as illustrated by the following quote:

One of things we are talking about is supporting people with these so-called alternative lifestyles ... transgender people and sex workers and so on ... ideally we want to ensure that anyone who needs a service can get it ... but we have to be aware that we are [operating] in a society that is conservative.

Factors that support the implementation of HRBAs to mental health care and support services

Coalition-building. Participants noted that they were able to make significant progress in building a community of practice to engage in HRBAs through building coalitions with like-minded organizations. For example:

There are some other organizations also working in this field, and this has had the effect of helping to create a coalition ... It makes advocacy easier.

In this way, organizations that share an interest in HRBAs to mental health can act as partners. Even so, interviewees acknowledged that this was not always the case, particularly when competition for resources is acute.

Self-advocacy by mental health service users.

Respondents noted that a significant supportive factor in developing and advocating for HRBAs to MHCPS services is the fact that these services are preferred and argued for by mental health service users themselves, as highlighted by the following quote:

I think there is no more powerful tool to advocate for HRBAs to mental health than having someone who has used such a service state unequivocally that it is the best way.

Ultimately, it seems that this enthusiasm for self-advocacy may also be somewhat tempered by doubts about the receptiveness of policy makers. Another participant stated:

When I share my story, I think sometimes they are surprised ... It makes them notice, but I wonder what happens after they have noticed.

Discussion

This research project identified key principles of HRBAs to MHCPS based on the perspective of stakeholders themselves. These guiding principles form the basis for an ethos that underpins HRBAs. The results have also demonstrated that while the guiding principles of numerous definitions of an HRBA are indeed useful as overarching themes, there is a need to add particularized context to those principles and to engage with the actual interventions that might be said to operationalize them. In keeping with criticism of many definitions of HRBAs “privileging consensus over specificity” and their general nature that makes them “difficult to operationalize,” the results show that it is in the interventions described and the actual programming contemplated that HRBAs become more implementable, making standardization for good

practice possible.³⁵

This study also focused on the key contributions that an HRBA to MHCPS can make, including a clear orientation toward dignity and autonomy, toward prevention, and toward the self-efficacy of mental health service users. Impediments to implementation—such as the need for further research, stigmatization among policy makers, and the lack of sustainable financing—were also highlighted by participants. At the same time, there were some encouraging signs related to the strengthening of user voices, opportunities for coalition-building, and a sense that while it is not clear whether HRBAs might be considered more or less cost-effective, they are unequivocally the “right thing to do.”

The findings of this study offer useful insight into the potential challenges and opportunities in low-resource settings, but the small sample size and geographical limitation to Kenya mean that the transferability of these findings might be limited. Circumstances such as cultural norms, provisions in law and policy, and social attitudes toward mental health might be substantially different in other settings, despite their low-resource status.

For this reason, multiple studies across contexts are needed. Tensions related to the role of coercion and the place of traditional and faith-based modalities in HRBAs have also been highlighted here, suggesting that further research would be warranted to capture nuances that were not possible in our study. A longitudinal study that seeks to establish the impact of HRBAs over time would also be an essential addition. Alongside an examination of the practice of HRBAs to MHCPS, there is arguably a need for an interrogation of the perception of these approaches among policy makers and funders to consider ways in which buy-in for them might be fostered.

What is made clear by our study is that an HRBA to MHCPS requires more than merely the elucidation of principles—it requires a clear sense of interventions to operationalize those principles and a strong understanding of local context. As more information is gathered and more practices are documented, the content of HRBAs to MHCPS will likely become more clear, and their contribution will be foregrounded. A necessary step will then also be the development of sound indicators,

TABLE 2. Key principles of a rights-based approach to mental health care and the interventions that can operationalize them

KEY PRINCIPLES	INTERVENTIONS							
	Quality, affordable mental health care and psychosocial support	Education	Medical treatment as a support to psychosocial care	Providing care and support that is sensitive and receptive to diversity and accommodating of difference	Community, peer, and family supports	Building livelihoods and meeting basic needs	Advocating for legal and policy change	Access to justice and fostering accountability
Mental health as a human right and the right to access mental health care								
A focus on dignity and autonomy								
Access to information								
A user-centered and directed approach								
Right to family life and life in the community								
Prevention and the need to focus on the social, economic, cultural, spiritual, and legal determinants of well-being								
Accountability								

appropriate impact assessment, and refinement to ensure that mental health service users benefit from monitoring and evaluation.³⁶ As a field where human rights concerns have been so pervasive, this should be welcomed and supported. This is true now more than ever, as policy makers and practitioners around the world grapple with the ramifications of the COVID-19 pandemic and seek out ways to imagine healthier, more equitable, and, ultimately, more just societies.

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Intimate Partner Violence, Human Rights Violations, and HIV among Women in Nairobi, Kenya

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Abstract

This study presents qualitative results from a mixed-method investigation conducted between May and August 2012 into the prevalence and consequences of four forms of intimate partner violence among women living with HIV who attended the Comprehensive Care Clinic at the Kenyatta National Hospital in Nairobi. As a part of the research, a quantitative survey found that among 600 sexually active women living with HIV aged 18–69, all reported experiencing emotional abuse; 20%, 17%, and 15% experienced controlling behavior, physical violence, and sexual violence, respectively. Qualitative research using focus group discussions with 19 women from the quantitative survey sought to contextualize these experiences and place them within a larger social structure where institutionalized gender inequality sets the tone for intimate partner violence against women in households. Participants reported that intimate partner violence led to their exposure to the virus and made them leery of disclosing their positive status or seeking support from a male partner for fear of a violent reaction. This fear and the socio-structural conditions in Kenya limit their ability to actively pursue comprehensive care, the stress of which can exacerbate symptoms and make managing the disease more difficult.

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Introduction

“The life I have led has been a life of struggle.” This statement, made by a participant in the study described below, captures the daily reality and lived experience of a woman living with HIV in Nairobi, Kenya. The set of conditions that defined her life prior to acquiring the disease has only been compounded by the difficulty of managing life with HIV, including maintaining her antiretroviral treatment and protecting her body from opportunistic infections, all while looking after her children and trying to ensure that their basic needs are met. This struggle, experienced by many in her situation, is multilayered and multifaceted. Poverty, stigma, structural violence, human rights violations, gender inequality, and interpersonal abuse all coalesce to put women at heightened risk of acquiring the virus and also serve to exacerbate symptoms and limit access to adequate health care once infected. This study presents the findings of the qualitative portion of an investigation into the prevalence and consequences of intimate partner violence among HIV-positive women attending the Comprehensive Care Clinic at the Kenyatta National Hospital in Nairobi.

The World Health Organization (WHO) identifies four forms of intimate partner violence, including physical, sexual, and emotional violence, and controlling behavior.¹ While several studies have considered the increased vulnerability to HIV exposure among women who experience intimate partner violence, few studies to date have evaluated all four forms of intimate partner violence among women living with HIV, with controlling behavior being the most often neglected category of intimate partner violence.² This mixed-method study considers the link between particular sociodemographic factors and the likelihood of experiencing a specific form or forms of intimate partner violence among women living with HIV in Kenya, home to the third-largest HIV epidemic in the world.³ The quantitative portion of this study surveyed a cross-sectional sample of 600 sexually active women living with HIV aged 18–69 on sociodemographic characteristics, health care decisions, and experiences of intimate partner violence with a current partner within the previous six months.

All participants reported experiencing emotional abuse from their partners. In addition, 20% of the sample reported experiencing controlling behavior, 17% reported physical violence, and 15% reported sexual violence. Women with lower socioeconomic status were more likely to report experiencing controlling behavior. Unemployed women were more likely to suffer physical violence, and non-Christian women experienced higher rates of physical and sexual violence.⁴ The qualitative aspect of the study sought to contextualize the statistical analysis by letting women speak about their experiences of violence and abuse, as well as to contextualize these experiences within the larger social structure—one that keeps women financially dependent on men and constrains their personal agency. These factors are both cause and consequence of violence, and they inform the lived experience of HIV for women in these situations. Ultimately, this portion of the study is an effort to call attention to the lived experiences of women and increase our understanding of the specific ways in which women in Nairobi experience intimate partner violence and what meaningful impact this has on their lives and livelihoods. Like the woman in the opening quote, all of the women interviewed in this study struggle to live in a complex web of social, psychological, and physical suffering that accompanies a life of insecurity, oppression, violence, and HIV.

Background

HIV in Kenya

Globally, an estimated 38 million individuals are living with HIV.⁵ Seventy percent of these individuals live in sub-Saharan Africa.⁶ In 2019, 1.7 million new cases were reported, with young women and adolescent girls accounting for one in four new infections.⁷ In fact, young women aged 15–24 are twice as likely to be living with HIV as men in the same age bracket. In Kenya in 2019, 1.5 million people were living with HIV—nearly 5% of people aged 15–49—and there were 42,000 new HIV infections and 21,000 AIDS-related deaths.⁸ According to the UNAIDS *2020 Global AIDS Update*, Kenya is one of 25 countries that has reduced its incidence-prevalence

alence ratio to under 3%, indicating that Kenya is making progress toward “ending the epidemic.”⁹ Legal victories, an increase in comprehensive care and supportive services for women living with HIV, and new rights-based and community engagement approaches have been successful in this effort. The report also shows that Kenya achieved the 90-90-90 target for 2020 in two areas—90% of people living with HIV know their status (the first “90”), and 90% of those receiving treatment have suppressed viral loads (the third “90”). However, Kenya has yet to reach the 90% milestone with regard to those who know their status and are receiving treatment. Reasons for this shortcoming are likely to include the barriers posed by gender inequity generally and intimate partner violence specifically, as many women are dependent on male partners for accessing care but are also fearful of the repercussions they face when seeking this type of support, especially if their partners are not receiving treatment themselves.

The HIV and human rights nexus: Intimate partner violence

Human rights have shaped the discourse and response to the HIV epidemic. As early as the late 1980s, WHO began framing HIV and AIDS as issues of ethics and human rights, stressing that structural violence, human rights violations, and other social determinants account for the spread of the disease, thereby contradicting the predominant view at the time that individual behavior is to be blamed.¹⁰ The link between human rights abuses and the spread of HIV is now generally accepted in both practice and literature.¹¹ As Paul Farmer notes, “violence, poverty, and inequality are the fault lines along which HIV spreads.”¹² Structural and interpersonal violence, human rights violations, stigma, and discrimination are interwoven and integral to understanding and combatting HIV, especially among women and other underrepresented groups. Hierarchical power structures such as socioeconomic class systems and cultural ideals of male dominance engender inequalities, and for those occupying the lower rungs of these systems, these structures impede personal agency, limit choice

and movement, and hinder the realization of civil, political, economic, social, and cultural rights. Violations of the right to association and equal access to information, for example, can lead to lack of education about the disease, the inability to engage in preventative measures, and less access to medical care and participation in support groups in the event of infection. Stigma attached to presumed or known HIV status can increase isolation and lead to discrimination and disparities in employment, housing, and health care.¹³ This is compounded for marginalized groups, including women. Women’s ability to access information about and treatment for HIV and their willingness to disclose an infection is significantly influenced by structural violence and discrimination, including the “fear of negative reactions, abandonment, and abuse.”¹⁴

As a form of gender-based violence, violence inflicted by an intimate partner is one of the primary drivers of the HIV epidemic, and women in situations of poverty are at particularly high risk of suffering some form of intimate partner violence and, consequently, for contracting HIV.¹⁵ In delimiting four forms of intimate partner violence, WHO defines physical violence as beating, kicking, biting, and slapping; emotional violence as insulting or belittling comments or actions, constant humiliation, intimidation, threats of harm, or threats to take away children; and sexual violence as forced sexual intercourse and other sex acts.¹⁶ Controlling behavior includes isolating a person from family and friends, monitoring their movements, and restricting their access to financial resources, employment, education, or medical care. The latter is the least studied among the four distinct forms of intimate partner violence.¹⁷

Evidence indicates that women at highest risk for HIV are those (1) in a heterosexual marriage or long-term union in a society where men commonly engage in sex outside the union and (2) in cultures in which gender-based violence, including intimate partner violence, is widespread and culturally accepted.¹⁸ Victims of intimate partner violence are overwhelmingly women, and women in situations of poverty are at increased risk of experiencing this form of violence.¹⁹ Other social and cultural factors

associated with increased risk of intimate partner violence are institutionalized gender inequality, weak legal and community sanctions against intimate partner violence within marriage, acceptance of violence as a way to resolve conflict, and male dominance within the family.

Several studies have identified a strong correlation between intimate partner violence and HIV infection.²⁰ In sub-Saharan Africa, for example, women who experience violence are one and a half times more likely to become infected with HIV.²¹ Power or the ability to influence behavior within the family was traditionally conferred according to age or kin group status. After colonization, however, gender relations were reconfigured, and power shifted considerably to men.²² This left women more reliant on men to meet their basic needs; as a result, they have less agency in making decisions about their lives and their health, and they have little recourse to prevent abuse. Without treatment, opportunistic infections and other threats to health are more likely. This interferes with the ability to work, to care for their children, and to meet the basic needs of the household, the responsibilities of which often fall to women. Further, intimate partner violence associated with disclosure of status is communally sanctioned and rarely punished, leading women to be blamed for bringing the disease home.²³

In Kenya, nearly half of all women have experienced some form of violence in their lives.²⁴ It is estimated that 33% of Kenyan girls have been raped by the time they are 18 years old.²⁵ Twenty-two percent of girls aged 15–19 describe their first experience with sexual intercourse as unwanted or forced.²⁶ For women, marriage is one of the largest risk factors for contracting the disease. Emily Mendenhall and colleagues found that 84% of HIV-positive women in Nairobi reported experiencing interpersonal abuse, primarily in the form of physical and emotional abuse from partners.²⁷ Traditionally, state-led initiatives and prevention efforts in Kenya warn men of the dangers of having sex with sex workers, which perpetuates the idea that all women who have HIV have high levels of sexual activity and that women are to blame for the

epidemic.²⁸ This exacerbates the stigma related to HIV and AIDS and often causes women to delay disclosing their status and seeking treatment.

Health as a human right in context of HIV and AIDS

The right to health is one of the most fundamental human rights and indispensable for a life with human dignity. It is anchored in a number of human rights documents, including the Universal Declaration of Human Rights (article 25), the International Covenant on Economic, Social and Cultural Rights (article 12), and numerous regional and specialized documents. With regard to women, the Convention on the Elimination of All Forms of Discrimination against Women states in its article 11(1)(f) that women have the right to the protection of their health, including reproductive health. Additionally, article 12 calls on state parties to eliminate discrimination in health care. In the context of HIV and AIDS, the need for a tangible implementation of right to health has led to a number of human rights-based documents, including the *International Guidelines on HIV/AIDS and Human Rights*, special reports, and meetings. In addition, a number of legal battles over access to antiretroviral medicines has significantly advanced the right to health and serves as an example of how economic, social, and cultural rights can be implemented through domestic judicial systems.²⁹ Recent developments in Kenya have strengthened legal protections for women facing violence and HIV. For example, a 2006 law that criminalized acts that exposed other persons to HIV and required individuals who tested positive for HIV to disclose their status to “any sexual contact” or face jail time for up to seven years was ruled unconstitutional by the Kenyan High Court for reasons of gender-based discrimination, among others.³⁰ The petitioners moved that the law targeted women because women who become pregnant are often tested for HIV, which often means they are the first in the household to know they have HIV and therefore required by law to inform their partners, which may lead to blame, violence, and other consequences of disclosure. While the law seemed like an effective way of preventing the

spread of HIV, the court recognized that the lack of clarity around what “sexual contact” means (does it apply to children during pregnancy, delivery, and breastfeeding?) and the burden it placed on women was unconstitutional. Nevertheless, women continue to face myriad social, cultural, and institutional barriers in accessing judicial institutions and encounter legal ambiguity in many situations, including relating to HIV.³¹

Additionally, organizations such as WOFAK (Women Fighting AIDS in Kenya) and other human rights-based initiatives in Kenya have focused on implementing WHO’s *Consolidated Guideline on the Sexual and Reproductive Health and Rights of Women Living with HIV* through engaging all stakeholders in a comprehensive effort to end the epidemic by reducing the vertical (structural) and horizontal (interpersonal) fault lines along which the disease spreads.³² These organizations recognize that the protection of human rights and women’s rights is essential “to safeguard human dignity in the context of HIV and ensure an effective, rights-based response” and have been instrumental in providing support services and engineering policy changes to this end.³³

Unfortunately, values, norms, and practices related to gender roles still lead to gendered biases in the public health system, the justice system, and social protection programs. Situated and perpetuated within the larger context of gender inequality and gender-based violence, intimate partner violence acts as both a risk factor and a barrier to care for women. A human rights approach is necessary to dismantle these systems of oppression and combat the spread of HIV in Kenya and beyond. An important aspect of the human rights approach is the recognition of the prevalence of all forms of intimate partner violence and the way these shape the transmission and the lived experience of HIV for women in Kenya.

Methods

The qualitative portion of this study was designed to capture the perspectives of women living with HIV in Nairobi and get a sense of how women talk

about and manage the dual epidemics of intimate partner violence and HIV in their everyday lives. Data collection took place from May to August 2012. Two separate focus group interviews were conducted with 19 HIV-positive women between the ages of 18 and 69 who were receiving medical care at the Comprehensive Care Clinic at the Kenyatta National Hospital in Nairobi. All of the women interviewed had been sexually active in the previous six months with a man they considered an intimate partner. The interviews lasted about two hours and were facilitated by a trained moderator and assisted by two note takers. Women who were not HIV positive, who were out of the 18–69 age range, who were not sexually active, who had multiple sexual partners, or who were engaging in commercial sex work were excluded from the study. Recruitment of volunteer participants for the focus groups was done in collaboration with the nongovernmental organization Working Mothers with HIV and AIDS in Kenya. Ethical guidelines for participatory research developed by the International Community of Women Living with HIV and AIDS were followed, as were WHO’s recommendations for conducting research on violence against women.³⁴ Each participant signed an informed consent form and an audio-tape release. The two sessions were audio recorded and transcribed for the purpose of analysis. The interviews were designed to assess issues related to experiences of violence at the hands of an intimate partner, including how it affects well-being generally and as it relates to HIV specifically. Participants were asked how they acquired HIV, when and how they were diagnosed, whether they knew their partner’s status, and whether they had disclosed their status to their partner. Women were also asked if they had experienced violence or abuse from their partners in the past six months. If they answered affirmatively, they were asked to describe the type and frequency of the violence and how it has affected their adherence to HIV treatment, including taking the prescribed medication and attending support groups at the Comprehensive Care Clinic. Finally, participants were asked about what kinds of support they have received and from whom, as well as what would help them in terms of resources, services, information,

educational programs, or other forms of support in dealing with partner abuse and HIV management. The questions and probes elicited conversations about thoughts and experiences around gender stereotypes, inequalities, and violence, as well as what coping strategies women use and how they manage these problems in their daily lives. The following section reviews the results of the qualitative analysis, focusing on the predominant themes and overarching issues that condition the lives of women living with HIV in Nairobi and compound the difficulty of managing life with the condition.

Findings

Diagnosis and disclosure

I started seeing discharge and [foul] smell so I kept on wondering what is all this because I have never experienced such a thing so when I went to be treated [for] the UTI ... and that's when they asked me if I would like to do an HIV test so I said yes ... You know I was so naïve I didn't expect I could have this HIV because I thought it was for the people who walk around so I never thought it could get me, so when I did the HIV test in August in 1996 it was found positive so when I confronted this man he left me, he refused me and it finished just like that.

None of the participants were able to say for sure when or how they acquired the virus, only when and under what conditions they were diagnosed. Four women were diagnosed during pregnancy, four were diagnosed after their partners tested positive, and one was diagnosed after her ex-partner fell ill. Six of the women had been tested more than once, meaning that at some point they had tested negative. Five of the women went to the hospital on their own accord specifically to be tested, while six were at the hospital for some other reason and were asked if they wanted to be tested. Three women got tested after they suspected their partners of cheating. Three women said that they spent a significant period of time in denial but agreed to begin treatment once they started falling ill with opportunistic infections. With the exception of one woman who was diagnosed after her partner left her, all of the women interviewed had disclosed their status to

their partners. Several women mentioned that their partners reacted in a negative way, and two women reported that their partners reacted with physical violence upon learning of the women's positive status. While all of the women in the focus groups had disclosed their status to their partners, not all of the women knew their partner's status. Among those who did know their partners to be HIV positive, one woman said she discovered this by accident when she found antiretroviral medicine in her partner's coat pocket. Two of the women said that their partners refused to get tested.

Intimate partner violence and management of treatment

I remember when we got tested and we went home I asked him how he got this thing, and then I remember after I noticed that this man knew all along even before we got married he knew that he was infected but he never told me and he never went for the testing before. So when I asked him he started beating me. He used to beat me every night and as if that's not enough he used to force himself on me whether I like it or not. When he wants sex he will have it even if it's at midnight he will have it. So it went on like that for two years until he settled but the only thing is that he doesn't like using protection. So whenever you talk about protection he will refuse that time you want it and then when you are sleeping that's when you will hear someone on top of you that he wants sex.

This quote sums up several overarching themes related to intimate partner violence and abuse among the women interviewed in this study. When asked what comes to mind when they hear the term gender violence, several of the women mentioned forced, unprotected sex. Refusal to use a condom was frequently mentioned as a form of abuse in both focus groups, with one respondent stating, "When he comes to me he wants sex without a condom so I feel abused." One woman explained that when women do ask men to use condoms, they are often beaten or verbally abused because men often interpret that as the woman not wanting to bear his children. Another explained that women always prefer that their men use a condom during sex; however, there are consequences to suggesting

this, and sometimes women find that it is not worth the abuse to make such a demand. The next most common response was emotional or psychological abuse, followed by physical violence and the denial of rights. Two women mentioned verbal abuse, with one woman describing her partner as “using negative words towards me.” Emotional abuse was described as the partner being negligent, inattentive, or uninterested, as well as engaging in affairs with other women. One woman said that her partner tells her she is just pretending to be sick. Another woman said that her husband complains that the medication is “making her sexual performance low,” and he gives her a hard time for this. Three women mentioned frequent physical abuse, with one woman describing several beatings a day.

Some women reported their partners’ refusal to get tested as a form of abuse. Other women said that their partners were in denial about their own status, which made sticking to a treatment regimen more difficult for them. Sometimes women were beaten if they were caught taking their antiretroviral medicine or attending support groups at the clinic. Several women dealt with this by taking their medication secretly. “When my husband is in I can’t take them even if the time for taking medicine arrives, I just skip that day because he doesn’t want to see the medicine. When he is around I hide them in my neighbor’s house,” one participant explained. This type of controlling behavior led women to skip medication altogether or take it only when their partners were not around. One woman said that her partner threw her medicine away because the shaking of the pills was annoying him. Several women mentioned that they do not get financial support from their partners, which makes day-to-day living difficult, in turn making it even harder to maintain a treatment regimen.

Stigma

My neighbors don’t talk when I’m around because they fear me.

The women interviewed for this study describe how stigmatization leads to social isolation from family members, neighbors, and the larger community.

One woman reported enduring abuse from her brother, describing an instance where he broke a teacup in front of her after she drank from it while berating her for putting his children at risk of contracting the disease by being in his home and using his utensils. Another woman described a similar situation: “[The family] discriminated me until when I eat with a plate they didn’t clean it because it has the virus [and no one was willing to touch it] and nobody will eat with what utensils I used [even after they had been cleaned].” One woman said that her parents were originally supportive of her and tried to help her manage her condition, but eventually her “father changed and he chased [her] out,” and this has been very painful for her. Another woman said that when her brothers get drunk they shout at her that she is dying, which typically leads to a violent confrontation. Another woman described the same kind of verbal abuse from her sister-in-law, who blames her for bringing home the disease, and another woman reported that her siblings refer to her as a “walking corpse.” While the Christian church is sometimes identified as a source of refuge and assistance, a few women interviewed for this study reported that the church harbors discrimination against women living with HIV. One woman reported that she was fired from her job as church secretary when the pastor found out about her status. Another woman said she confided in her pastor that she was positive, and he told everyone in the congregation, after which she was forced to leave the church. Women also described being discriminated against in the workplace, where they are relegated to the least desirable jobs or they are fired outright. This is a vertical violence, coming from managers, but a horizontal violence as well, coming from friends and co-workers. One woman described a situation in which she offered a painkiller to a co-worker who was complaining of a headache, but the co-worker would not accept it because there was no way to be sure it was not antiretroviral medication. One of the women explained that people who have a positive diagnosis often try to keep it a secret. However, the problem is that the women see one another at the clinic or at support groups and they reveal one another’s

status to others: “So this stigma we bring it to ourselves, if you know somebody is positive out of their own mouth you need to keep it secret, but if you go and tell somebody who is negative they are going to spread it out in a very negative manner.” Responding to this, another woman said, “You see this is what is causing infections to spread because of stigma and discrimination.”

Blame

I feel that when a woman is infected and other family members know that she is infected they do not blame the husband; they always blame the woman ... So for me, I have faced all that and I am carrying the burden alone.

“We are blamed a lot,” lamented one woman on the topic of gender violence, suggesting that women are blamed for contracting the disease and spreading it to their partners. Among the women interviewed, there was an initial assumption that only women with high levels of sexual activity contract HIV. This widespread gendered bias, they explain, leads to discrimination in nearly all domains of life, including within the family. Reinforcing this sentiment, one woman stated, “It’s easier for the society to stand and say that it’s the woman who wandered around. So you face lots of discrimination because it’s easier to discriminate against the woman.”

Clinical care and support

I have noted something—that the woman’s immunity is affected more, so the woman gets sick more often than the man.

The women interviewed in this study were all taking antiretroviral medication, and most of them believe that it is helping them feel better and reducing their risk of contracting opportunistic infections. One woman commented that there are negative side effects; another said the medication was making her fat. Good nutrition is considered an important component of self-management, but the ability to eat healthy is limited by financial constraints. Participants reported that the support groups at the Kenyatta National Hospital

are helpful in terms of educating them on how to manage the disease, meeting new friends who are suffering in similar ways, and providing a source of encouragement, strength, and refuge. Attending support groups at the clinic is also something women identify as an important aspect of treatment, but getting to and from the clinic can be difficult for many women. Those whose husbands are supportive are much more likely to maintain a treatment regimen than those who receive little or no support from their partners. For the women participating in this study, financial support from partners is the most desired form of support, and emotional support from partners and friends is also very important. Five women reported that their partners were supportive, reminding them to take their medicine and sometimes offering to take them to the clinic. Most of the women, however, did not receive much support or assistance from their partners. “My husband does not support me in anything, he is just waiting for me to die,” one woman lamented. Another said she does not get support from her husband because “the word HIV is hard to him” and he refuses to talk about it. Another woman said she does not tell her partner when she is going to the clinic in order to avoid getting into a scuffle. One partner refuses to pay for the medication because he insists that the woman is faking the disease. Another partner insists that the woman take only herbal medications, so she takes her antiretroviral medicine in secret whenever possible. Several women said their partners refused to get tested or were in denial about their own status, which made accessing and maintaining treatment more difficult for the women.

When asked about what would help women with HIV who are dealing with abuse from partners, responses included making counseling available, providing more employment opportunities, offering AIDS education to raise awareness and reduce stigma in churches and workplaces, and empowering women to communicate more effectively about their needs. One woman suggested that women should be asked about violence and abuse in the household each time they come to the clinic. Another woman suggested that there be a govern-

ment mandate to get tested for HIV.

Limitations and future research

Nineteen is a small sample size and cannot reflect the diversity of experiences of the 1.6 million people living with HIV in Kenya. Certainly, there will be a different set of concerns for women living in more rural areas as opposed to the city of Nairobi or for women who do not have access to medical care at the Kenyatta National Hospital. However, the purpose of the qualitative portion of this study was to contextualize the findings of the larger cross-sectional survey by giving women the opportunity to speak about their experiences and express their concerns regarding intimate partner violence and managing HIV. While Kenya has been actively changing its approach to the HIV epidemic to be more rights oriented, the perspectives of these women reflect that entrenched cultural ideas around gender inequality, stigma, and blame are difficult to change even with these high-level efforts. Future research should focus on if and how women's day-to-day experiences are changing in light of these new initiatives and policy changes. This would provide a comparative framework to better understand whether new approaches are in fact effecting widespread changes in gender relations at the local level (and particularly within the household) and therefore working to combat the spread of the disease.

Additionally, while all of the women participating in this study were receiving treatment at the clinic, future research should focus on those not receiving biomedical care. Considering the prevalence of abuse in a sample of women who are receiving some level of care in the hospital, it is likely that those outside the national health care system are experiencing abuse as well and that it is affecting their ability to seek treatment.

Discussion: Intimate partner violence as a risk factor and barrier to treatment for women living with HIV

The quantitative portion of this study found that all

four forms of intimate partner violence are prevalent among women living with HIV in Nairobi. The results and analysis described here offer important perspectives from a subset of this population and suggest that intimate partner violence is persistent and pervasive in all aspects of managing life with HIV. From acquisition to diagnosis to treatment, gender-based violence conditions every aspect of living with HIV for women in Kenya. This violence is built into cultural, social, and political institutions, and it functions at every level of society, permeating down to the household, where women are at greater risk for exposure to HIV and have fewer recourses in the case of infection. The fact that all of the women interviewed had disclosed their status to their partners but not all of them knew whether their partners were positive (or had discovered this by accident) is an indication that women are disadvantaged by the male-dominated system. Participants expressed a reliance on men to provide the financial resources necessary to obtain medical care for HIV, while men are better positioned to hide their status. This also allows men and other members of the community to blame women for "bringing the disease home" simply because they were the first to disclose their status. Additionally, one specific form of abuse that came up in both focus groups is that male partners often refuse to get tested, which allows them to remain in denial about their own condition and makes them less likely to be supportive of their partners with regard to treatment. In addition to blame (a form of emotional violence), several of the women in this study related that physical violence followed the act of disclosing their status to their partners. For many of the women, the abuse has continued and made management of the disease much more difficult. Many participants recounted being beaten or verbally attacked for taking their medicine, which led them to try to do it in secret and at irregular times.

Controlling behavior by male partners poses a significant barrier to adhering to a treatment schedule and attending support groups for women with HIV. While controlling behavior is often neglected as an analytic category in studies of violence against women, this study suggests that it should be

considered as a cause and a barrier to treatment and health management for women living with HIV in Kenya. Participants considered the acts of refusing to wear a condom during sex, withholding financial and logistical support necessary for treatment, restricting access to medication, and controlling other aspects of treatment examples of controlling behavior that they had experienced. Both the survey and the narrative data from this study showed controlling behavior to be a common experience, especially for women of lower socioeconomic status, and something that very much impedes adherence to prescribed treatment and access to other forms of support. Therefore, we recommend that all four forms of intimate partner violence be regarded as both risk factors and barriers to treatment and assessed in communal and clinical settings.

Stigma was another commonly mentioned barrier to treatment, as well as to employment and to positive social interaction with members of the community. This stigma is isolating and serves to preclude the formation of strong support networks for women living with HIV, which participants spoke of as vital to managing life with the disease. We agree with the participants that more educational programs geared toward reducing stigma are needed. With regard to everyday needs, participants mentioned the need for more economic opportunities—not in the form of government handouts or from their male partners but from gainful employment—and more accessible ways for women to report violence without fearing the repercussions. They also mention the need for better access to counseling services.

Conclusion

These findings support calls for both the prevention and the reduction of HIV to be addressed alongside human rights violations against women and for trauma-informed care to be the basis of care delivery. While studies show that the majority of Kenyans know how HIV is transmitted and that they are well-versed in prevention techniques, the gendered structural determinants of HIV make women differentially more vulnerable to violence,

human rights abuses, and constraints on the ability to exert agency in acting according to their knowledge of transmission and prevention.³⁵ To be effective, programs focused on the prevention and reduction of HIV among women need to address the underlying structural issues and human rights abuses, including all four forms of intimate partner violence. Health care providers need to be aware of the potential social, economic, and human rights consequences of an HIV diagnosis. Similarly, interventions and policies focused on women's empowerment must consider the implications of the HIV epidemic for women's health and their status in society. While legal developments over the past decade, including the 2010 Constitution and recent court cases, have improved the situation for women in Kenya, many deep-rooted societal issues still need to be addressed. It is important not just to have these services available to women but to actually empower and enable women to utilize the services. Proactive leadership and increased funding is necessary to ensure that women are free from physical, sexual, and psychological abuse and that their human rights, including the right to health and freedom from violence, are implemented. We support the notion advocated by Paul Farmer and others that approaches to the prevention and treatment of disease must be dynamic, systemic, and critical.³⁶ Rather than focusing on individual factors that increase "risk," these approaches should focus on the underlying causes of poverty, violence, and gender inequity. This shifts the burden of resolving this crisis from individuals in vulnerable situations to the broader institutional system that perpetuates those vulnerabilities. For example, Kenya is part of the Global Fund's "Breaking Down Barriers" initiative.³⁷ This is a rights-based and gender-responsive approach to identifying and addressing barriers to HIV services through interventions related to stigma and discrimination reduction, training for health care providers on human rights and medical ethics, sensitization of lawmakers and law enforcement agents, legal literacy and legal services, monitoring and reforming laws, and reducing HIV-related gender discrimination, harmful gender norms, and violence against women and girls.

These policy interventions have the potential to address the context in which women receive care and can serve as a framework to develop a more targeted approach to supporting HIV-positive women who experience intimate partner violence. Importantly, any efforts to address barriers to HIV prevention and reduction using a human rights-based and gender-responsive approach must consider the lived experience of HIV and make space for stakeholders to express their personal perspectives, needs, and concerns in their own words and then explore how these articulate with the structural limitations and deleterious outcomes imposed by a sociopolitical system that undervalues women, engenders women's rights violations, and tolerates abuse in its many forms. In addition to legal and economic constraints and lack of access to public and health services, these efforts seek to identify and address gender violence at all levels of society. Based on our findings, we recommend that these initiatives include an assessment of all four forms of intimate partner violence that women may experience in the home. This may be particularly relevant in the context of COVID-19, as there is already evidence of an increase in domestic violence as a consequence of the social isolation measures implemented to combat the spread of the virus.³⁸

Winnie Byanyima, the executive director of UNAIDS, has called on leaders to support a United Nations General Assembly High-Level Meeting on Ending AIDS in 2021 with the purpose of “address[ing] with urgency the outstanding issues that are holding us back from ending the epidemic as a public health threat by 2030.”³⁹ We recommend that studies like ours and initiatives like the one by the Global Fund—those that highlight the needs and concerns of those living with HIV, including factors related to and barriers imposed by intimate partner violence and other human rights abuses—be considered in any discussions of how to move forward with this goal. Amplifying these voices, especially those of women, will help leaders better understand how the suggested structural changes manifest at the local level and whether they have a meaningful impact on the lives of the individuals they seek to help.

Ethical approval

Ethical approval for the study was obtained from the Institutional Review Board of the University of Alabama at Birmingham (approval no. X120314015) and the Kenyatta National Hospital/University of Nairobi Ethics and Research Committee. Written informed consent was obtained from each participant prior to enrollment in the study, and the study was conducted in accordance with the Declaration of Helsinki.

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Assessing a Human Rights-Based Approach to HIV Testing and Partner Notification in Kenya: A Qualitative Study to Examine How Kenya's Policies and Practices Implement a Rights-Based Approach to Health

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Abstract

Kenya encourages HIV testing and notification services, especially for key and affected populations (KAP), in order to identify persons living with HIV and link them to treatment. Kenya and international supporters of its HIV program have sought to scale up these services through increased capacity and training. However, little is known about how the HIV strategy is implemented and sustained, particularly regarding human rights. Kenya aspires to support human rights in adherence to a human rights-based approach (HRBA) to HIV. This exploratory qualitative study assesses Kenya's progress in implementing an HRBA to HIV. KAP participants conveyed mixed perspectives on their HIV care services, conveying distrust in Kenya's public health care system while also recognizing improvement in some patient-provider interactions. Providers see the need to better engage KAP through community-based organizations and undergo improved, consistent training to sustain practices and policies that promote their rights realization. We believe that our study contributes to both HIV and human rights research by capturing successes and challenges in Kenya's implementation of an HRBA to HIV. These findings should inform future collaboration between Kenyan health authorities and KAP, and shape HIV policies and practices to improve health care utilization and human rights realization.

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Introduction

Human rights-based approaches (HRBA) are a field of study within legal and public health research. HRBA is a conceptual framework based on international human rights norms and laws and is, operationally, oriented to the protection, respect, promotion, and fulfillment of human rights that anchors public authorities (duty-bearers) to be accountable to individuals and communities (rights-holders) when developing, implementing, and evaluating programs and policies.¹ In practice, following an HRBA means integrating the principles of nondiscrimination, participation, empowerment, accountability, and linkages to other rights into the design, implementation, monitoring, and evaluation of health-related programs and interventions.²

Scholars identify rights-based approaches to health, deriving them from best practices and lessons learned, which informs policy development and contributes to advocacy for human rights and health.³ Better understanding the “approach” in HRBA could bolster the monitoring and evaluation of a program, policy, or practice and support the construction of indicators for achieving rights realization in service to supporting health outcomes.⁴ Operationalizability is important to avail HRBAs of the policy analysis capacities that many public health professionals are trained in and to provide legal analyses and respective tools to support accountability.⁵

HRBAs are significantly discussed within the context of HIV.⁶ An investigation into whether and how a rights-based approach is adhered to, in a context where public health authorities embrace HRBAs and recognize the right to health, could yield rich outcomes describing the implementation successes and challenges that come with operationalizing an HRBA to HIV. Developing a practice for HRBAs would include measurable—and contextual—indicators both for achieving targets in HIV testing, treatment, and prevention and for comprehensively realizing human rights among people living with HIV and key populations at risk of acquiring HIV.⁷

Background

HIV and human rights in Kenya

Kenya recognized the human right to health in its 2010 Constitution.⁸ The HIV and AIDS Prevention and Control Act (2006) enumerates the rights of people living with HIV that are inherent to realizing the right to health (including consent, confidentiality, and privacy).⁹ In addition, Kenya is a signatory to numerous international human rights treaties whose committees (the authorities overseeing each treaty’s implementation and growth) have recognized the right to health, including for the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women, and the International Covenant on Economic, Social and Cultural Rights.¹⁰ Kenya is also a member of the East African Community, which passed (and Kenya assented to) the HIV and AIDS Preventions and Management Act (2012).¹¹

Kenya’s HIV epidemic remains substantial.¹² Kenya is one of the top five most-burdened countries globally in spite of successes in expanding HIV testing and connecting people living with HIV to treatment.¹³ In Kenya, the burden of HIV falls disproportionately on “key and affected populations,” or KAP, a group of communities that includes gay men and other men who have sex with men (MSM), people who inject drugs (PWID), female sex workers (FSW), and young women aged 15 to 24. Approximately half of all people living with HIV in Kenya were unaware of their HIV status in 2018.¹⁴ Testing rates among key populations and young women remain suboptimal: while 80–90% of FSW in Kenya report having tested for HIV within the past 12 months, only 77% of MSM, 84% of PWID, and about 50% of women aged 15–19 report having done so (though 80% of young women aged 20–24 reported testing).¹⁵

To address this health inequity, the Kenyan National AIDS and STI Control Programme, the Ministry of Health, other Kenyan public health authorities, and international supporters such as the US President’s Emergency Plan for AIDS Relief (PEPFAR) have been scaling up their HIV testing

strategies to increase testing rates and to widely implement assisted partner notification services in order to identify people living with HIV and connect them to treatment. (On January 1, 2020, PEPFAR issued guidance to its programs and partners calling for the suspension of partner notification services, citing concerns raised over confidentiality, consent, and respect for human rights, particularly among key and affected populations such as sex workers, MSM, and adolescent girls and young women. This guidance came after our study's data collection had concluded.)¹⁶

Voluntary testing for HIV, and encouraging—without coercing—partner notification services, are cornerstones of the rights-based approach to HIV.¹⁷ The National AIDS and STI Control Programme's 2015 *HIV Testing Services Guidelines* detail several approaches to facilitate access to HIV services, testing, and treatment. Primary approaches involve facility- and community-based settings that offer both client- and provider-initiated testing and counseling.¹⁸ Assisted partner notification services have been particularly effective in identifying persons for outreach and testing, utilizing an index case (a person living with HIV) to identify other parties to simplify case finding. Building several avenues to connect persons at risk for HIV, or living with HIV, is a public health priority.¹⁹

HIV and patients' rights

Human rights concerns with HIV testing and notification services relate to how these strategies pursue their objectives to increase testing rates, with particular attention paid to communities already experiencing vulnerability with respect to their rights. KAP in Kenya and elsewhere have described their fears of coerced disclosure, erasure of privacy and confidentiality, heightened stigmatization and resulting discrimination, and violence (physical, emotional, and otherwise) from their partners, families, or communities.²⁰ Such fears are not based solely on perceptions; sex work is illegal in Kenya, as is homosexual behavior and drug use. Young women in Kenya and East Africa experience pervasive forms of coercion, which hinders their autonomy and rights realization.²¹

Fear of coercive approaches to encourage testing undermines both health objectives and individuals' rights. In 2013, the nonconsensual disclosure of individuals' HIV positive status in Kenya was strikingly commonplace, and coerced testing was also prevalent, affecting community perspectives on health services and HIV testing generally.²² A 2016 qualitative study in Kenya found that individuals' sex highly influenced how and when they disclosed their HIV status, with some women expressing fear of social and financial abandonment or violence if they disclosed their status.²³ A 2018 study echoed these findings, reporting that 13% of Kenyan women living with HIV were unlikely to disclose to their partners.²⁴

Effective HRBAs to HIV training require a strong legal and policy framework for education and practice, and as of 2020 neither the National AIDS and STI Control Programme's guidelines for partner notification services nor the required privacy regulations under the 2006 HIV and AIDS Prevention and Control Act were being implemented. The laws that exist in Kenya are meaningful only if the rights they protect are perceived as real and held by KAP—and if, where violations occur, the violators are held accountable swiftly and transparently.

Assessing Kenya's HRBA to HIV

Our exploratory qualitative study examined how Kenyan health care professionals implement a rights-based approach to HIV testing and notification practices with respect to KAP. At the same time, we spoke with KAP individuals to better understand why they under-test relative to their risk, what they perceive as barriers and areas for reform, what concerns they have regarding disclosure, and how those concerns might be addressed.

The key research questions were as follows: (1) How is Kenya implementing an HRBA to HIV testing and assisted partner notification services?; (2) How are KAP experiencing these services?; and (3) Where can Kenya strengthen its HRBA to ensure KAP's rights realization and utilization of HIV services? We posit that perspectives, attitudes, and opinions from rights-holding communities

(KAP in our study) provide a measurable indicator for rights realization (the self-perceived enjoyment of rights and means to redress violations thereto) and, importantly, assessing how effectively a public health program or policy adheres to a rights-based approach. HRBA studies are infrequent in the public health literature, and studies on HRBA implementation even more so. Our study aimed to help bridge the gap between theoretical HRBAs and applied HRBAs within Kenya’s HIV and KAP context.

Limitations

Measuring the impact of HRBAs is challenging, particularly as perceptions of one’s rights realization may be subject to several intersectional determinants. Our hypothesis—that Kenyan KAP’s perceptions of their rights and Kenya’s HIV programs can function as one possible indicator—is novel but contributes to understanding the successful operationalization of HRBAs to HIV.

Methods

Our protocol and other methodology details have been published in another issue of this journal.²⁵ In brief, we worked with community-based organizations to establish four study sites across southern Kenya that represent significant population centers for the four KAP communities included: Nairobi (MSM), Mombasa (PWID), Kisumu (FSW), and Homa Bay (young women). Table 1 summarizes our engagement with participants. We also invited senior leadership from Kenya’s HIV programs

to participate, and we informed pertinent county and national authorities of our study’s purpose and utility.

Kenyans familiar to these communities transcribed the interview recordings. Interviewers provided analytic memos following their transcription to ensure that our analysis was informed by and reflected participation from the communities. A Kenyan qualitative analyst provided memos for each study site’s outcomes; we (the authors) then conducted a legal analysis based on these memos and the original transcriptions.

We adopted a grounded theory approach for this study. However, we hypothesized that human rights realization as enabled through a rights-based approach to HIV testing will contribute to greater trust and confidence in the health care system and result in more persons at risk for HIV voluntarily testing and using notification services.

Results and discussion

Several participants reflected positively on their interactions with HIV care services; many felt that their situation had improved compared to earlier accounts from their own histories or the shared experiences within their groups. Nevertheless, our results indicated mixed sentiments among KAP with regard to government-affiliated health services. While we found only a few disagreements, the general consensus was that KAP are not utilizing services (including testing services) owing to a lack of trust, confidence, and continued stigmatization or anticipation of stigma.²⁶ We interpret KAP’s

TABLE 1. Participants

Study site (KAP community)	Number of participants in focus group discussions (KAPs)	Number of participants in in-depth interviews (KAPs)	Number of participants in in-depth interviews (health care professionals)
Nairobi (MSM)	9	2	2
Mombasa (PWID)	9	3	2
Kisumu (FSWs)†	9+2	0	0
Homa Bay (young women)	8	2	4
TOTAL*	37	7	8

*n=52

† No suitable in-depth interviewees were identified or willing and able to participate in Kisumu. A small (n=2) group interview with FSWs independent from the focus group discussion provided similar outputs as the focus group discussion.

under-utilization of HIV testing and notification services as relating to under-implemented mechanisms for the protection, respect, promotion, and fulfillment of the rights to privacy, confidentiality, consent, and dignity.²⁷

Men who have sex with men expressed distrust and anticipation of stigma from interactions with public health care providers.

Interviewees reported feeling objectified by health care providers and having their confidentiality and privacy breached through gossip. They also noted the comparative lack of KAP-friendly services in Kenya outside of Nairobi. Given that homosexual activity is illegal in Kenya, MSM participants were concerned about having any records that might be accessed and put them in future jeopardy. One MSM interviewee in Nairobi said:

You know government facilities, people know that they're owned by government. [T]hey keep records, they keep reports, people will fear the government facility has to say how many gay men did you see? How many sex workers did you see? Do you know where they live? That fear of giving real information that they feel it may end up with the government.

Judgmental interactions also diminished MSM participants' trust and confidence in their health care providers. For example, one health care worker told a patient that they needed to "change their sexuality" and "needed prayers to change [their] way of living."

MSM participants did not want to lose control of their privacy and personal information, and they worried that disclosing their status might encourage violence against them. They shared the perception that testing is mandatory at government hospitals and clinics, which by itself might act as a barrier to testing.

People who inject drugs expressed concerns about interacting with government-affiliated authorities, stemming from histories of negative interactions and prejudice.

Participants felt stigmatized when interacting with public health care services, notably at the

point-of-care level provided by nurses. One PWID interviewee said, "I cannot trust [them] because of the way they treat us, both nurses and doctors treat us as animals. They use so many harsh words on us that's why we tend to avoid such places." If community-based organizations and KAP-friendly services are not available, PWID health care-seeking is less likely or is delayed. At the same time, PWID were more accepting of partner notification services. They felt that once a person's status is known, sharing that status with others in their community is proactive and supportive of others' testing. Still, PWID felt that their rights are often precarious, particularly when interacting with police and government-affiliated services (that may expose them to police).

Female sex workers felt vulnerable to coercion and prejudice.

FSW participants in Kisumu harbored negative sentiments toward government facilities and nurses in particular. They expressed reservation in sharing information with health care providers out of concern for their confidentiality and privacy, noting that health care providers and workers tend to gossip, which can lead to disclosing patients' personal information. Multiple interviewees felt that some providers coerce their community to test, and several felt that providers are judgmental and unlikely to respect privacy and confidentiality. While most FSW participants felt that partner notification services are beneficial, some also had concerns over how Kenya has encouraged partner notification in its HIV testing and treatment strategy. They felt particular pressure to provide contacts for partner notification services and to disclose one's HIV status (or allow it to be disclosed) to third parties.

On the topic of confidentiality, one sex worker from Kisumu said:

Thirty minutes after testing positive, you will see four people—the person for PNS [partner notification service], another with a file, and allocator for treatment, including the adherence counselor crowding, so it is stressful. Even the guys who dish out food will get to know that somebody tested positive. No confidentiality because of the numbers

that NGOs [nongovernmental organizations] want.

Experiences like this may not be universal, but any incident can be shared to other members of the KAP community and influence that person's perception just as much as it would the victim of a rights violation.

Young women shared positive interactions with health care professionals, while also reflecting experiences of disrespect and paternalistic attitudes.

Young women in Homa Bay reported that their interactions with health care professionals are often constructive. At the same time, they shared instances of being disrespected on account of their age or sex, and several participants reported that coercion to test for HIV or pregnancy is commonplace. Several young women stated that NGOs “should stop pressuring their employee[s] to find HIV positive clients during testing” and that they themselves “have been pressured to test for HIV.” One woman even remarked, “HIV is nowadays a compulsory test.” Shared experiences informed perceptions: if another young woman in a community had a positive or negative experience with a particular health care provider or clinic, her experience had an impact on how other young women engaged with that provider or clinic. Young women were particularly concerned about social stigmatization, including as a result of being seen in or near an HIV clinic.²⁸

Health care professionals recognized significant hurdles in building trust with KAP communities.

Health care professionals recognized that the unacceptance of KAP—socially and legally—impedes their HIV testing and health care utilization. Several professionals reported having received trainings on sensitization or human rights but noted that these trainings were inconsistent and under-resourced. One interviewee, a senior HIV policy expert in Kenya, reported that providers do receive training on human rights and National AIDS and STI Control Programme guidelines for HIV testing and notification services; however, no

other health professional interviewee (including providers) personally recalled receiving formalized training or comprehensive human rights education. Several noted that the key issue for providers is attitude, with one interviewee stating, “That is the most important thing because they already have the technical trainings on the services that they need to get and everything else, the biology, it's just all about the attitude which includes the human rights-based training.”

Interviewees praised community-based organizations and community partnerships in identifying and empowering peer leaders to encourage HIV testing, disseminate information, and form support groups. Interviewees recognized that legal awareness for patients' human rights is underdeveloped, even where clinics or hospitals have written policies or standards of practice outlining the rights. The under-enforcement of protocol compliance may lead health care professionals to inadvertently violate rights, as may the zealous pursuit of a public health objective without consideration for human rights. The concern raised by some KAP that HIV testing contributed to reaching a quota was noted by a health care professional interviewee as well:

We often go for [rapid results initiatives], which sometimes motivate health care providers walking door to door where they get people in the villages, convince and test them. What is bringing the services down and making people fear is the habit looking for number! And giving people targets that you must test this number of people within this time. This has made it humanly difficult, and even worse for those found to be sero-positive.

Key findings for HIV testing

Perspectives from KAP indicate that Kenya's HRBA is insufficiently understood and implemented at the point of care. The disconnect between what may be espoused as a norm or policy and what is experienced within the scope of that policy's effectuation mirrors the rights context for KAP in Kenya. Health professional interviewees appeared sincere in their commitment to ensuring that all patients are treated well regardless of their demo-

graphics but recognized that incidents occur that might undermine trust building and fidelity to training or best practices. Speaking about the rural community context in particular, one health care professional from Homa Bay said:

I have seen a lot of people literally running away when you approach their villages because they associate you with previous project that came tested them, took their results away and left them there ... little do the providers consider the psychological torture left with the individual after knowing their status.

Perceptions that HIV testing is required in order to access other services is troubling. One FSW participant said, “Many sex workers know their status because when you go to the hospital, the first mandatory thing they do before you see the doctor is being tested. If you don’t get tested, then you are not going to get any treatment.” Testing is, as a matter of Kenyan law and global norms, supposed to be entirely voluntary, yet concerns from each KAP study group challenged the voluntariness of HIV testing in Kenya.²⁹

Participants from all study sites noted that fear of a positive result discourages some individuals from testing for HIV and accessing health services, underscoring the importance of counseling services. The importance of this finding is that it shows that these communities do not need to have personal experiences or patterns of experience that dissuade them from going to clinics—they need only be afraid of disrespect or a violation of their rights, including their dignity.³⁰ Addressing fear, then, must go beyond the mere presence of an HIV clinic or provider. One health care professional from Homa Bay summed it up well: “You have built it and they don’t come. Why? We have health facilities where [HIV testing] services are offered to everybody, but you still find young women and adolescent girls do not come ... We want them to come for services, but we don’t want to go to them.”

A rights-based approach to HIV must begin with the rights themselves, through which the implementation and practice of Kenya’s HIV testing and treatment strategy is put to practice.

KAP must feel trust for Kenya’s institutions, and that their rights will be respected and fulfilled by the community-facing agents of those institutions (including providers and health care workers). Trust building is predicated on understanding and compassion, which can emerge through histories of positive interaction and respectful engagement.³¹ Kenya’s rights-based approach to HIV would improve through a rigorous educational structure for providers, paired with substantive community engagement.

Key findings for assisted partner notification services

Participants expressed mixed support for assisted partner notification services as a means to support case finding and treatment. Supporters, however, reflected that good counseling and engagement from their HIV caregivers before, during, and after disclosure can make the process acceptable. All participants felt it was important to disclose, but pressure to disclose early worked against their willingness to disclose at all.³² Each KAP group recognized the potential for violence (physical, emotional, sexual, otherwise) in disclosing. For effective assisted partner notification services, substantial screening for such harms must be incorporated into the practices of HIV counselors and care providers, must address safety concerns, and must have PLWHV’s consent. KAP’s perceptions on assisted partner notification services are the same as for HIV testing: KAP’s trust (or distrust) in their provider is a significant factor in their willingness to consent and participate.

Community-based organizations’ KAP-friendly services: A model for the national HIV program

Participants’ universal praise for KAP-friendly services speaks to how providers and communities alike see the reach and approach of community-based organizations as an effective stratagem for accessing vulnerable populations.³³ All KAP groups and health professionals lauded the work of community-based organizations engaged in HIV care services, including in raising rights awareness. Although the limited capacities of these organizations’ KAP-friendly services inhibit their potential

to deliver on Kenya's HIV testing and treatment goals, in collaboration with local and national authorities they might be well positioned to support reform and sustained community outreach. Importantly, such collaborations may build trust and confidence in government-affiliated services and providers among those same communities, thereby leading to better health outcomes through better health care interactions.

Conclusion

In our study, KAP participants expressed concerning perspectives regarding their rights realization, with a high degree of inconsistency with respect to whether their rights are being respected. Kenya's HIV health care professionals recognized that barriers in practice and policy hinder their outreach to and inclusion of KAP, in spite of individual provider attitudes that may be sensitized and welcoming. Experiences—whether personal, community based, or historical—influence KAP's dispositions toward Kenya's HIV care system and the extent to which they feel safe and confident in accessing testing and treatment. Kenya's HRBA to HIV stands to improve in several discrete ways that could strengthen Kenya's HIV programs by improving perceptions and trust among KAP for those same programs and the authorities tasked with implementing them.

KAP and health care providers both agree that HIV testing and notification service strategies need to include training “on [KAP] friendly services.”³⁴ Such training necessitates sensitivity toward, recognition of, and familiarity with KAP's concerns, as well as follow-through to address them.³⁵ Training must also take into account historical trauma and reconcile the role that public health agencies, health care providers, and other authorities have played in fostering stigma and discrimination. Training programs and outreach efforts are more effective when led by trusted and respected individuals or organizations.³⁶ Community-based organizations working with KAP are well regarded and positioned to help improve public health programming, from workforce education to policy and implementation. In Mombasa, one health care professional suggest-

ed getting “health care workers to be attached to institutions, NGOs, [and] partners who actually provide care to KAP ... for a week or so, so that they see [and] engage with [KAP] one-on-one [and] they realize [KAP] are individuals like any other.” Kenya's human rights obligations compel a commitment to address long-standing distrust of government-affiliated facilities and providers.

Implementing an HRBA in practice requires that Kenyan authorities embrace accountable, uniform protocols to ensure that the human rights of KAP and all Kenyans are enjoyed. In particular, it requires ensuring that HIV testing and care is free from coercion and respects patient privacy and confidentiality. Ensuring that the health care workforce is sustainably sensitized to KAP issues would be a good step for strengthening Kenya's HRBA and one that may be welcomed by health care providers.³⁷ KAP want health programs that empower providers with the literacy and tools they need to be duty-bearers who protect, respect, promote, and fulfill the rights of KAP and people living with HIV, as enumerated in Kenya's laws and international treaties.³⁸ Enforcement and accountability will be key, and establishing mechanisms for reporting potential violations must go hand in hand with a process that addresses violations in accordance with human rights principles. Where essential, lawmakers and policy makers should revise, promulgate, and amend Kenya's laws and regulations to ensure a robust legal environment for KAP's rights realization.

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Ethical approval

Georgetown University's Institutional Review Board (2018-1148) and the Kenya Medical Research Institute's Scientific and Ethics Review Unit (Non-KEMRI No. 654 (2019)) approved this study. The University of Washington's Institutional Review Board consented to Georgetown University's approval.

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Identifying Strategies to Advance Health Equity through Action on Social Determinants of Health and Human Rights for Street-Connected Children and Youth in Kenya

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Abstract

Despite the fact that street-connected children and youth (SCY) in low- and middle-income countries experience numerous social and health inequities, few evidence-based policies and interventions have been implemented to improve their circumstances. Our study analyzed strategies to advance health equity through action on the social determinants of health (SDH) for SCY in Kenya based on General Comment 21 of the United Nations Committee on the Rights of the Child. To identify policies and interventions, we analyzed archival newspaper articles and policy documents and elicited ideas from a diversity of social actors across Kenya. Our results identified three types of policies and interventions: repressive, welfare oriented, and child rights based. We then situated these strategies within the World Health Organization's conceptual framework on SDH inequities to understand their mechanism of impact on health equity. Our results demonstrate that a child rights approach provides a strong avenue for advancing health equity through action on the SDH for SCY in Kenya. As a result of these findings, we developed a checklist for policy makers and other stakeholders to assess how their policies and interventions are upholding human rights, addressing needs, and working to advance health equity for SCY.

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Introduction

Street-connected children and youth (SCY) in Kenya, for whom the streets play a central role in their everyday lives and social identities, experience premature and preventable mortality as well as numerous avoidable morbidities, including growth and developmental disparities, mental health issues, the consequences of violence, a high prevalence of HIV and sexually transmitted infections, and poor reproductive health outcomes.¹ We postulate that these adverse health outcomes are the result of significant health, social, and economic inequities, including stigma and discrimination.²

Despite SCY experiencing these inequities, few policies or health interventions have been implemented to reduce them in Kenya or in other low- and middle-income countries.³ Multiple reviews suggest that there is insufficient evidence regarding appropriate and effective policies and interventions to reduce the harms associated with street involvement and rehabilitation for SCY and conclude that more research is needed.⁴

Kenya's Constitution (article 53) recognizes the need for all children to be protected from abuse, neglect, harmful cultural practices, all forms of violence, inhumane treatment and punishment, and hazardous or exploitative labor. The Constitution also affirms that children have basic rights, including the right to education, nutrition, shelter, health care, and parental care.⁵ In Kenya, SCY under 18 years of age are protected by the Children's Act, which outlines children's rights and welfare in accordance with the Convention on the Rights of the Child (CRC), to which Kenya is a signatory.⁶ Moreover, in 2003, the Kenyan government established the Street Families Rehabilitation Trust Fund, which seeks to address the needs of SCY and street families and safeguard their rights. However, the program's reach and impact have not been evaluated, and there is no national policy on SCY.⁷ Additionally, evidence demonstrates that SCY in Kenya experience significant human rights violations and are not adequately protected in accordance with the Children's Act and the CRC.⁸

We postulate that the substantial health inequities experienced by SCY are the result of structural and social determinants of health (SDH) and human rights violations that are a product of policies and practices rooted in the country's socioeconomic and political context.

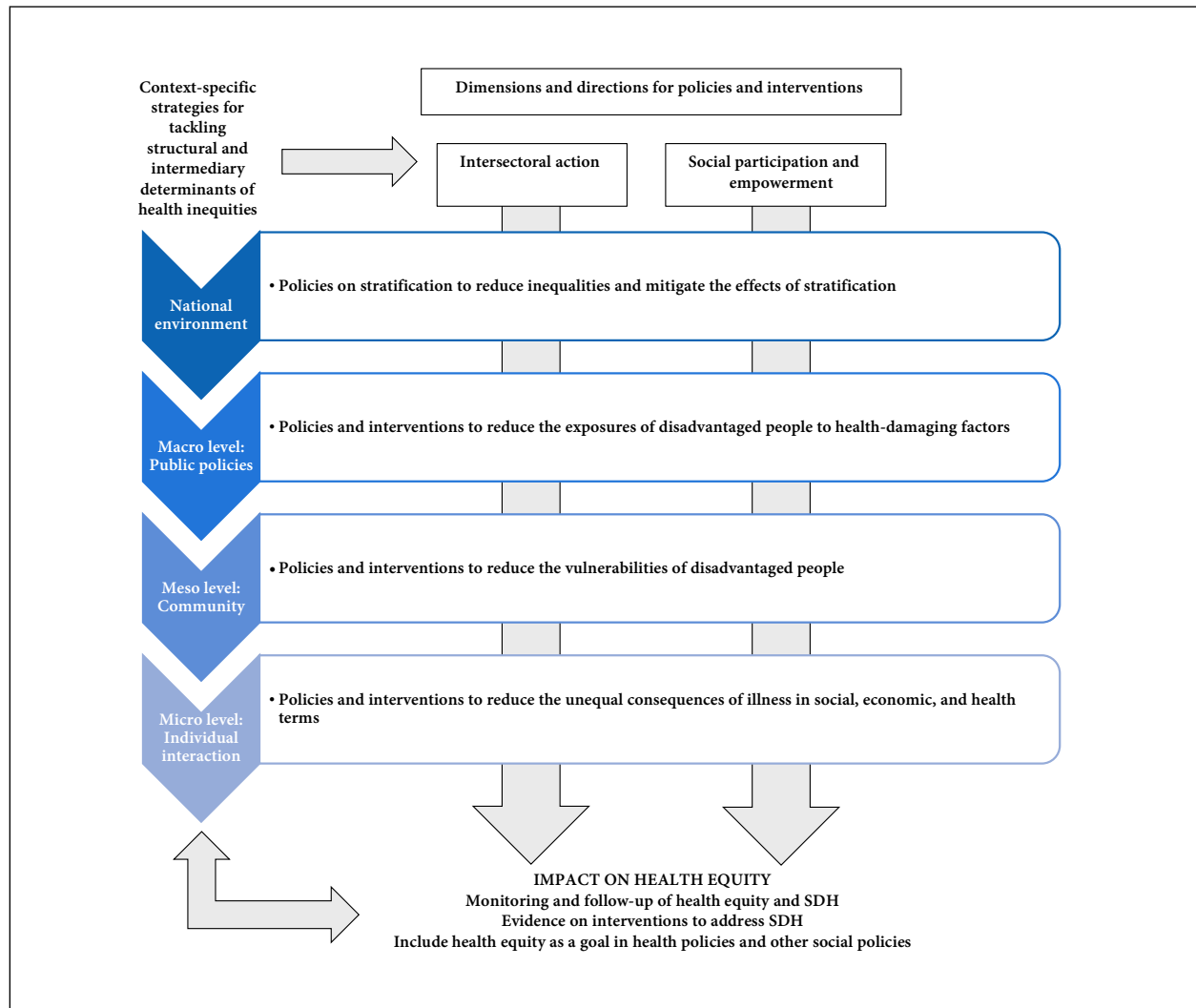
Health inequities are systematic differences that are socially produced and unfair, arising as a result of the SDH.⁹ In the World Health Organization's conceptual framework on the SDH, a country's social, economic, and political conditions influence an individual's social position in society and their exposure and vulnerability to health-compromising conditions. According to this conceptual framework, policies and interventions to advance health equity require context-specific action on structural and intermediary determinants to reduce social stratification, differential exposures and vulnerabilities, and unequal consequences of ill health (Figure 1).¹⁰ Strategies to advance health equity may use universal or targeted public policies and interventions at various entry points (including the national context, public policy, and community and individual levels). Universal policies are those that affect the whole population in the national environment (macro level), while targeted policies are those that focus on a disadvantaged group or target health gaps at the community or individual levels. Action on SDH to reduce health inequities is a political process and requires governments to take responsibility to address structural and social inequities to ensure that citizens can exercise their right to the highest attainable standard of health.¹¹

The World Health Organization states that "the international human rights framework is the appropriate conceptual structure within which to advance towards health equity through action on SDH." Therefore, to reduce SDH inequities experienced by disadvantaged populations, such as SCY, international human rights instruments, such as the CRC, provide a legal framework for states to construct policies that work toward achieving equity, while providing a mechanism for civil society to hold states accountable.¹² General Comment 21 on children and street situations was released in

2017 by the Committee on the Rights of the Child to provide authoritative guidance, in line with the CRC, to states seeking to respond to injustices experienced by SCY and to improve this population’s circumstances using a child rights approach.¹³ A child rights approach is one whereby the child is consulted in decisions affecting their health and well-being and is respected as a rights holder. This contrasts with welfare strategies, whereby the child is seen as a victim to be rescued, and repressive approaches that consider SCY to be delinquents and

that often criminalize them. It is essential to use a child rights approach when seeking to improve health equity. SCY-related policies and interventions that apply General Comment 21 will intersect with the conceptual framework for tackling SDH inequities at various entry points to influence health equity (Figure 2). For example, when SCY’s right to accessible, free, safe, relevant, and quality education (CRC article 28) is upheld, this will help alter social stratification by reducing inequalities that lead to different socioeconomic positions, which affect

FIGURE 1. Framework for tackling structural and intermediary determinants of health inequities



Source: O. Solar and A. Irwin, A conceptual framework for action on the social determinants of health, Social Determinants of Health Discussion Paper 2 (Policy and Practice) 2010, World Health Organization, Geneva, Switzerland.

health equity. Education can prevent children and youth from ending up in street situations and—for children and youth already on the street—can offer a pathway to transition from the streets and alter their future socioeconomic position.¹⁴

Given the lack of effective evidence-based policies and interventions for this population, substantial health inequities, and under-realization of SCY’s rights, we sought to identify existing and proposed policies and interventions for SCY in Kenya through interviews with policy makers, health care providers, community and government stakeholders (for example, SCY opinion leaders, county children’s officers, and the police), and SCY. In our analysis, we categorize these existing and proposed policies and interventions into child rights, welfare, or repressive approaches, and analyze how they intersect with the World Health Organization’s conceptual framework for tackling SDH inequities to increase or decrease health equity. Given the resource constraints typically experienced by low-

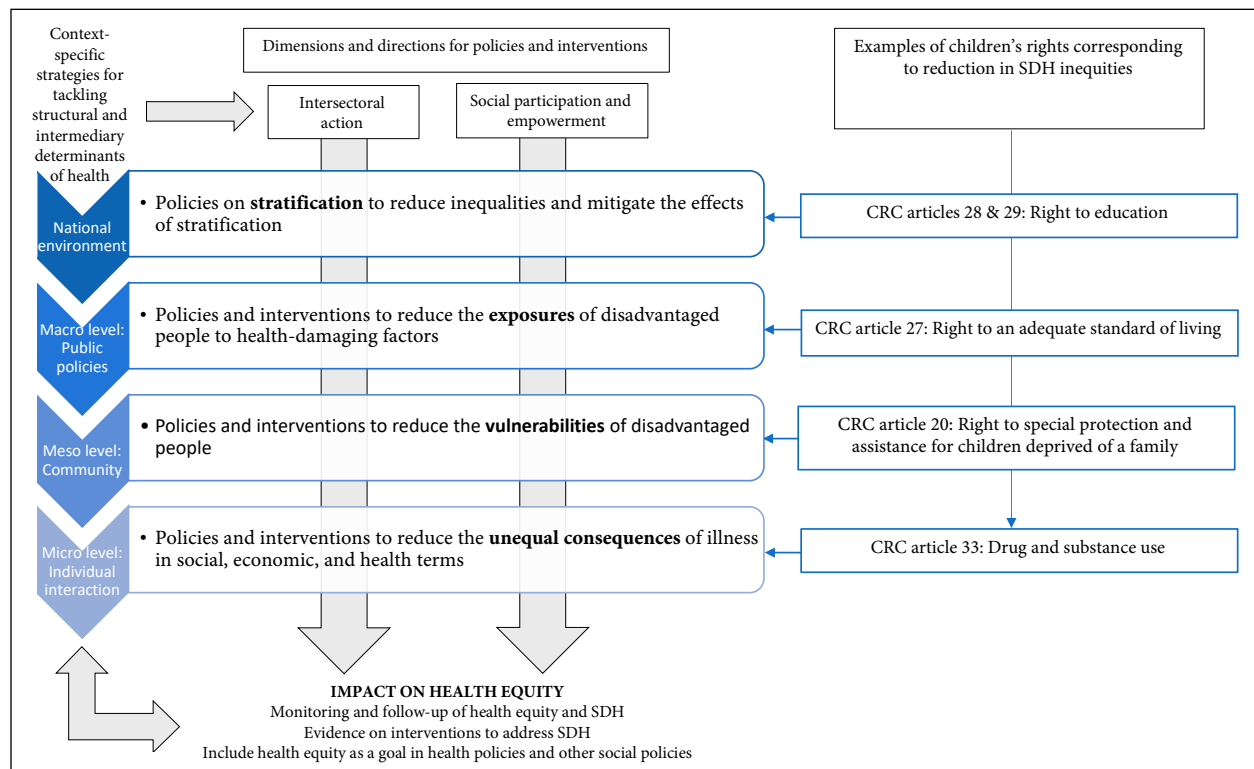
and middle-income countries, we further present how the use of Abraham Maslow’s hierarchy of needs can help governments and other stakeholders prioritize interventions and policies for implementation.¹⁵ This study is vital for informing effective policymaking that respects SCY’s rights and for providing evidence for the design and implementation of responsive and contextually relevant policies and interventions that reduce health inequities.

Methods

Study design

This multi-method qualitative study was conducted from May 2017 to September 2018. We conducted focus group discussions and in-depth interviews with a broad range of social actors, analyzed archival newspaper articles, and analyzed a government policy document to explore and describe proposed and existing policies and interventions that seek to respond to the needs of SCY in Kenya.

FIGURE 2. Examples of how child rights policies for SCY can increase health equity at various entry points in the conceptual framework for tackling structural and intermediary determinants of health inequities



Study setting

We purposively selected five counties in western Kenya as study sites (Trans-Nzoia, Bungoma, Kisumu, Uasin Gishu, and Nakuru) where large numbers of SCY are known to reside. Our primary study site was the town of Eldoret, the administrative capital of Uasin Gishu, home to Moi University, Moi Teaching and Referral Hospital, and the Academic Model Providing Access to Healthcare (AMPATH), a long-standing partnership between Moi University, Moi Teaching and Referral Hospital, and a consortium of universities from North America.¹⁶

Study participants

Participants included a diverse range of social actors, such as community leaders (chiefs and elders), the county children's coordinator, children's officers, police officers, vendors, general community members, stakeholders such as SCY opinion leaders and directors of relevant nongovernmental organizations, parents of street children, former and current SCY, peer navigators, and health care providers at Moi Teaching and Referral Hospital and AMPATH in Uasin Gishu County given our established relations with the local community. In all other counties, we engaged children's officers, police officers, and SCY.

Ethical considerations

This study received ethical approval from Moi Teaching and Referral Hospital's Institutional Research Ethics Committee and the University of Toronto's Research Ethics Board. The study received a waiver of parental consent for minors. Written informed consent was obtained from all participants. Participants were made aware that their interviews would be audio recorded; nine participants declined to be audio recorded but agreed to be interviewed and gave the interviewer permission to take notes. Community participants and SCY were compensated for their time with 200 Ksh (US\$2), and government officials were compensated with 1,000 Ksh (US\$10).

Recruitment and enrollment

We conducted street outreach and study sensitiza-

tion in street venues in each county to establish a relationship with SCY and explain the purpose of the study. SCY aged 15–24 were purposively sampled and invited to participate voluntarily in the study from these locations. We contacted community members (leaders, vendors, police officers, and parents of SCY) by phone or in person to explain the purpose of the study and invite them to voluntarily participate. For government officials, we initially contacted them with a formal letter and then followed up in person. At Moi Teaching and Referral Hospital and AMPATH, we purposively selected health care providers through our established networks and contacts.

Data generation

The study's data sources consisted of the following: 10 randomly selected newspaper articles focused on SCY in Kenya that were published between 2015 and 2018; one purposively selected international newspaper article; a government policy document; and 41 in-depth interviews and seven focus group discussions with a total of 100 participants (48 women and 52 men). The median age was 16 years for SCY participants and 42 years for community members. A team of eight trained interviewers conducted focus group discussions and in-depth interviews in either English or Swahili. In total, 22 interviews were conducted in English and 26 were conducted in either Swahili or a mix of Swahili and English. Focus group discussions and in-depth interviews used an interview guide that asked participants about their general perceptions of the population, their experiences interacting with SCY, their perceptions of SCY's needs, and areas for potential intervention. A separate interview guide was developed for SCY, which asked about their experiences and interactions with the community, their perceived needs, their ability to access health care and other social services, and their interest in specific interventions. Focus group discussions lasted an average of 1.5 hours, and in-depth interviews lasted an average of 40 minutes.

Qualitative data analysis

After conducting an in-depth reading of our data,

we held multiple collaborative analytic working group meetings. We developed a codebook in an iterative manner drawing on the Committee on the Rights of the Child's General Comment 21 and the World Health Organization's conceptual framework on the SDH.¹⁷ We developed a series of codes based on each article of the CRC to capture how existing and proposed policies and interventions respond to the needs and rights of SCY. We then analyzed how each policy or intervention relates to a specific article of the CRC and whether it could be categorized as a child rights, welfare, or repressive strategy. We used the World Health Organization's conceptual framework on SDH inequities in our analysis to demonstrate how these proposed and existing policies and interventions intersect with the conceptual framework to determine their potential influence on health equity for SCY. We developed the final codebook by repeatedly testing its validity and comprehensiveness through test-coding transcripts. Four of the authors coded the transcripts and compared them for consistency. Analytic notes and annotations were documented and used in a series of interpretive meetings to define and refine themes.

Findings

Our analysis explores existing and proposed policies and interventions that seek to respond to the needs of SCY in Kenya. We categorize these strategies according to three major themes: repressive, welfare, and child rights-based approaches in line with the CRC.¹⁸ We explore how each type of strategy may affect socioeconomic stratification, exposures to hazards and risks, social and economic vulnerabilities, and unequal consequences for SCY in the context of the conceptual framework for tackling SDH inequities (Figure 1). In Tables 1, 2, and 3, we identify each policy or intervention, provide a supporting quotation by a study participant, categorize whether the policy or intervention is existing or proposed by study participants, identify the CRC article(s) it relates to, and outline how the policy or intervention intersects with the World Health Organization's conceptual framework for tackling SDH inequities to reduce or increase health equity.

Repressive strategies

Table 1 shows a number of repressive strategies that exist in Kenya or were proposed by participants to respond to the issue of child and youth street involvement. Existing strategies include forced displacement and migration, targeted violence, "street sweeps," the criminalization of street involvement, juvenile detention, the separation of children from street families, and extrajudicial killing, all of which contravene the CRC and result in decreases in health equity. Situated within the framework for tackling SDH inequities, the majority of these strategies can be seen as public policies that result in increasing SCY's exposures and vulnerability to specific health-compromising conditions. One exception is the criminalization of street involvement, which may increase social stratification by further affecting SCY's socioeconomic position (for example, by leaving them with a criminal record). Nonetheless, some participants recommended the criminalization of street involvement as a policy to reduce and prevent street involvement:

We need laws in Kenya to govern the street children, a law prohibiting any child from going to the streets so that we can control that movement. (clinician)

Despite the fact that the criminalization of street involvement was abolished when the Vagrancy Act was repealed in 1997, numerous laws continue to contain provisions allowing for the arrest and detention of SCY, including the power to arrest without warrant and offenses related to idle and disorderly conduct.¹⁹ As explained by a children's officer, SCY are frequently arrested through street sweeps, detained in prison, and eventually released back to the streets, suggesting that street involvement remains criminalized:

So the only thing they will do is sweeping them off the street, arresting them, throwing them in prison, and the prisons will reach a point where it is overwhelming because you can't just get over 300 youths and children, bring them at the prisons, and then dump them there. What was their capacity, what plans did you have? Because even at that time, we felt bad that this is what the county government can do, doing raids at 2 a.m. in the night, gathering

the children and then bringing them here. We start assessing. From the assessment, there is no aftercare plan. What do you do? Take them to prison or remand and then tomorrow again you will meet them in the street? (children's officer)

As the children's officer suggests, this process of criminalization does nothing to rehabilitate children and youth or reduce the harms associated with street involvement. Instead, it leaves children and youth further oppressed and provides a legal avenue to enact related repressive strategies, such as street sweeps, juvenile detention, and imprisonment.

Welfare strategies

The existing and proposed welfare strategies that we documented include family reunification and repatriation, rehabilitation and rescue centers, children's homes (orphanages), and education (Table 2). The majority of these welfare strategies are situated at the public policy and community levels, require targeted public policies and investments, and seek to uphold article 20 of the CRC on the right to special protection and assistance for children deprived of a family environment. The impacts of these welfare strategies on health equity are variable, and many may increase or decrease health equity depending on how the policy or intervention is implemented, the quality and standards of care, and the extent to which the child's right to be heard and involved in decision-making is considered.

Family reunification and repatriation. Immediate and extended families are the first line of care for orphaned and vulnerable children when they are able to provide a safe and appropriate care environment.²⁰ Family reunification and repatriation represents one welfare strategy for SCY who have a home, as explained by a county children's coordinator:

Ideally, those who have homes have to be integrated back to the community where they come from and in an organized manner. (county children's coordinator)

However, SCY who are repatriated frequently return to the streets, as stated by a children's officer:

Even if you are able to trace their homes and re-integrate them, after two weeks they will be back on the streets. Sometimes it is annoying, and you end up being harsh on them. When they are apprehended, some of them are remorseful and they say that they will never come to the streets again and they want to go to school. (children's officer)

SCY report that abject poverty, family conflict, neglect, abuse, and alcoholism in the home precipitate their migration to the streets.²¹ As a result, it is likely that a large proportion of SCY being repatriated home subsequently return to the street due to unsafe home environments and the inability of parents or guardians to provide an adequate standard of living, including education, thereby increasing exposures and vulnerabilities and decreasing health equity. As stated by a children's officer, many children report that "they want to go to school," suggesting that their families were unable to send them to school and hence they returned to the streets. SCY may be repatriated without careful consideration of their best interests (CRC article 3) and without being consulted in the decision-making process (CRC article 12). When SCY willingly agree to be repatriated home, impoverished households should be supported through the provision of social protection programs (CRC article 18) and support to parents and caregivers (article 27).²² In cases where a family is unable to care for the child, temporary or permanent alternative care in institutions such as rescue centers or children's homes may be an option.

Rescue centers and rehabilitation facilities. When children and youth connected to the streets are without parents or guardians, the state is the *de facto* guardian and is obliged to ensure safe alternative care to any child temporarily or permanently deprived of his or her family environment; this does not include detention cells or closed centers where children and youth are deprived of liberty.²³ Safe

alternative temporary care may reduce exposures and vulnerabilities, thus increasing health equity. The use of rescue centers is an existing welfare strategy promoted by children's officers across counties as an alternative care environment that should be expanded:

Number one, street children do not belong to remand homes because these are just children in need of care and protection, and the same applies to adults living on the streets. What should be the number one priority? Because these people need rehabilitation, not just picking and taking them back home. We need a place of safe custody and what we call rescue centers. (children's officer)

When appropriate and quality rescue centers exist, SCY may be hesitant to access them due to fear and distrust of the government as a result of the frequent use of repressive strategies. As explained by a children's officer, SCY are reluctant to use a government child protection center that is run in partnership with a nongovernmental organization:

Like I told you before, they fear accessing this place. So, you can stay even for months without seeing a single street child being brought here at the center because of the perspective they have knowing this is the juvenile, so they imagine, "I am taking myself to be arrested." But we try our best to tell them you can come here, access counseling. (children's officer)

SCY's participation in the design, implementation, and day-to-day service provision at rescue centers may build trust and therefore ensure that interventions are responsive, appropriate, and used. SCY have a right to be heard (CRC article 12) and to participate in the decision-making process regarding their placements and care environment (CRC article 20).²⁴ Failure to consider the child's views and their willingness to enter a specific care environment may result in them returning to the streets or being unnecessarily exposed to inequitable health outcomes.

Child rights strategies

Table 3 shows child rights strategies proposed by

participants to respond to the issue of child and youth street involvement. The proposed strategies are both universal and targeted. They intersect at multiple levels with the conceptual framework for tackling SDH inequities, and so decrease social stratification, exposures, vulnerability, and unequal consequences of ill health. Despite the fact that our findings indicate that the majority of existing policies and interventions implemented in Kenya use repressive and welfare strategies, children's officers across counties recognized that SCY are rights holders and that the CRC should guide policies and interventions for this vulnerable population. For example, one officer stated:

Here the situation is so pathetic, I remember even the UN Convention on the Rights of the Child states that a nation is supposed to create programs for such children—therefore, we must actually address the problems and give them their rights, like shelter, where something beneficial to them should be ongoing like vocational training. There should be something for each one of them, especially to prepare for their future. (children's officer)

While the child rights strategies in this section do not exist in practice, they represent an array of contextually relevant child rights strategies that policy makers and other stakeholders could employ to address SDH inequities and improve health equity for SCY. Below, we explore the following subthemes that emerged from these proposed strategies: political representation; education, vocational training, and life skills; and housing and basic needs for an adequate standard of living.

Political representation. National governments are responsible for protecting and advancing the health equity and human rights of SCY. SCY's participation in shaping social and health policies and interventions upholds their right to be heard (CRC article 12), right to freedom of association in civil and political space (CRC article 15), right to freedom of expression (CRC article 13), and right to access information (CRC article 17).²⁵ One former street-connected young woman recommended that the government elicit the opinions of SCY in order

to inform policy:

The government should summon them so that they can air their views so that the government knows how to help them because you cannot just push them to a place. (former street-connected young woman)

The suggestion to involve SCY in policymaking extended to the election of a representative to advocate on their behalf, as proposed by a clinician:

We should bring a bill where we treat them as a special group of people, like we treat the disabled [and] then we elect someone to represent their interests in Parliament because they are many—the data shows there are about 100,000 street children in Kenya. (clinician)

The social participation and empowerment of disadvantaged groups to shape social and health policies is an essential component of promoting health equity.²⁶ Political representation and inclusion in dialogue and decision-making regarding social and health policies and interventions upholds SCY's rights while also increasing the likelihood that strategies are responsive and relevant to their circumstances and needs.

Education, vocational training, and life skills. Access to free, safe, appropriate, and quality education (CRC article 28) is vital not only for preventing street involvement but also for supporting children and youth already on the streets and who are interested in returning to school. The education system should have a range of options from which SCY can choose with proper guidance.²⁷ This may include formal and informal education, vocational training, and life skills training, all of which may reduce social stratification and thereby positively affect SCY's health equity. As suggested by one community leader, free educational facilities could be established specifically for SCY:

A school should be built to educate street children, but there should be order so that you know who the street children are, these children know each other so you just can't bring in someone new ... It has to

be free because they can't afford, but if they have to pay, they can get sponsors when they advance with education. (community leader)

Another community leader explicitly suggested that children and youth be included in the decision-making process on education: "Ask them what they want to do and give them options to the available courses." In addition, a peer navigator explained that entry into any education system requires consideration of SCY's age, length of street involvement, gender, and readiness for change:

I would enroll all of them according to their ages so that you know where to fix whom, because the young ones may not be thinking about life. For those below 13 years, they can go back to school or adult learning, like at the drop-in centers there can be teachers there to help them and be taught about behavioral changes like quitting gum [glue sniffing]. If they change, if they want to learn, take them to school and do a follow-up. Some may become mechanics; take them to someone to train them. For girls, you can train them sewing and open up a place for them. That is, if they want to change. (peer navigator)

SCY across counties expressed that those who wished to return to school should be supported in doing so. The type of education they are offered should be dependent on their ages, as explained by one street-connected young man:

We think the young ones should go to school and if someone can volunteer to be their guardian so that their lives can change ... The young ones should be taken to school, for some of us we can provide for ourselves so if one has a talent, help us to nurture the talent to help ourselves. (street-connected young man)

Nurturing talents may be done through vocational and other life skills training. Older SCY generally suggested they be trained and supported in finding jobs and starting income-generating activities in lieu of returning to formal education. Safe, quality, appropriate, and free education in all of its forms may improve SCY's socioeconomic position, lead to changes in occupation and income, and in turn

help reduce social stratification and increase health equity.

Housing and basic needs for an adequate standard of living. SCY have a right to an adequate standard of living, adequate nutrition, clothing, safe housing, and free and accessible medical care and education (CRC article 27). Additionally, children deprived of a family environment have a right to special protection and assistance (CRC article 20). Housing, a care environment, and access to basic services all affect an individual's material, social, environmental, and psychosocial circumstances, which influence their exposure and vulnerability to health-compromising conditions.²⁸

A large proportion of participants recommended that shelter and essential basic needs be a priority in responding to the crisis of SCY in Kenya. As suggested by a clinician, "We should first consider human basic needs; they need a house, clothing, and food." Participants proposed different strategies with respect to shelter, from the general provision of housing to that of night shelters, as stated by a vendor:

I would have a place built for them where they can come to sleep even if they loiter the whole day. Shelter is very important because they are really dying from pneumonia due to cold. On the streets you can't tell a sick one, but if they live somewhere you can be able to tell, some even die, and you won't know. (vendor)

Beyond housing and shelter, SCY have a right to adequate nutrition under CRC articles 6 (right to life) and 27 (adequate standard of living). Nutrition is fundamental to a child's survival and development and can reduce the unequal consequences of ill health. One religious leader suggested implementing a feeding program:

Maybe feeding because most of them suffer from malnutrition, sometimes they don't eat. Or they eat things from the dustbin. A good feeding program is important. (religious leader)

However, the use of feeding programs was opposed by children's officers in some counties, due to fears

of "pull factors" (that is, drawing children to the street):

We also need to do away with these feeding program which people think is the best even within the business community not knowing that this is a pull factor. (children's officer)

To avoid this risk, some suggested that feeding programs be connected to broader long-term services:

I am not for the idea of a feeding program that is not connected to a long-term solution, so feeding them and allowing them to go back to the streets is not right. If you feed them, even those in estates will always come for lunch, even if they are in schools. (county children's officer)

The fact that children and youth not connected to the streets might leave school at lunchtime to access a feeding program may point to a broader community issue of household food insecurity among vulnerable children and youth living in informal settlements. Therefore, a feeding program intervention may require a universal rather than targeted policy—such as a universal school lunch program in addition to feeding programs for SCY—to address vulnerable children's right to adequate nutrition regardless of their street involvement.

A model to advance health equity for street-connected children and youth

Our findings suggest that existing repressive and welfare-based strategies may contribute to health inequities for SCY in Kenya by increasing socio-economic stratification, exposures to hazards and health risks, vulnerabilities, and unequal health consequences. As a result, we have developed a checklist for policy makers and other stakeholders to help them assess how their policies, programs, and services are upholding SCY's human rights, addressing their needs, and working to advance health equity (Figure 3). This checklist can also guide local and national governments and other stakeholders in prioritizing their responses to the many needs of SCY. Using a child rights approach and drawing on Maslow's hierarchy of needs, we propose that at the foundation of any response be

an immediate obligation to meet SCY's physiological needs.²⁹ The overall goal of this checklist is to assist stakeholders in ensuring that SCY are able to enjoy minimum essential levels of their social, economic, and cultural rights, while doing so in a manner that meets SCY's most pressing needs in a hierarchy of influence. While all of the rights outlined in the CRC are essential, implementing policies and interventions to respond to the issue of child and youth street involvement and reduce the harms associated with street life requires careful consideration of which basic needs must be met before an individual is able to modify their behavior and shift their motivation to the next emerging need in the hierarchy.³⁰ For example, a child will not be able to actively participate and learn in school (safety), or in sports and other recreational activities (self-actualization), if their basic physiological need for food is unmet. Therefore, we suggest using the checklist to work from implementing policies and interventions that support SCY's physiological needs first and foremost, followed by safety, love and belonging, self-esteem, and self-actualization.

Discussion

Our findings indicate that the majority of policies and interventions that have been implemented to respond to the issue of SCY in Kenya are repressive and welfare strategies that contravene the CRC.³¹ It is important to note that policies and interventions that we classified as welfare strategies (such as family reunification and repatriation, as well as rescue centers and rehabilitation) may be rights-based when children and youth are involved in the decision-making process regarding their care. Notably, our results suggest that a diverse range of actors, including government officials, across Kenya recognize the importance of children's rights and have recommended numerous contextually relevant child rights strategies that can be implemented and evaluated for their effectiveness and impact on health equity for SCY.

It is clear that a range of policies and interventions are required to tackle structural and intermediary determinants by reducing social

stratification, differential exposures and vulnerabilities, and the unequal consequences of ill health; no one intervention will meet all of SCY's rights and needs. The social, economic, and health inequities experienced by SCY are multiple and require a coordinated intersectoral government and civil society response.³² Our checklist outlined above can be used to support policy makers and civil society in doing so within a framework that upholds SCY's human rights. Given the lack of existing evidence-based policies and interventions for SCY in low- and middle-income countries, governments, stakeholders, and researchers should collaborate to design, implement, and evaluate strategies that may be situated within this checklist.³³

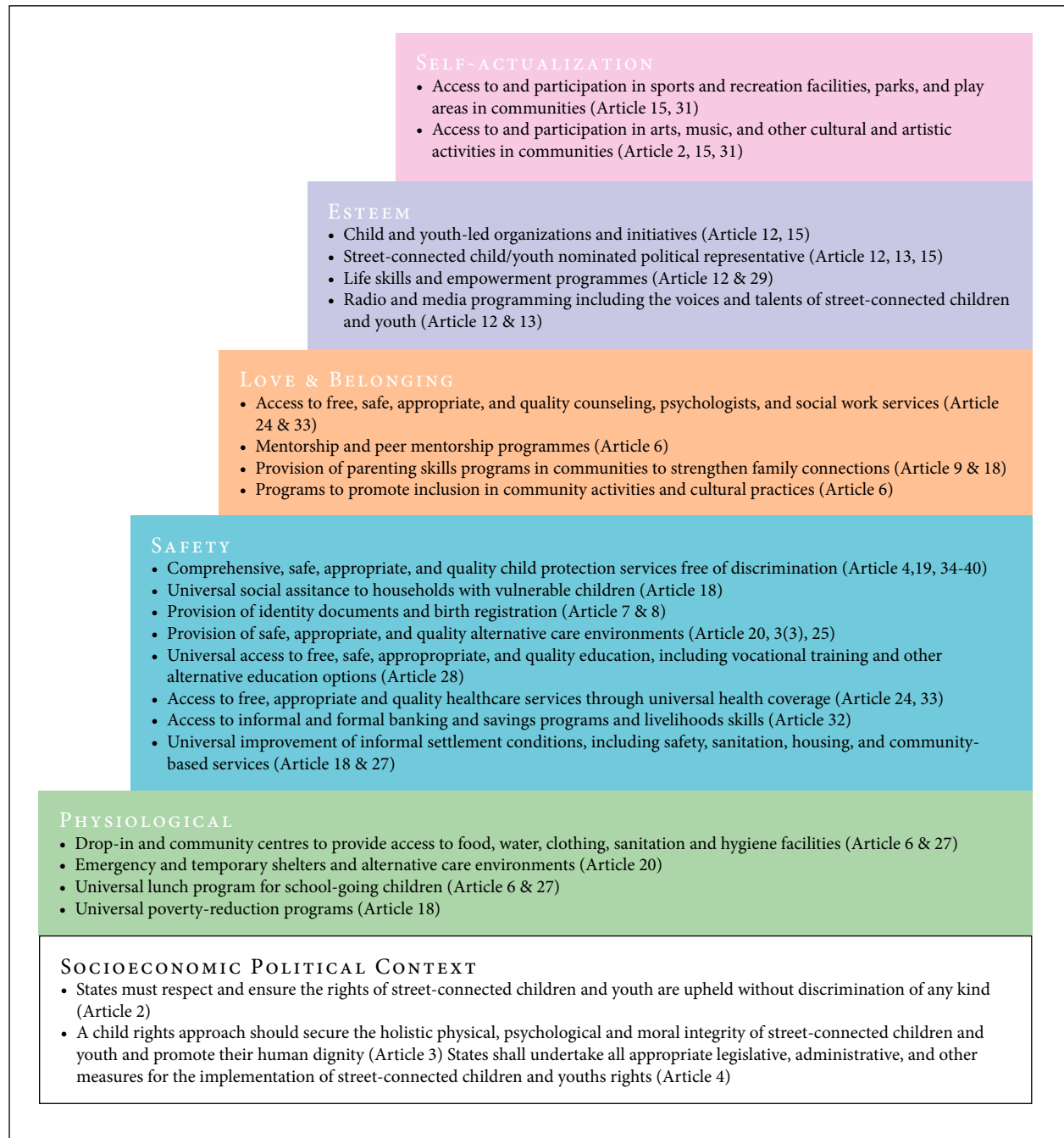
Existing child rights and evidence-based poverty reduction strategies, such as Kenya's cash-transfer program for orphaned and vulnerable children, could, for example, be extended to all impoverished households caring for the most vulnerable children and youth.³⁴ Given that household poverty is a primary structural determinant of children and young people's street involvement, alleviating poverty and improving households' ability to adequately care for children will likely reduce the number of children and youth who migrate to the streets.³⁵ Critically, there is a need to develop and implement social welfare programs for children and youth who are already connected to the streets. Direct assistance to children and youth through the provision of food, safe places to live, and free and accessible medical care and education is fundamental to their rights to special protection, assistance, and an adequate standard of living.

This study has both strengths and limitations. Our investigation solicited the ideas of a diverse range of actors across Kenya. We also upheld SCY's right to be heard by actively involving former and current SCY in identifying policies to advance health equity—a crucial component of an effective plan for action on SDH equity. Moreover, our analysis was situated in the World Health Organization's widely used and well-regarded conceptual framework on SDH inequities in conjunction with the CRC, making it appropriate for and applicable to addressing health equity through legal and polit-

ical reform. Despite these strengths, the geographic limitations of our study mean that our findings may not be generalizable to all counties in Kenya or to other low- or middle-income countries. Nonetheless, we believe that our recommendations can

be adapted to other low- and middle-income countries, given their foundation in the CRC and the World Health Organization’s framework on SDH inequities. While our checklist is meant to provide guidance, we recognize that it is not exhaustive

FIGURE 3. Checklist for assessing whether policies and interventions are upholding SCY’s human rights and addressing their needs



and that other child rights policies and intervention options may exist. We encourage those using this tool to situate their child rights policies and interventions within the hierarchy and carefully consider the context for implementation and their mechanisms of action and impact on health equity.

Conclusion

Child rights strategies and intersectoral collaboration are required to respond to the epidemic of child and youth street involvement and to reduce the harms associated with street life. Although repressive and welfare strategies are the ones most employed in Kenya, utilizing a child rights approach would provide a strong framework for advancing health equity through action on the SDH for SCY in Kenya. Our findings point to several policies and interventions that can be evaluated for their effectiveness in reducing street involvement and ameliorating the health and well-being of SCY.

TABLE 1. Repressive strategies to mitigate child and youth street involvement, human rights concerns, and impacts on health equity

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Forced migration	"The county government of Uasin Gishu tried, they took all of them and took them elsewhere in Western, but they came back. The governor of Busia is the one who returned them, he said that they came from that direction [laughs]." (nurse/counselor/social worker)	X		<ul style="list-style-type: none"> Article 2 on non-discrimination Article 15 on the right to freedom of association and peaceful assembly 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities
Targeted violence by county askaris and law enforcement	"We have the local chief who is very brutal to us. Anytime we go for his help, he beats us up and we are often locked up by his AP officers after thorough beating." (street-connected young person)	X		<ul style="list-style-type: none"> Article 2 on non-discrimination Articles 19 and 39 on freedom from all forms of violence Articles 37 and 40 on juvenile justice 	Macro level: Public policy Meso level: Community Micro level: Individual	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities ↑ Unequal consequences
Street sweeps and roundups	"There is a time we did a sweep in town, we got over 247, we tried to take them to institutions for temporary placement and planning on how we can try and trace maybe their homes, families, relatives, so it became a challenge because some of them will run away." (children's officer)	X		<ul style="list-style-type: none"> Article 2 on non-discrimination 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities
Criminalization of street involvement	"Being on the street should be made an offense by the bylaws of the county government. It is a crime to be seen on the street according to the Children's Act. If there is a bylaw, they will not be taken to prison. Children should be taken to institutions under the bylaw. The law should be that you pick a street child and take them to an institution. They are in the street because of bad associations, but actually it is illegal." (police officer)	X	X	<ul style="list-style-type: none"> Article 2 on non-discrimination Articles 37 and 40 on juvenile justice 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Stratification ↑ Exposure ↑ Vulnerabilities
Remand homes, juvenile detention, and prison	"We also have a remand hall in [location redacted] and there was a time that street children and youths engaged themselves in crimes and the public was very hostile to them because two polytechnic students were murdered, and it was alleged that the street people did it, so in order to save them we had to round them up at the remand hall for sometime because it turned out very ugly." (county children's officer)	X		<ul style="list-style-type: none"> Article 2 on non-discrimination Article 20 on the right to special protection and assistance for children deprived of a family environment Articles 37 and 40 on juvenile justice 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities

TABLE 1, *continued*

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Separation of children from families	"I feel bad when I meet ladies with children, I usually feel like taking them home. If you take the mother, she will come back [to the street] so you just take the child." (community member)	X		<ul style="list-style-type: none"> Article 9 on separation from parents 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities
Forced sterilization and one-child policy	"For their population to be limited, the government should start a home for them and maybe force them and to stop more reproduction on the streets ... We should develop a policy like China, one family one child [laughs] because I have not read anywhere that there are street children in China, when you want another kid you must have a very good reason ... If you have one kid, there is a slim possibility that this child will run to the streets." (clinical officer)		X	<ul style="list-style-type: none"> Article 18 on parental responsibility Article 6 on the right to life, survival, and development 	Macro level: Public policy	<ul style="list-style-type: none"> ↑ Vulnerabilities ↑ Unequal Consequences
Extrajudicial killing	"Activists are convinced that the county government has embarked on a policy of trying to rid Eldoret of its street children population by killing them or killing enough of them to force the others to flee." (Guardian, October 10, 2016)	X		<ul style="list-style-type: none"> Article 6 on the right to life, survival, and development 	Macro level: Public policy Meso level: Community	<ul style="list-style-type: none"> ↑ Exposure ↑ Vulnerabilities

TABLE 2. Welfare strategies to mitigate child and youth street involvement, human rights concerns, and impacts on health equity

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Family reunification and repatriation	"Some said they had homes, but a small percentage had nowhere to go, and I remember working with the police and the civil society to remove them from the streets. We took them home and barely two weeks later they were back on the streets." (children's officer)	X		Article 20 on the right to special protection and assistance for children deprived of a family environment	Macro level: Public policy Meso level: Community	↓↑ Exposure ↓↑ Vulnerabilities
Rescue centers and rehabilitation facilities	"Yes, because I feel these children are really suffering and they sniff glue. They should be well taken care of, even if they are locked up somewhere and given security and leave only when they have been rehabilitated. They should also be educated." (police officer)	X		Article 20 on the right to special protection and assistance for children deprived of a family environment Article 3(3) on standards of care and protection institutions, services, and facilities Article 25 on periodic review of placements	Macro level: Public policy Meso level: Community	↓↑ Exposure ↓↑ Vulnerabilities
Children's home	"For the small ones, there should be a children's home that is funded partially by the community and partially by government, it would really help them. They are bright and they can learn." (vendor)	X		Article 20 on the right to special protection and assistance for children deprived of a family environment Article 3(3) on standards of care and protection institutions, services, and facilities Article 25 on periodic review of placements	Macro level: Public policy Meso level: Community	↓↑ Exposure ↓↑ Vulnerabilities
Education	"Find ways of handling those who are already here by forcing them to go to school, of course talk to them first and they may do what you are telling them. Some may want to go to vocational trainings. Give them a period and those who would still refuse after this period, take actions on them because sometimes force is good." (religious leader)		X	Article 28 on education Article 29 on the aims of education	Macro level: Public policy	↓ Stratification ↓ Exposure

TABLE 3. Child rights strategies to mitigate child and youth street involvement, human rights concerns, and health equity impacts

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Political representation	"We should bring a bill where we treat them as a special group of people, like we treat the disabled [and] then we elect someone to represent their interests in parliament because they are many—the data shows there are about 100,000 street children in Kenya." (clinical officer)		X	Article 12 on the right to be heard Article 15 on the right to freedom of association and peaceful assembly Article 13 on freedom of expression Article 17 on access to information	Global level Macro level: Public policy	↓ Stratification
Education	"Those willing to go back to school, they go back to school." (clinical officer)		X	Article 28 on education Article 29 on the aims of education Article 27 on an adequate standard of living	Macro level: Public policy	↓ Stratification ↓ Exposure
Vocational training	"In terms of investment as a country we are losing a lot, these are people with energy who can do much for this country because they need to participate in country building and we have to think on how to empower them through education and informal education for some like vocational training." (community stakeholder)		X	Article 28 on education Article 29 on the aims of education Article 27 on an adequate standard of living	Macro level: Public policy	↓ Stratification ↓ Exposure
Life skills and empowerment	"Girls need to be made to believe in themselves, that even if they are found on the streets there is something good in them and they can work towards that and be better people later in life. Like giving them insight so that they can identify what they can do in life. We can start variety of things so that they know what to pursue, maybe they won't want to go back to school but they can do vocational training like beadwork, sewing and even gardening." (nurse/counselor/social workers)		X	Article 28 on education Article 29 on the aims of education Article 6 on the right to life, survival, and development Article 27 on an adequate standard of living	Macro level: Public policy Meso level: Community	↓ Stratification ↓ Exposure ↓ Vulnerabilities
Economic and livelihood strategies	"If it's mostly youths, we will have to set up economic programs that will empower them so that they can have their own families and provide. You will find that in town they have started engaging in some economic activities, they are directing traffic and parking lots, they are doing car wash so I will go for that economic program to empower them." (clinical officer)		X	Article 28 on education Article 29 on the aims of education Article 27 on an adequate standard of living	Macro level: Public policy Meso level: Community	↓ Stratification ↓ Exposure
Social protection	"I know the national government has programs targeting orphans and vulnerable children, but there should be a special program for the street families." (community stakeholder)		X	Article 18 on parental responsibility	Macro level: Public policy	↓ Stratification
Empowerment of parents and families	"We should make the parents able. Most are from a poor family and unable to receive basic needs. We should empower parents by creating businesses and chamas [savings groups]. We can offer them rehabilitation from alcoholism." (police officer)		X	Article 18 on parental responsibility	Macro level: Public policy Meso level: Community	↓ Stratification ↓ Exposure
Issuing identification and documents	"What the government can do is to provide ID cards for those above 18 years and any other social support." (clinician)	X	X	Article 7 on birth registration Article 8 on identity	Macro level: Public policy	↓ Stratification

TABLE 3, *continued*

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Comprehensive rehabilitation centers	“And the only way is having that facility where rehabilitation can be done, where they can access medical care, they can be able to access education, clothing and food.” (children’s officer)		x	Article 28 on education Article 20 on the right to special protection and assistance to children deprived of a family environment Article 27 on the right to an adequate standard of living Article 24 on health	Macro level: Public policy Meso level: Community	↓ Stratification ↓ Exposure ↓ Vulnerabilities ↓ Unequal Consequences
Medical insurance	“There is the government initiative of NHIF [National Hospital Insurance Fund], we should create a small package of taking care of their health needs that they can be able to access. It should be a social responsibility for NHIF, I am sure they are making profit.” (clinician)		X	Article 24 on health Article 33 on drug and substance use Article 27 on an adequate standard of living	Macro level: Public policy	↓ Stratification Vulnerabilities
Access to health services	“According to our Constitution, it’s a basic and fundamental right of every citizen of our country to be provided for health care by the government. If we say we are providing a special kind of medical cover for these people, you know we like free things—people will enlist themselves as street youths and children. It’s better we make health universal to everyone.” (clinicians)		X	Article 24 on health Article 33 on drug and substance use Article 27 on the right to an adequate standard of living	Macro level: Public policy	↓ Stratification ↓ Vulnerabilities
Medical outreach	“I think there should be more medical camps for them, because when you get a street child coming to the hospital, trust me they are very sick. Most of them don’t seek medical attention until it’s maybe too late. So, you see the way we go to the communities to do the health camps, we could also take them to the streets for the purpose of preventions of some of these conditions.” (nurse)		X	Article 2 on non-discrimination Article 17 on access to information Article 24 on health Article 33 on drug and substance use	Meso level: Community Micro level: Individual	↓ Vulnerabilities ↓ Unequal Consequences
Trauma-informed primary care	“Specialized programs should be there for them because we have said that it’s the responsibility of each individual. When they come to the hospitals, we should enroll them in different programs and involve the social worker and psychological counselor and try to talk to them in order to get them off the streets and find them a place to go to. Don’t just see them and leave them to go back to where they were.” (nurse)		X	Article 24 on health Article 33 on drug and substance use	Micro level: Individual	↓ Unequal Consequences
Housing and shelter	“Shelter. We should be rented for houses or taken to a safe place.” (street-connected young person)		X	Article 20 on the right to special protection and assistance to children deprived of a family environment Article 27 on the right to an adequate standard of living	Macro level: Public policy Meso level: Community	↓ Exposure ↓ Vulnerabilities

TABLE 3, *continued*

Policy or intervention	Quotation from study participant	Existing	Proposed	Relevant provision(s) from the Convention on the Rights of the Child	Context	Impacts on health equity
Feeding programs	"Find a way of giving them food, even just one meal a day. If possible, those who want to live outside the streets, a place should be found for them to live in, but the most important one is food." (community stakeholder)	X	X	Article 27 on the right to an adequate standard of living Article 6 on the right to life	Meso level: Community Micro level: Individual	↓ Vulnerabilities ↓ Unequal Consequences
Clothing	"As long as they get food, shelter, and clothing, these children will change." (former street-connected young woman)	X	X	Article 27 on the right to an adequate standard of living	Macro level	↓ Exposure
Drop-in services	"Dropping centers will help them because they will come and shower, get food but at long last they will go back to the base." (peer navigator)		X	Article 20 on the right to special protection and assistance to children deprived of a family environment Article 27 on the right to an adequate standard of living	Meso level: Community Micro level: Individual	↓ Vulnerabilities ↓ Unequal Consequences
Counseling, social work, and emotional support	"They also need love. If you rehabilitate me yet you hate me, it won't add any value." (clinician) "These children usually feel like they are not needed, and when you want to come up with a rehabilitation center or any program that deal with them, you will have to focus on psychological and emotional issues and you must therefore invest a lot in counseling." (community stakeholder)		X	Article 24 on health Article 33 on drug and substance use	Micro level: Individual	↓ Unequal Consequences
Parenting skills	"We should also educate the parents to treat their children like humans and not abandon them because there are parents who send their children to the streets to fend for themselves." (community leader)		X	Article 18 on parental responsibility	Meso level: Community Micro level: Individual	↓ Vulnerabilities ↓ Unequal Consequences
Sports and recreation	"Open up a football academy in town and they form a team that has support groups so that every day after training they leave with something in their pockets and can pay rent. After that they can even play for AFC or Gor and we will say we helped them." (peer navigator)		X	Article 31 on rest, play, and leisure	Micro level: Individual	↓ Unequal Consequences

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Police Discrimination, Misconduct, and Stigmatization of Female Sex Workers in Kenya: Associations with Delayed and Avoided Health Care Utilization and Lower Consistent Condom Use

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Abstract

Discrimination and violence against sex workers by police are common in many populations and are associated with negative health outcomes, as well as being per se violations of human rights laws and norms. There is a close and mutually reinforcing nexus between legally actionable rights violations and stigma, and reducing human rights violations against sex workers likely requires both legal and societal interventions that address both. In this paper, we first aim to estimate levels of discrimination, violence, and stigma against women sex workers by police in Kenya. Second, we aim to estimate the association between manifestations of discrimination and stigma, on the one hand, and general health care

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utilization and consistent condom use, on the other. Using data from a survey of Kenyan sex workers, we document widespread discrimination and stigma. Through regression analyses, participants with the highest levels of all three categories of manifestations of discrimination and stigma reported significant lower consistent condom use. Those with the highest levels of witnessed/heard manifestations were significantly more likely to delay or avoid needed health care, and the highest level of experienced manifestations were associated with a marginally significant increase in delay or avoidance. Our findings document a plethora of violations of human rights obligations under Kenyan and international law.

Background

There is a close nexus between discrimination, violence, and other abuses that are actionable under international and national human rights regimes, on the one hand, and stigma as a social process, on the other. Discrimination, the remediation of which is an obligation of immediate effect in international human rights law, essentially occurs when members of groups that are situated similarly are instead treated differently. For discrimination to be legally actionable, disparate treatment must burden a protected group or be on prohibited grounds that are defined in international law and domestic constitutions and law.¹

Stigma, meanwhile, is seen by social scientists as a process that distinguishes and labels differences, causes those differences to be associated with socially disfavored traits, and separates outgroups from ingroups. This, in turn, allows power to be exercised in such a way that further diminishes the power and social status of those who are stigmatized.² Discrimination is thus a cause of the process by which stigmatization occurs. Once marking and treating individuals as “the other” is authorized by governments—either directly or indirectly, such as by failing to redress discrimination by private actors—stigma is exacerbated.³

Simultaneously, the process of stigmatizing a group is an important mechanism by which discrimination comes into being. Once groups are stigmatized in a society, it is harder for them to

make claims to being equally situated in the eyes of the law. Policies concerning such groups become increasingly likely to be based in animus or stereotype because those who make and enforce policies wrongly believe the distinctions to be material, and diminished power precludes effective protection against animus or contestation of stereotypes.⁴ Thus, while legal measures to prevent and remedy discrimination and other acts that harm marginalized groups are necessary to reduce stigma, steps to reduce stigmatization are often also required to create the political space in which anti-discrimination law can be effectuated.⁵

In the usual social science framework, then, discrimination and stigma are mutual causes with a partial conceptual overlap.⁶ Though stigma is commonly thought of as a mental state, social scientists think of it as a social process with measurable manifestations. Stigma can be measured in its various manifestations: the experience of discriminatory and othering acts (experienced stigma), the observation (witnessed or heard stigma) or secondhand perception of their likelihood, the anticipation of such acts (anticipated stigma), and internalization toward oneself (internalized stigma). Usually, multiple and layered manifestations act on the same person.⁷ Acts of discrimination are measured within the concept of experienced stigma and are often actionable under the law. Other manifestations of stigma are often not legally actionable but cause meaningful harm to both individuals and groups, and failing to address them undermines the effec-

tive protection of human rights.

Around the world, sex workers encounter high levels of discrimination, violence, and stigma by police. While the problem is ubiquitous, levels are highest in settings where sex work is criminalized, granting police the opportunity to exploit power differentials over sex workers, and exacerbated where legal systems and policing culture do not provide accountability for misconduct.⁸ Abuses committed by police include verbal and physical abuse, arrest, refusal to protect, and confiscation of condoms. This conduct violates state duties to respect a variety of human rights protected under international law and most countries' domestic law. These rights include the right to be free from discrimination; freedom from cruel, inhuman, and degrading treatment; the right to the security of one's person; the right to be treated with dignity; the right to privacy; the right to personal autonomy; and the right to equality before the law.⁹ When conduct directly impedes access to public health or health care—either because sex workers experience wrongful acts or because of anticipated, witnessed or heard, or internalized manifestations of stigma created by police—violations of the right to the highest attainable standard of health also exist.¹⁰

Links between discrimination, violence, and stigma against sex workers, greater exposure to health risks, and reduced health care access and utilization are well documented across a variety of contexts.¹¹ Existing research framed through the lens of stigma against sex workers by police and health outcomes has focused primarily on experienced stigma. It has focused principally on outcomes related to HIV and other sexually transmitted infections, finding strong evidence that experiencing negative police interactions is associated with reduced condom carrying and use, as well as increased risk of HIV and other sexually transmitted infections.¹² UNAIDS has recognized the criminalization of sex work as a driver of HIV risk among sex workers, who bear disproportionate levels of HIV risk.¹³ Additionally, violent injury at the hands of police is well documented, and research also indicates that stigma manifesting as police refusal to protect increases the likelihood of

injury by private actors.¹⁴

Only a few studies have examined linkages between police conduct and health care utilization outside of HIV services, and research is lacking from sub-Saharan Africa.¹⁵ Additionally, while a few studies have found aspects of anticipated and witnessed or heard stigma by police to be extensive, little work has examined the association between anticipated and witnessed or heard manifestations of police stigma and health outcomes. Anticipated and witnessed or heard stigma against sex workers by other actors is associated with a variety of adverse health outcomes.¹⁶ While the interconnectedness of the right to health and violations of other human rights is central to the modern conception of health and human rights, achieving a more nuanced understanding of this relationship is important for both effective human rights advocacy and public health programming.¹⁷

Kenya is a particularly important country in which to understand linkages between human rights violations or manifestations of stigma against sex workers by police and health care outcomes. Though Kenya has made substantial progress in reducing HIV incidence and increasing access to treatment nationwide, the prevalence of HIV remains very high among sex workers—with estimates in Nairobi of about 30%.¹⁸ While accurate estimates of the number of people engaged in sex work are difficult to acquire, a recent study estimates that about 5% of urban women aged 15 to 49 engage in sex work.¹⁹ Simultaneously, Kenya has progressive constitutional provisions that should limit police misconduct and impunity for it; however, it also has a long legal tradition—reaching back to the colonial era—of failing to respect and protect the rights of sex workers.²⁰ As a result, recent studies suggest that violence against sex workers, including by police, increased in Kenya between 2013 and 2017.²¹

This study aims to answer the following questions. First, how often are manifestations of stigma—including those rooted in discrimination and expressed as various rights violations—by police reported by a sample of female sex workers in Kenya? Second, are these manifestations associated

with reductions in general health care utilization and consistent condom use among Kenyan female sex workers—and if so, to what extent?

Methods

Participants and procedures

Survey data on which this analysis is based have been more fully described by Laura Nyblade et al. and are briefly summarized here.²² We drew a sample of 497 female sex workers in January 2015 with a modified respondent driven sampling (RDS) approach, stratified by four locations in Kenya to capture rural, urban, and transit corridor settings. Participants were eligible for inclusion if they were at least 18 years old, had lived in a study location for at least six months, and reported earning a significant portion of their income from sex work during the past three months. Partner sex worker organizations recruited 96 initial participants, who recruited up to four additional participants apiece. Those participants could then recruit up to four additional participants, and so forth. Because participation was greater than anticipated, the survey's target sample was achieved within two waves, precluding full RDS analysis. (A companion sample of 232 male sex workers was also drawn but not included in this analysis due to insufficient sample size.)

Trained third-party interviewers collected information through face-to-face interviews conducted in private spaces at partner organizations' offices. We selected interviewers through a competitive process to enhance surveying quality. All interviewers were trained on stigma, research ethics, and the survey instrument. We obtained ethics approval from the institutional review boards at the Kenya Medical Research Institute and Health Media Labs. All participants gave written informed consent prior to participating, and we complied fully with the Declaration of Helsinki.

Measures

Outcomes. We examined two principal outcomes, both self-reported: (1) avoidance or delay of general health (non-HIV) services perceived to be needed

and (2) consistent condom use. To construct the health care avoidance or delay variables, we first asked respondents if they or their children had needed any services in the last 12 months and, among those who had needed health care services, whether they had ever not sought or delayed the service. Respondents were then separately asked to classify what health services they had used, avoided, or delayed up to the three most recent services (for example, maternal health, treatment for injury, etc.). Respondents were classified as avoiding or delaying a service if it was reported at least once. Condom use was assessed by asking respondents, "Of all the times you had sex in the last 12 months, how often was a condom used?" Response options were never, almost never, sometimes, often, and always. We dichotomized the variable into always or any other response.

Discriminatory and othering acts by police. The development of the discrimination and stigma items has been previously described.²³ We focused on three types of manifestations of police-related discrimination and stigma in this analysis: anticipated stigma, discriminatory and othering acts (experienced stigma), and witnessed or heard discrimination and othering acts.

Anticipated stigma and discrimination—the fear that stigma and discrimination will happen—was assessed by six items. They included fear of insult, harassment, or threat and fear of physical harm by police. Additionally, respondents indicated whether they feared carrying condoms because of trouble with police or askaris (as two separate items, the former referring to national government law enforcement officers and the latter referring to officers under the jurisdiction of county government) and whether they feared taking condoms from outreach workers because of possible trouble with police or askaris (again, two separate items). Fear about police and askaris were collapsed because responses were highly correlated, leaving four variables. Respondents were asked to report frequency and could respond never or not in the last 12 months (collapsed into one category), once, a few times, or often. For ease of interpretation, we

assigned these responses values from 0 to 3 and summed respondents' responses. We then categorized respondents as reporting none (a summed score of 0) or into tertiles of those who had anticipated police stigma and discrimination. We assessed the anticipated items' internal consistency using ordinal alpha, and it met generally accepted criteria (0.87).²⁴

The experience of discrimination and othering acts (experienced stigma) was constructed from respondents' report of police engaging in five types of conduct toward them: verbal assault or harassment, physical harm, confiscation or destruction of condoms, arrest, or refusal to protect or take a statement. Witnessed and heard stigma was constructed from respondents' report seeing or hearing of the same types of conduct toward other female sex workers. We constructed scores and categorized respondents' experiences of discrimination and othering acts and witnessed/heard stigma the same way as for anticipated stigma. Both scales demonstrated good internal consistency using ordinal alpha (discrimination and othering acts=0.92; witnessed/heard=0.92).

For inclusion in secondary analyses, we also constructed variables specifically measuring manifestations related to condom possession. For discrimination and experienced stigma, responses to the item about how often police had confiscated or destroyed the respondent's condoms in the last 12 months were categorized as never, once or a few times, and often. A single item asking how often respondents have witnessed or heard about police destroying or confiscating sex workers' condoms was categorized the same way. Four anticipated stigma and discrimination questions, how often the respondent was fearful of either carrying or taking condoms because she might get into trouble with either police or askaris, were collapsed and then categorized into a comparable three-level variable.

Control variables. We included anticipated stigma and discrimination from health care workers as a control variable because we expected it to reduce health care utilization based on previous research, and it may correlate with manifestations of stigma

and discrimination from police.²⁵ We measured this using two items—how often the respondent reported being fearful of gossip and how often the respondent reported being fearful of verbal harassment, insult, or threat from health care workers (never to often in the last 12 months). Because the items were strongly correlated, we constructed an ordinal variable for whether the respondent reported never, once or only a few times, or often anticipating at least one of these fears.

Other control variables included the site from which the respondent was recruited, the frequency with which she reported needing health services in the last 12 months (once, a few times, or often), quintiles of age, education (primary or less, secondary, or tertiary), marital status (never versus ever married or partnered), quintiles of time as a sex worker, and quintiles of income from sex work. All items can be found in the survey instrument, provided in the link to supplement 1.

Statistical methods

We described the sample using standard approaches: means, standard deviations, frequencies, and percentages. We then examined the association between discrimination and othering acts (experienced stigma), anticipated stigma, and witnessed or heard stigma by separately fitting logistic regression models. For avoidance or delay of general health care services, the base model also included the variable for how frequently the respondent had needed services in the last 12 months, and it was restricted to those respondents reporting that they needed services at least once. The base model for condom use included only stigma and discrimination and recruitment site. Fully adjusted models additionally included control variables for age, education, marital status, length of time as a sex worker, income from sex work, HIV status, and anticipated stigma from health care workers (in models of health care utilization only). Because odds ratios are often misinterpreted, we estimated and graphed adjusted probabilities of our outcomes of interest at various stigma and discrimination levels using marginal effects with other covariates held at their observed levels.

As a robustness check, we constructed tertiles of discrimination and othering acts, anticipated stigma, and witnessed or heard stigma in an alternative manner that has fewer assumptions about the survey items. Supplement 2 presents results from regression models substituting these discrimination and stigma variables, as well as the concordance between scores from this and our main approach. Finally, we used structural equation modeling to construct path models to test a hypothesis that lower consistent condom use was directly associated with the highest level of discrimination and othering acts (experienced stigma) and anticipated stigma, that experienced discrimination and othering acts transmitted an association through anticipated stigma, and that

witnessed or heard stigma transmitted an association only through anticipated stigma. Supplement 2 provides fuller details of the approach we used.

All analyses used Stata, version 15.1.

Results

Participant characteristics

Participant characteristics are provided in table 1. Of note, most participants had primary schooling or less (58.6%), reported needing health care services for themselves or their children at least once in the last year (89.9%), and were not living with HIV (72.2%). Participants had been engaged in sex work for a median of four years and earned a median of 312,000 Kenyan shillings from sex work

TABLE 1. Participant characteristics

	Median (interquartile range)
Age (years)	27 (24 to 32)
Years in sex work	4 (2 to 7)
Annual income from sex work (shillings)	312,000 (156,000 to 520,000)
	% (n)
Education level	
Primary or less	58.6% (291)
Secondary	35.8% (178)
Tertiary	5.4% (27)
Not reported	0.2% (1)
Marital status	
Single or never married	52.5% (261)
Ever married or with partner	46.9% (233)
Not reported	0.6% (3)
Frequency needing health services in last 12 months	
Never	10.1% (50)
Once	7.0% (35)
A few times	51.9% (258)
Often	30.4% (151)
Not reported	0.6% (3)
HIV status	
Positive	23.1% (115)
Negative	72.2% (359)
Does not know	0.2% (1)
Never tested	1.2% (6)
Not reported	3.2% (16)
Location	
Nairobi	36.8% (183)
Kitui	15.3% (76)
Busia	25.6% (127)
Homa Bay	22.3% (111)

(approximately US\$3,000) annually. Missing data were rare, with choice not to report HIV status the most common (3.2%).

Prevalence of manifestations of discrimination, othering acts, and stigma

Three-quarters of respondents experienced one or more manifestations of discriminatory and othering acts (experienced stigma) by police in the past year, with 50% reporting often experiencing at least one manifestation in the past 12 months (table 2). The most common manifestations were arrest (62.4% at least once; 35.0% often), verbal abuse (59.0% at least once; 36.0% often), and physical abuse (45.3% at least once; 24.5% often). Forty percent reported at least one instance of police refusal to take the respondent’s statement or render protection. Two-thirds of respondents were fearful of one or more manifestation in the prior year. The most common anticipated manifestations were physical abuse (55.3% at least once; 37.6% often), verbal abuse (50.3% at least once; 33.4% often), and fearing trouble with police or askaris for carrying condoms (23.1% at least once; 13.5% often). Ninety percent of respondents reported witnessing or hearing about one or more manifestation, including, most fre-

quently, arrest (84.5% at least once; 69.0% often), verbal abuse (73.6% at least once; 53.0% often), and physical abuse (68.3% at least once; 47.8% often).

Associations with avoidance and delay of health services

As respondents reported increased witnessed or heard manifestations, avoidance or delay of general healthcare services monotonically increased. Those reporting the highest level had 2.7 times the odds of delay or avoidance (95% CI 1.1–6.6) in the fully adjusted model (supplement 2). This corresponds to a 20.0 percentage point (95% CI 0.7–39.3) increase in avoidance or delay compared to those reporting no witnessed or heard manifestations (figure 1). Respondents reporting the highest level of discrimination and othering acts (experienced stigma) had 2.2 times the odds (95% CI 1.0–4.7) of avoiding or delaying general health services in the fully adjusted model, but the association was only marginally significant (p=0.055).

Though overall levels of experienced and witnessed/heard manifestations were associated with greater avoidance or delay of services, the only specific conduct that was by itself associated with delay or avoidance of health care services was po-

TABLE 2. Prevalence of discrimination and stigma manifestations from police over the last 12 months

Category of stigma, discrimination, or othering acts (n=497)	Manifestation	At least once	Often
Experienced or enacted	One or more of the below	76.1%	50.5%
	Arrest for selling sex	62.4%	35.0%
	Verbal assault, harassment, or threat	59.0%	36.0%
	Physically hurt	45.3%	24.5%
	Refusal to protect or take statement	40.1%	16.9%
	Condom confiscation or destruction	33.4%	16.9%
Anticipated: Fearful of...	One or more of the below	67.0%	50.7%
	Physically hurt	55.3%	37.6%
	Verbal insult, harassment, or threat	50.3%	33.4%
	Trouble for carrying condoms	23.1%	13.5%
	Trouble for taking condoms from outreach worker	21.1%	12.7%
Witnessed or heard	One or more of the below	89.5%	76.2%
	Arrest for selling sex	84.5%	69.0%
	Verbal assault, harassment, or threat	73.6%	53.0%
	Physically hurt	68.3%	47.8%
	Refusal to protect or take statement	56.0%	28.4%
	Condom confiscation or destruction	49.8%	30.2%

lice refusal to protect or take a statement from sex workers. In the fully adjusted model, those often experiencing this form of conduct had 2.6 times the odds (95% CI 1.3–5.4) of avoidance or delay than those who had never experienced it, which corresponds to an increase of 17.8 percentage points (95% CI 6.0–29.6). Those who often witnessed or heard about refusals to protect or take statements had 1.8 times the odds (95% CI 1.0–3.4) of avoidance or delay, corresponding to a 11.7 percentage point (95% CI 0.3–23.2) increase.

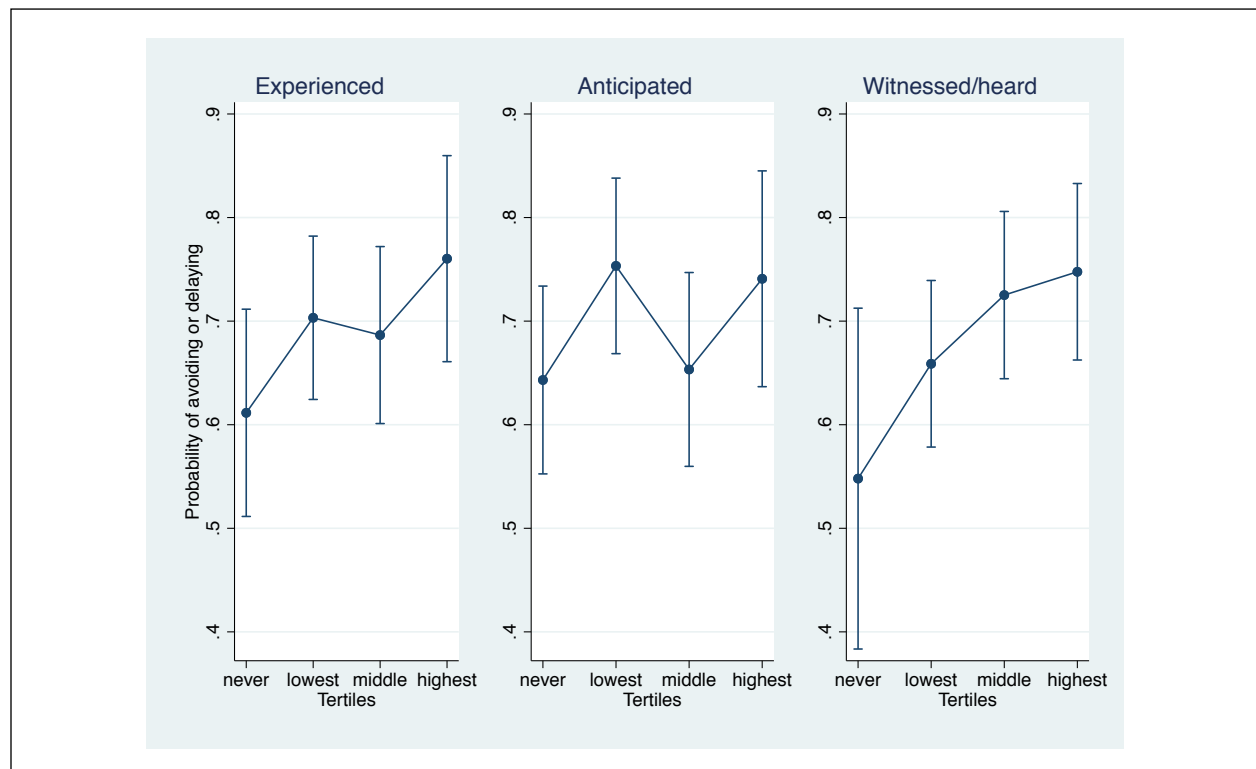
Associations with condom usage

Adjusting for confounders, women in the highest category of experienced acts of discrimination or other othering acts from police had one-third the odds (OR=0.32, 95% CI 0.17–0.62) of always using a condom over the previous 12 months, which corresponds to a reduction of 24.0 percentage points (95% CI 10.6–37.3) (figure 2). The highest category of witnessed or heard manifestations was

associated with a similar reduction (OR=0.28, 95% CI 0.12–0.64), corresponding to a reduction of 26.9 percentage points (95% CI 10.8–43.0); for anticipated manifestations, the odds ratio was 0.50 (95% CI 0.27–0.92), corresponding to a reduction of 14.8 percentage points (95% CI 1.8–27.8).

Women who experienced police confiscation of condoms “often” in the last 12 months had about one-quarter the odds of always using condoms than those who never experienced confiscation in the fully adjusted model (OR=0.26, 95% CI 0.15–0.47) (supplement 2). This corresponds to a reduction of 28.8 percentage points (95% CI 16.6–40.9) (figure 2). Among those who often witnessed or heard about police confiscating condoms, the odds of use were about half (OR=0.48, 95% CI 0.29–0.79), corresponding to a reduction of 16.0 percentage points (95% CI 5.1–26.9). Among those often anticipating trouble, the odds ratio of always using a condom was 0.56 (95% CI 0.33–0.95), corresponding to a reduction of 12.7 percentage points (95% CI 1.1–24.3).

FIGURE 1. Probabilities of avoiding or delaying general health care services and consistent condom use by levels of manifestations of stigma and discrimination by police, adjusting for potential confounders



Path analysis for condom usage met generally accepted guidelines for model fit (supplement 2). Often experiencing condom confiscation was directly associated with being 28.1 percentage points (95% CI 16.3–39.9) less likely to always use condoms and 15.1 percentage points (95% CI 2.5–27.7) more likely to often anticipate trouble with police. Similarly, those who often heard about or witnessed confiscation were 15.0 percentage points (95% CI 5.1–24.9) more likely to often anticipate trouble. However, there was no independent direct association between anticipated trouble with police and reduced condom use.

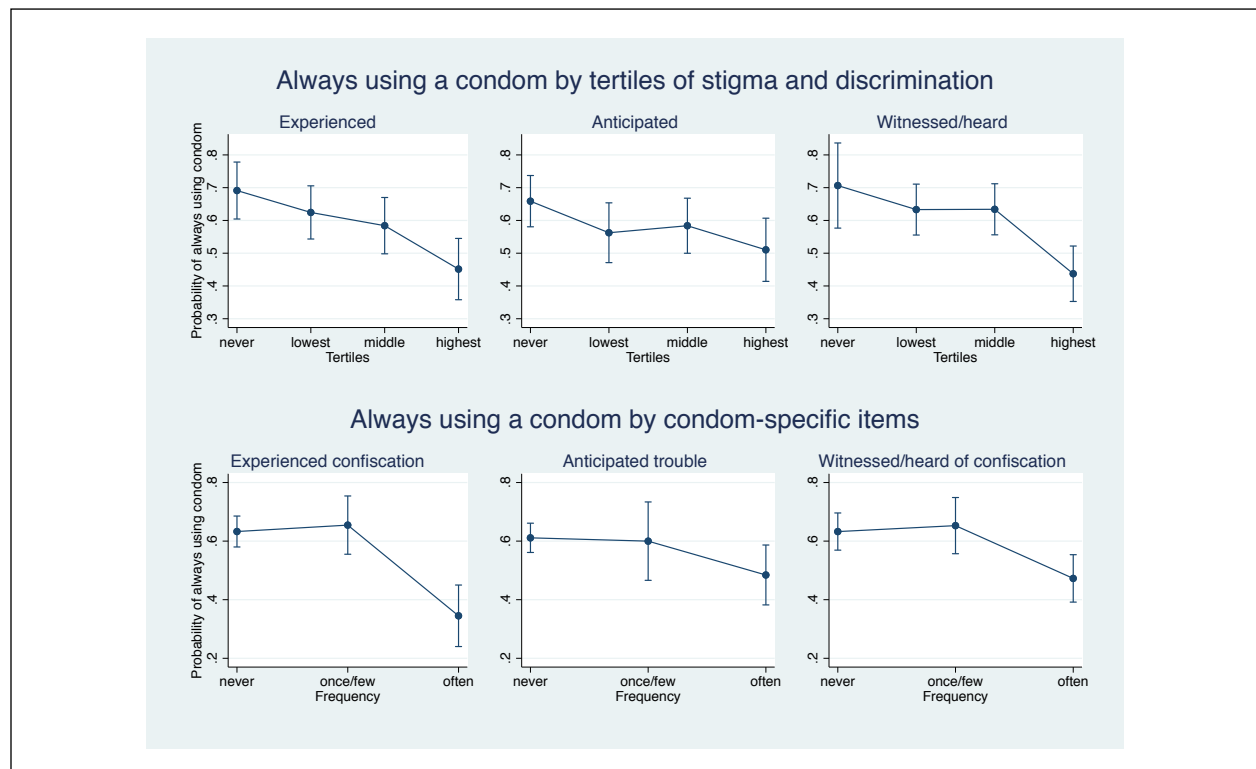
In all models, unadjusted results were similar to the fully adjusted results. There was a high degree of concordance between scores based on summing items and factor scores based on polychoric correlations. Estimates did not change meaningfully in a robustness check when categories were based on the factor scores (supplement 2).

Discussion

This study documents that Kenyan female sex workers encounter widespread acts by Kenyan police that constitute discrimination, abuse, and othering acts that are manifestations of stigma. Most respondents reported experiencing at least one manifestation, and virtually all had witnessed or heard of such acts from others. Those who had experienced, witnessed, or heard the highest levels of manifestations were markedly more likely to avoid or delay general health care services that they reported needing. Adjusting for confounders, respondents who often experienced police confiscation of condoms were 25 percentage points less likely to consistently use condoms.

Our findings are broadly consistent with existing research. Prior studies have documented that discriminatory and othering acts by police is a common experience for sex workers in sub-Saharan Africa.²⁶ A few studies find that negative interactions with police are associated with more

FIGURE 2. Probabilities of consistent condom use by levels of manifestations of stigma and discrimination by police and condom-specific manifestations, adjusting for potential confounders



inconsistent condom use.²⁷ In particular, studies from sub-Saharan Africa provide evidence that police harassment leads to hurried condom negotiation and sex workers being less likely to carry condoms.²⁸ There is relatively little research on the links between such manifestations by police and general health care utilization, a gap this study helps fill. Further, few studies examine anticipated or witnessed/heard stigma and discrimination among sex workers, especially regarding police, though several existing studies have found anticipated and witnessed/heard manifestations from police to be extensive across contexts.²⁹

Much of the conduct reported by respondents in this study are per se violations of Kenyan constitutional law and international human rights law. At minimum, we document acts against sex workers that are violations of the following Kenyan constitutional provisions:

- Article 29(c)'s guarantee of the "right not to be subjected to any form of violence from either public or private sources" is violated by physical violence perpetrated by police. In a case decided under Kenya's pre-2010 Constitution—but which made clear that comparable rights exist under the revised Constitution—the Kenyan state is liable for "acts ... directly perpetrated against [victims] by the police."³⁰
- Article 29(f)'s protection from being "treated or punished in a cruel, inhuman, or degrading manner" is violated by both acts of physical violence and severe verbal abuse.³¹
- Article 31(b)'s guarantee of a "right to privacy, which includes the not to have their person ... searched [and] possessions seized," is likely violated by the unwarranted confiscation of condoms and predicate harassment.³²
- Article 28's guarantee that "every person has inherent dignity and the right to have that dignity respected and protected" is likely violated by all of the above acts, as well as police refusal to take statements from and render protection to female sex workers.³³ While this right is not fully defined in Kenyan law, there is precedent that both hu-

miliation and the refusal to provide "care and attention" by those with a duty of care violates article 28.³⁴ Further, while government liability for failure to protect from third parties' misconduct is limited in Kenyan case law, "where a report is made ... and the police without any justifiable reason refuse to act ... they have abdicated their duty to protect."³⁵

Sections 153 and 154 of the Kenyan Penal Code—part of its provisions on "offenses against morality"—make living on the earnings of sex work a felony.³⁶ The criminalization of sex work has repeatedly been identified by UNAIDS as a driver of HIV risk among sex workers, as well as giving police cover to engage in abuse.³⁷ It is an actionable form of discrimination that both results from and causes further stigma and discrimination. As we identify in this paper, manifestations of stigma and discrimination by police are associated both with decreased health care utilization and decreased consistent condom use. As evidenced by the finding that police refusal to take statements from or render protection to sex workers was individually predictive of delayed and avoided health services, it is likely that police refusal to protect magnifies the effect of discrimination and stigma by private actors.³⁸ The nexus between criminalization, police misconduct, and increased health risk renders criminalization inconsistent with Kenya's constitutional article 43(1), which enshrines the "right to the highest attainable standard of health."³⁹ While this study is cross-sectional and therefore cannot directly establish a causal relationship between police conduct and health outcomes, there are empirical and theoretical grounds for inferring causality.⁴⁰

Additionally, while our analysis focuses on the protection of rights that are actionable under the Kenyan Constitution, police conduct violates comparable proportions of international agreements to which Kenya is a state party and which Kenya automatically gives effect in its domestic law, including the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the African Charter on Human and Peoples' Rights, and

the International Covenant on Economic, Social, and Cultural Rights.⁴¹ More specifically, we note that verbal and physical harassment and violence by police targeted to sex workers violate the rights to security, dignity, freedom from inhuman and degrading treatment, and nondiscrimination.⁴² To the extent that police misconduct against sex workers occurs without redress, it also violates rights to equal justice. Refusal by police to take statements and to protect sex workers violates the rights to personal security and to dignity.⁴³ The criminalization of sex work, which leads to sex workers being arrested, criminalizes voluntary and consensual sexual activity and further violates the rights to privacy and to personal autonomy, and, as noted above, the confiscation of condoms violates the right to health.⁴⁴

Reducing discrimination against sex workers and those manifestations of stigma identified in this and other studies will require multifaceted interventions focusing on law reform, economic and social empowerment, and norm changes within police agencies. We note that discrimination and other human rights violations are a cause of further societal stigma, and the effective enforcement of international and domestic human rights law is critical. Similarly, we note that the types of conduct documented in this study are endpoints of the processes by which sex workers are marked and othered by society, so addressing stigma as a root cause of rights violations is also important. Strong evidence suggests that the decriminalization of sex work would reduce rights violations by police by reducing opportunities for abuse and improving the ability of sex workers to organize for their own protection.⁴⁵ Indeed, limited evidence from Senegal suggests that the legalization of sex work there has improved access to health services and reduced rights violations.⁴⁶

Several studies suggest that partnerships between police and sex worker organizations can reduce harm, but creating such partnerships likely requires policy change and buy-in from police leadership.⁴⁷ Successful interventions in India have included advocacy with senior police officials as a critical component.⁴⁸ In particular, interventions

should be multilevel, including components such as changing policy and law, training police, providing awareness to media (which can increase police accountability), and empowering sex workers.⁴⁹ Though not focused on police, we note that successful interventions to reduce stigma in health care settings in sub-Saharan Africa have been successful when employing a similar whole-of-institution approach.⁵⁰ The mobilization of sex workers as advocates for their own right has been particularly successful in India, though criminalization often poses a substantial barrier to mobilization.⁵¹ Collectivization has been found to reduce rights violations and improve agency and resilience in African settings where sex work remains criminalized.⁵² There is a vital need for more research on interventions to reduce discrimination and stigma and its manifestations by police, particularly in sub-Saharan Africa.

This study has a number of limitations. First, our data are cross-sectional, so the time-order between explanatory and outcome variables cannot be conclusively established and reverse causation cannot be excluded. However, existing literature and theoretical expectations make it more likely that police misconduct leads to less health care utilization and condom use than vice versa. Longitudinal studies to elucidate these relationships more deeply would be valuable. Second, respondents were recruited through sex worker support organizations, so our participants may have better-than-average access to health and social services than sex workers who are not linked to support organizations. Because we likely failed to equivalently sample sex workers most vulnerable to discrimination and manifestations of stigma, we likely underestimate their prevalence and may also underestimate the strength of its association with health care and condom use outcomes. Third, our sample of respondents living with HIV was too small to examine HIV treatment outcomes or investigate whether HIV status is an effect modifier, and there is likely some degree of misclassification of HIV status in our data because it is both self-reported and sensitive. Finally, all data are self-reported, so there is a risk of response biases. We aimed to re-

duce this risk through the use of carefully screened and trained interviewers and through procedures and study locations that underscored respondents' privacy.

As identified in this study, police conduct that constitutes human rights violations against sex workers is widespread in Kenya. Such misconduct is associated with worse health outcomes. It violates rights protected by Kenya's constitution and international agreements to which Kenya is a party. The government of Kenya has a duty to protect sex workers from discrimination and stigma and its manifestations by police, to educate the public on the need to reduce stigma and its manifestations against sex workers, and to investigate allegations of legally actionable discrimination and other rights violations and hold police accountable.

Appendices

Supplement 1: Survey Instrument. Available at <https://perma.cc/W6V6-2SLJ>.

Supplement 2: Supplemental analyses, data tables, and figures. Available at <https://perma.cc/9K4Z-LHZ2>.

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Community Mobilization to Promote and Protect the Sexual and Reproductive Rights of Women Living with HIV in Latin America

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Abstract

Between 2009 and 2014, the International Community of Women Living with HIV in Latin America and the Mexican feminist civil society organization Balance coordinated a five-country community-led intervention that brought together women living with HIV (WLHIV), trans women, sex workers, and feminist lawyers to document and respond to sexual and reproductive health and rights (SRHR) violations of WLHIV and advocate for legal, policy, and programmatic changes to fulfill SRHR. The experiences of involved community leaders (n=26) indicate that knowledge of national, regional, and international human rights commitments and up-to-date medical information positively influenced personal health behaviors, empowered WLHIV as subject matter experts, and emboldened them to hold duty-bearers to account. The research evidence generated through collective action was critical for legitimating SRHR violations of WLHIV with decision-makers and for positioning the issue in the advocacy agendas of national and regional HIV and women's movements. Collective action contributed to social cohesion among diverse groups of women living with and affected by HIV and increased available technical, financial, and organizational resources and political opportunities by linking organizations and networks. Collectively, community leaders mobilized to influence policy, legal frameworks, and service delivery to promote and protect the SRHR of WLHIV.

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Introduction

UNAIDS recently stated that the Sustainable Development Goals—including ending the HIV and AIDS pandemic—will not be achieved without advancing women’s full enjoyment of their human rights, particularly to bodily autonomy and sexual and reproductive health and rights (SRHR).¹ This recognition coincides with resurgent interest in community-led responses in HIV among international organizations and donors.² There is also a growing body of evidence on the contributions of community mobilization to HIV prevention, treatment, and care among diverse groups of women.³ Approaches grounded in human rights and the meaningful involvement of people living with HIV have been identified as critical for responding to HIV and AIDS for more than 30 years and strongly advocated for by women living with HIV (WLHIV) as necessary to improve quality of life and well-being, and specifically to realize SRHR.⁴ Nevertheless, documentation and analysis of human rights-based, community-led initiatives to advance the SRHR of WLHIV is limited in the gray and peer-reviewed literature.⁵

From 2009 to 2014, the International Community of Women Living with HIV in Latin America (ICW-Latina) and the Mexican feminist nongovernmental organization Balance implemented community-led research, advocacy, and coalition-building to promote and protect the SRHR of WLHIV in five countries (El Salvador, Guatemala, Honduras, Mexico, and Nicaragua). The first section of this paper draws on interviews with participants, participant observation, and project documents to describe the development and evolution of this participatory community mobilization intervention and the collective action taken by participants to promote and protect the SRHR of WLHIV.

In the second section, we draw on concepts from the community mobilization literature to analyze interviews with participating community leaders about the individual and institutional effects of engaging in collective activities to promote and protect the SRHR of WLHIV. We analyze

how gaining knowledge about SRHR and local, national, and regional human rights mechanisms and generating their own evidence about SRHR violations affected community leaders’ critical consciousness about SRHR, sense of agency, and internalization and ownership of human rights discourses.³ We also analyze the role of collective action for strengthening social cohesion (bonding social capital) and organizational networks and structures (linking and bridging social capital), as well as its consequences for advocacy efforts to promote and protect the SRHR of WLHIV.⁶

Methods

We conducted in-depth semi-structured interviews (n=26) with community leaders to explore the personal, professional, and organizational effects of participating in the community mobilization intervention to promote the SRHR of WLHIV. All community leaders who participated in the community mobilization and the interviews were women. In each country, interviewees included at least one feminist lawyer or leader of the national women’s movement, one sex worker, one trans woman, and one WLHIV affiliated with ICW-Latina (El Salvador n=4, Guatemala n=4, Honduras n=5, Mexico n=8, Nicaragua n=5). These categories can and do overlap, but for sampling purposes we treated them as discrete to ensure the inclusion of perspectives and experiences from the different subpopulations. Interviews were conducted between May 2014 and February 2015 by a research assistant who had not been involved in the intervention; they were conducted in Spanish over the telephone or by Skype, were recorded, and were then transcribed verbatim. We thematically coded the interviews using a combination of *a priori* codes (such as *impact_personal*, *impact_professional*, *impact_funding*, and *coalitionbuilding*) and inductive codes (such as *appropriating SRHR and legal tools*). Overt participant observation was conducted by Tamil Kendall during meetings and trainings (November 2009–December 2012). We also analyzed related project documents such as

reports and meeting minutes. We managed data using the qualitative analysis package Atlas-ti 7.0. Ethics approval was granted by the Institutional Review Board of Harvard University (IRB14-1132) and the University of British Columbia Okanagan Behavioural Research Board (H09-00738).

The intervention: Taking collective action to promote and protect the SRHR of WLHIV

Background

In 2008, the International Community of Women Living with HIV (ICW) identified fulfilling SRHR as a global priority.⁷ At this time, in Latin America, the SRHR of WLHIV were not well integrated into national HIV plans and were not an advocacy priority for either the broader HIV or women's movements. Moreover, despite the existence of ICW-Latina, WLHIV leaders at the national level were isolated and institutionally weak, with limited political and social capital to advance their priorities.⁸

From 2009 to 2014, ICW-Latina and Balance implemented a community-led intervention focused on promoting and protecting the SRHR of WLHIV. The initial phase of this community-led intervention (2009–2010) involved participatory prioritization, which is described in the community mobilization literature as the process of problem identification (or issue framing) and the development of critical consciousness.⁹ The second phase (2011–2014) refined the collective action frame—that is, the “action-oriented sets of beliefs and meanings that inspire and legitimate the activities and campaigns” of a social movement to focus on documenting SRHR violations experienced by WLHIV and responding using human rights mechanisms and legal strategies.¹⁰

The “what” and the “how” of collective action was developed collaboratively and evolved over time in response to the goals and aspirations of participants. The importance of a truly participatory process was expressed clearly by a participant who explained that what they most liked about the process of documenting SRHR violations was that “it

wasn't imposed. We validated [the data collection tool], we readapted it, and we reached consensus ... because we were a bit fed up with everything coming from other countries and just being used” (interviewee 14).

The section below describes the implementation and evolution of the community mobilization intervention and shares the results of collective action identified by the participants.

Phase one of the intervention: Analyzing SRHR commitments and articulating gaps and priorities (2009–2010)

In 2009 and 2010, ICW-Latina and Balance convened week-long participatory workshops in El Salvador, Honduras, Guatemala, Mexico, and Nicaragua to build the capacity of WLHIV community leaders in the area of SRHR, identify advocacy priorities, and begin to work collaboratively on these priorities with national women's organizations. International and regional guidelines and commitments relevant to the sexual and reproductive health of WLHIV were presented, and a content analysis of national HIV, reproductive health, and violence against women plans was discussed.¹¹ The analysis identified that HIV was not well integrated into national reproductive health or violence plans and that national HIV plans did not consider comprehensive services to promote and protect the sexual and reproductive health of WLHIV, specifically the prevention and treatment of sexually transmitted infections (including human papillomavirus and cervical cancer), contraception, and information and services for safer conception; all plans identified the provision of antiretrovirals for the prevention of vertical (mother-to-child) transmission.¹² When national plans included actions to promote sexual and reproductive health, ICW members identified gaps in service delivery. For instance, even if the HIV plan mentioned contraception, WLHIV reported that if they disclosed their HIV status, the only contraceptive options available to them in public services were male condoms or sterilization.

The content analysis of national plans focused on service delivery, but during strategy sessions

to prioritize advocacy issues and actions, WLHIV shared experiences of HIV-related discrimination that violated SRHR. Such experiences included providers' refusal to provide or unwarranted delays in the provision of caesarean sections and pap smears; providers making discriminatory comments to women who expressed that they wanted to become pregnant; discriminatory treatment by medical staff during pregnancy and childbirth; and sterilization without informed consent.¹³ WLHIV identified advocacy priorities and shared these with women's organizations at the conclusion of each workshop in order to identify opportunities for collaboration. Representatives of government and United Nations agencies also participated. Sharing the policy analysis and advocacy priorities was useful to begin conversations with policymakers; however, the SRHR violations described by WLHIV during the meetings were minimized by decision-makers as "anecdotal evidence." Further, while this initial engagement with women's organizations on SRHR did result in some cross training and joint advocacy—for example, highlighting the links between violence and HIV as part of the 16 days of activism against violence—it did not result in ongoing collective action.¹⁴

Phase two of the intervention: Documenting SRHR violations and using human rights mechanisms, including strategic litigation (2011–2014)

Strategic or impact litigation involves taking on a legal case as part of a strategy to achieve broad structural change. It can be a key tool in changing law, policy, or practice by setting legal precedent, as well as by placing an issue in the public eye and raising awareness.¹⁵ The potential of strategic litigation to compel states to progressively realize the right to health and respond to reproductive rights violations, in part by dedicating the maximum available resources, was perceived as an attractive antidote to WLHIV's frustration that national policymakers deflected or rejected demands for greater attention to SRHR in the HIV response by saying that resources were limited.¹⁶ Also, ICW-Latina and

Balance were strongly motivated to generate more evidence about SRHR violations to overcome the dismissal of WLHIV's accounts of serious rights violations as "anecdotal" and for broader advocacy purposes. In early 2011, ICW-Mexico began to work with Balance and FUNDAR, an organization specializing in public interest legal strategies, to develop a questionnaire to identify SRHR violations for the purposes of strategic litigation. In the spring, ICW chapters in El Salvador, Guatemala, Honduras, and Mexico decided to document SRHR violations among WLHIV and pursue strategic litigation.¹⁷

In June 2012, 47 leaders from 35 different networks and civil society organizations from El Salvador, Guatemala, Honduras, Mexico, and Nicaragua gathered in Mexico City for a week-long workshop that provided in-depth training on frameworks that guarantee SRHR (with a focus on the Convention on the Elimination of Discrimination against Women and the Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women) and detailed discussions of supportive strategies and practical considerations for strategic litigation.¹⁸ Country representatives from ICW, the regional transgender network RedLacTrans, the sex worker network RedTraSex, feminist lawyers, WLHIV affiliated with other organizations, and lesbian activists from Latin America participated in the training workshop. Selection criteria for participation included experience documenting rights violations, geographic location, and representation of or experience working with different populations, including indigenous women and women of African descent. This phase of the intervention explicitly sought to increase personal and professional contact and common objectives to strengthen trust and social cohesion among different groups of WLHIV, including those belonging to key populations. Social cohesion, or bonding social capital, is the strength or level of trust in social bonds, which influences a community's willingness and ability to take collective action.¹⁹ The intervention also sought to increase relationships with feminist

lawyers and other leaders of national women's movements (bridging and linking social capital) to position the issues of WLHIV, particularly those related to SRHR, more firmly and prominently in the agenda of national women's movements and mobilize additional political priority and resources from outside the HIV movement.²⁰

During the workshop, each country team adapted the questionnaire based on a comprehensive SRHR framework that included the principles of nondiscrimination, availability, accessibility, acceptability, and quality previously piloted in Mexico to reflect their country contexts. Consensus on the final questionnaire was reached by all meeting participants. Country teams also created an action plan and signed a memorandum of understanding that defined the processes to implement the questionnaire and to refer WLHIV who wanted to pursue an SRHR human rights complaint to the feminist lawyer who would provide legal advice and, if appropriate, litigate on behalf of the complainant. The memorandum represented a commitment on behalf of the organizations to participate in the collaborative research and advocacy strategy and was intended to clarify roles and responsibilities to support the community leaders in working together.

From July 2012 to February 2013, 60 peer researchers completed interviewer-applied questionnaires to assess SRHR violations with 347 WLHIV from 42 political districts (departments or states) in El Salvador (n=69), Guatemala (n=10), Honduras (n=100), Mexico (n=91), and Nicaragua (n=77). Participants then presented the results collaboratively at face-to-face meetings with national policymakers and at press conferences held in each country. The participants also implemented a referral system to link WLHIV who wanted to use judicial or quasi-judicial mechanisms to allied feminist lawyers.

Intervention results: Collective action to promote and protect the SRHR of WLHIV

Participants in this community mobilization process used courts and national human rights mechanisms to protect SRHR by getting access to

prevention and treatment services, sought redress for SRHR violations, and undertook joint advocacy to improve the promotion of SRHR in HIV laws, policies, and programs (Table 1). For example, in El Salvador, one of the participating human rights organizations brought a case alleging the forced sterilization of a 17-year-old WLHIV to the country's Constitutional Court. The WLHIV was admitted to hospital at 9:45 in the morning for a planned cesarean section. To increase the probability of preventing vertical HIV transmission, cesarean delivery should take place before the rupture of membranes; she was seeking a cesarean section because of her gestational age. However, she was not taken to surgery until 9:45 at night. Despite her testimony that health care providers refused to take her to the operating theater until she signed a consent form for sterilization and that she did so under duress during active labor, the court did not find that the sterilization was coerced or an act of discrimination on account of her HIV status. However, it did find that because the complainant was a minor and had not received comprehensive counseling on contraceptive methods during her prenatal care, her fundamental rights to reproductive health, reproductive autonomy, and personal integrity had been violated. The hospital was ordered to provide ongoing psychological treatment for the complainant, and the Ministry of Health was directed to update technical guidance and training for health care providers to align with national and international human rights law.²¹

Participants also promoted respect for the SRHR of WLHIV by influencing legal reforms and public policy. To illustrate, in Mexico, coalition members introduced language explicitly recognizing the reproductive rights of WLHIV into the HIV law and achieved recognition of the need for coordinated action and co-responsibility between the national HIV and reproductive health programs to address perinatal HIV transmission.²² In Nicaragua, coalition members negotiated the removal of draft language making partner notification obligatory from the HIV law, preserving the status quo that people living with HIV could not be forced or

coerced to disclose their HIV status.²³ Coalition members also worked with national governments and international organizations to develop and disseminate position papers and guidance to promote the SRHR of WLHIV. For example, in Guatemala, the Ministry of Health, UNFPA, and ICW-Guatemala published specific medical guidance on the SRHR of WLHIV.²⁴

Coalition members also took joint action to hold duty-bearers to account to deliver SRHR services to individual WLHIV in line with existing national standards. Examples included mobilizing to force local decision-makers to program cesarean sections and provide breast milk substitutes to WLHIV and, in one case, to provide antiretrovirals to a pregnant WLHIV who faced additional discrimination because she was a sex worker. Additionally, in four out of five countries, participating organizations raised additional funds to work on SRHR with other coalition members (Table 1).

These illustrative examples suggest the power of community-led collective action to advance SRHR by holding duty-bearers to account for service delivery, as well as by influencing laws and public policy. Below, we consider in greater depth how the intervention processes enabled effective collective action by changing knowledge and perceptions, promoting common goals, and developing relationships that strengthened bonding and

bridging social capital.

How did the community mobilization process affect SRHR knowledge, evidence, and advocacy?

Increased knowledge, critical consciousness, and agency

The intervention created opportunities for community leaders to deepen their knowledge of SRHR and engage in dialogue and critical reflection. This process resulted in common understanding, identification of solutions, and eventually individual and collective action. Developing a common understanding of injustice and strategies to respond has been denominated “critical consciousness” and “issues framing.”²⁵ During phase one, WLHIV identified SRHR violations as a problem because of gross and clearly discriminatory abuses that they or their peers had experienced. Through the intervention, community leaders acquired up-to-date information about WLHIV’s sexual and reproductive health options, including medical guidance on a range of contraceptive options and the fact that having an undetectable viral load allowed WLHIV to consider vaginal delivery and breastfeeding. Leaders deepened their analysis of the SRHR violations being committed and increased their ability and confidence to respond. One WLHIV leader

TABLE 1. Community leaders’ reports of collective action to promote and protect the SRHR of WLHI

	El Salvador	Guatemala	Honduras	Mexico	Nicaragua
Conducted collective action outside of formal coalition activities?	Yes	Yes	Yes	Yes	Yes
Worked with other coalition members to secure funding for SRHR?	No	Yes	Yes	Yes	Yes
Used SRHR evidence and advocated to influence the drafting of the national HIV law?	Yes	No (law not revised from 2009–2014)	Yes	Yes	Yes
Used SRHR evidence and advocated to influence the drafting of the national HIV plan?	No	Yes	Yes	Yes	Yes
Used SRHR evidence and advocated to influence the drafting of national violence or reproductive health plans?	Yes	Yes	No	Yes	Yes
Used national human rights mechanisms or national courts to defend the SRHR of WLHIV?	Yes	No	Yes	Yes	Yes
Shared information on violations of SRHR of WLHIV with regional or international human rights mechanisms?	Yes	Yes	Yes	Yes	Yes
Created national policy documents or guidelines to promote the SRHR of WLHIV?	No	Yes	Yes	Yes	No

explained:

Now I have foundational elements ... First, that if they have a viral load below 1,000 they can have a vaginal birth, two that there are options for assisted reproduction that should be offered, that there are family planning methods [appropriate for WLHIV], all of these [are] issues that I couldn't deal with before because I didn't have what we would call the scientific information. (interviewee 7)

WLHIV reported that the knowledge they gained improved their education and counseling efforts with their peers and their own health behaviors. As a consequence of participating in the coalition, WLHIV described changed health behaviors that ranged from seeking routine sexual and reproductive health exams (such as pap smears, mammograms, and tests for sexually transmitted infections) to beginning to contemplate becoming sexually active again post-diagnosis, to overcoming guilt about sexual pleasure and masturbation, to exercising increased autonomy in sexual decision-making with partners. Participants also described feeling more empowered and exercising greater decision-making autonomy in their relationships with health care providers. An illustrative testimony came from a relatively new WLHIV leader who explained that her engagement with the coalition introduced her to the idea of bodily autonomy and informed her about sexual and reproductive options. She said:

Our partner can even be the one who is violating our right to decide about our body ... Now, I can say when, how and where [I want to have sex], and I can exercise my right if I want to get pregnant, [and know] what the guidelines are for my care. (interviewee 12)

WLHIV linked their individual health-seeking behaviors to engagement in community monitoring of services and advocacy on behalf of themselves and other WLHIV. For example, one interviewee said:

Now I go and get a pap, and my mammography ... as a network [of WLHIV] we make our presence felt, we go to the clinics and we ask that they do

this or that, if we feel mistreated, we tell them. (interviewee 8)

Coalition participants who were not living with HIV also described changes in their health behavior and perceptions, with feminist lawyers frequently expressing increased awareness of vulnerability to HIV transmission:

I don't assume that because I'm in a monogamous relationship, I'm not vulnerable ... I am trying to get pregnant again and my gynecologist didn't order the HIV test, saying "you did it a year ago" and I said "yes, but that was a year ago, and you don't know and neither do I." (interviewee 22)

Participants made it clear that, overall, women in their countries lacked knowledge about SRHR, regardless of their HIV status. One WLHIV described the situation poignantly, saying, "I ask myself: Why is it necessary to have a diagnosis to discover so many things? Why didn't we learn before it happened?" (interviewee 4). In all five countries, participants identified the development of a "culture of rights" as a result of the intervention. For example:

Something that is really important is when you realize that a woman doesn't think that her rights have been violated, rather that it was the work of the Holy Spirit. Now there is a culture that talks about rights—there were many women who didn't know what their rights are, that that they have to fight for them, that they have to speak up—and that has changed. (interviewee 21)

Community leaders also described how their sense of agency increased upon learning that states have obligations to promote and protect human rights and that there are national, regional, and international mechanisms to hold duty-bearers to account. One theme that emerged was that applying the questionnaire, which was grounded in international human rights law, was important for community leaders' adoption of a rights-based perspective. For example, one trans leader living with HIV explained that, for her, the turning point for being able to communicate a rights-based perspective

with her peers and talk about SRHR was the process of repeatedly asking other WLHIV the questions in the questionnaire and internalizing the knowledge that “every point, every question in that survey is from a treaty that Mexico has with national and international organisms, and that Mexico signed and that isn’t being fulfilled” (interviewee 17).

Reflecting on the process of documenting SRHR violations, a feminist ally said:

When you hear [community leaders] say how useful what they learned is, it is really motivating. At one point, I thought that it was going to be a really academic exercise, very intellectual, but no. They really grasped the key issue of knowing the women that they work with better, recognizing rights violations that they hadn’t believed were violations, rights that they hadn’t believed were rights. (interviewee 20)

Community leaders also noted that their increased knowledge of administrative mechanisms to pursue human rights complaints gave them new tools and an increased sense of agency. This was exemplified by a WLHIV leader who said:

Before, they [WLHIV] didn’t really recognize what we call sexual and reproductive rights, how to respond, how to make a complaint if our rights are violated. So, in the process the women have become more empowered. (interviewee 26)

Participants described their new knowledge about the regional and international accountability mechanisms as hopeful and motivating. For example, one interviewee said:

There is a process, there is an administrative machine in my country, and if they don’t respond, I can go to the international level so that my voice is heard—maybe it won’t resolve anything for me, but it can help other women in the future. (interviewee 23)

According to community leaders, the process of gaining knowledge about SRHR and the national, regional, and international mechanisms that exist to protect human rights contributed to their development of critical consciousness about SRHR and resulted in the appropriation and dissemina-

tion of human rights discourses. It also resulted in increased agency, which allowed them to enact behaviors to promote and protect their SRHR and the SRHR of WLHIV as a group.

Focused advocacy: Positioning WLHIV as SRHR experts

The identification of SRHR as an institutional priority from 2009 to 2014 by the country and regional chapters of ICW, coupled with capacity building and the generation of evidence, provided coherence and substance for advocacy. The collective action frame strengthened community leaders’ advocacy efforts, as illustrated by one WLHIV leader who said that having

a political agenda gave the [WLHIV leaders] a tool, to be able to make the same argument at all of the tables ... [when modifications to the HIV law were discussed in each locality] the need for a chapter on sexual and reproductive health was always mentioned—that was the women’s position. (interviewee 26)

In each of the four countries where the HIV law was modified between 2009 and 2014, coalition members influenced outcomes in favor of SRHR (Table 1). Further, their increased knowledge and focus on SRHR allowed WLHIV, sex workers, and trans women community leaders to position themselves as experts, which in turn increased their standing with other civil society organizations, government representatives, and the United Nations:

These alliances have allowed us to do advocacy at a different level, and it has also allowed us to empower ourselves. Having knowledge gives you power and positions you politically. As the Guatemalan [chapter of ICW], we are the main reference point on the sexual and reproductive health of women living with HIV in Guatemala. They call us, they tell us—knowledge gives you strength, learning gives you power and legitimacy and arguments. (interviewee 9)

In some instances, at the very local level, increased knowledge of SRHR among community leaders and access to intellectual resources created through the coalition allowed them to quickly resolve

SRHR violations by sharing information with local authorities:

She is HIV positive, and they raped her, and she got pregnant. She went to the hospital, but they refused to give her an abortion [even though abortion is legal in cases of rape] and they didn't give her any information so that she could go to Mexico City [where abortion is available on demand up to 12 weeks]. They didn't give her any options. So that girl had a home abortion, and then they arrested her. So, we gave the information sheet on sexual and reproductive rights to the state prosecutor, and based on that, they let her free. (interviewee 25)

Using evidence about SRHR violations for advocacy: "These aren't urban legends"

During phase one of the process, when WLHIV shared examples of SRHR violations with policymakers, the examples were dismissed as "anecdotes." The evidence generated through participatory research with 347 WLHIV from five countries undertaken during phase two of the intervention was perceived by WLHIV and their allies as legitimating the importance of SRHR violations. The survey found that 41% of respondents had experienced discrimination when seeking reproductive health services, only 22% had received female condoms, only 34% had been tested for human papillomavirus, and almost a quarter reported coercion to sterilize or forced sterilization.²⁶ One WLHIV leader summed up the effects of having evidence when advocating before national decision-makers, saying that the research results prove that the SRHR violations experienced by WLHIV "aren't urban legends" (interviewee 7). That the evidence was quantitative and conceptually grounded in international human rights law was perceived by participants as increasing impact:

We have generated evidence that we didn't have before, systematized, that allowed us to use nonlegal mechanisms, but from a much stronger position ... We have percentages, and we have gotten press coverage because of the percentages that we have. So, we are still using nonlegal mechanisms, but starting to work within a legal framework strengthened our work a great deal. (interviewee 20)

In all countries, community leaders brought forward evidence from the community-led participatory research to influence the development of national plans on HIV, sexual and reproductive health, and gender-based violence (Table 1). The generation and presentation of evidence was perceived to favorably affect policy advocacy efforts. For example, a Mexican feminist attributed the integration of sexual and reproductive health with HIV in the HIV and reproductive health national sectoral plans to coalition members

insisting for years—with evidence—that HIV needs to be incorporated into the reproductive health response. And generating the evidence and being willing to work with decision-makers, and providing evidence to decision-makers. (interviewee 18)

The evidence generated was also incorporated into documents developed with the United Nations system and presented to regional and international human rights bodies, including the Special Rapporteur on torture (in the case of Mexico) and the Universal Periodic Review (in the case of Honduras).²⁷ A significant example for all countries was reporting the results to the United Nations Commission on the Status of Women via the confidential communications procedure. In addition to the commission providing the information to national governments and requesting a response, it highlighted the SRHR of WLHIV as an issue of concern in its conclusions.²⁸

Finally, sharing evidence about SRHR violations experienced by WLHIV was identified as important for helping community leaders position the issue on the agenda of the broader HIV and women's movements. A WLHIV leader explained that

we have used the evidence to convince other organizations, like [the network of people living with HIV] to fully embrace issues of sexual and reproductive health. (interviewee 16)

Similarly, research results were used to raise the visibility of the issue within the women's movement. For example, at the "national feminist summit, it was made visible and recognized that [the SRHR of

WLHIV] is also a feminist fight” (interviewee 24).

How did the community mobilization process contribute to building bonding and bridging social capital?

Strengthening social cohesion and bonding social capital

Working jointly to identify violations and to promote and defend SRHR contributed to a sense of common purpose and identity among diverse community leaders who are active in the HIV movement. In the words of one trans woman leader:

We have issues in common, a common fight, because it hurts us to see the suffering that our populations experience in Mexico and Central America because of their rights being denied. (interviewee 3)

Participation in the coalition didn’t overcome all discrimination based on professional and gender identity or completely erase political tensions between different groups of WLHIV, sex workers, and trans women. However, in general, respondents reported that working together on SRHR reduced stigma and discrimination and improved personal and working relationships. To illustrate, a sex worker explained that the initiative

brought us together, because there had always been a distancing with the network [of WLHIV] because they blamed us for their husbands infecting them with HIV and because the men came to us rather than bringing home the bacon, so these things got smoothed out, and now we take joint actions. (interviewee 11)

For their part, WLHIV leaders reported that collective action helped them overcome prejudices toward trans women and sex workers and created relationships that increased the scope of their advocacy and programmatic work:

Now I don’t only work specifically with women living with HIV, I also work with sex workers, and women who use drugs and trans women living with HIV. So, this joint collaboration totally expanded

my work because we can talk about the same issues and have a common goal. (interviewee 21)

Protecting and promoting the SRHR of WLHIV through bridging social capital

Feminist lawyers reported that working with WLHIV convinced them that the specific challenges faced by WLHIV were worthy of attention from the broader women’s movement:

The violations of human rights of all women are so severe in our countries that the specificities can become invisible. For me, the main change is that I can’t stop making [HIV] visible, I have to make the specific forms of discrimination that are experienced and the vulnerabilities with respect to accessing specific rights visible. (interviewee 24)

Beyond their focused technical support in filing human rights complaints and their formal and informal mentorship of WLHIV leaders in feminist analysis, the influential roles that the majority of the feminist lawyers held in national and regional women’s organizations—for example, as leaders of prominent sexual and reproductive health organizations or as founders of networks dedicated to addressing violence against women—increased the policy advocacy spaces available to WLHIV. For example, in El Salvador, relationships forged through the coalition resulted in ICW being invited to participate in the national working group for the Violence against Women and Gender Equality Law. Similarly, in Nicaragua, a coalition member stated that

the effort over the past years has been to try to bring feminist organizations together with organizations that work in HIV, particularly with women. They did come closer together which enabled [WLHIV] to provide feedback and experiences on violence, health care (interviewee 24)

Further, the relationships and evidence generated through the coalition were fed directly into policy and legislative processes through the intervention of feminist allies. For example, a participating

feminist lawyer said, “I had the report [on SRHR violations] in my hand” (interviewee 6) as she drafted the revised HIV law.

New relationships also allowed community leaders who lived outside of national capitals to inform national decision-makers about SRHR violations through coalition members located in the capitals. For example, a local Mexican HIV organization identified a pregnant WLHIV who had been discriminated against at a public hospital and who had not had her viral load or CD4 count evaluated or a caesarean section performed at 39 weeks’ gestation, even though national guidelines stated that a caesarean delivery should have been programmed at 38 weeks. The organization informed coalition colleagues in Mexico City, who immediately notified senior officials at the National AIDS Program and National Human Rights Commission; these officials, in turn, communicated to the State AIDS Program and hospital the urgency of providing health services in line with national medical guidelines, resulting in the prompt provision of a caesarean delivery.

The value added of relationships built through the coalition were frequently reciprocal and went beyond advocacy around the SRHR of WLHIV. For example, speaking about efforts to lobby for a law on gender identity, a trans leader explained that

we decided to bring it forward with other [coalition] organizations, because with strategic and organizational allies, it gives us more back up, it makes us stronger in the struggle. (interviewee 14)

In agreement with the community mobilization literature about the importance of bridging and linking social capital and organizational structures, bringing together feminist lawyers from women’s and human rights organizations with leaders from three HIV networks in the region (namely ICW-Latina, RedLacTrans, and RedTraSex) provided additional access to and support in political spaces, as well as technical resources.

Conclusion

This analysis of participant perspectives on the

effects of a five-year community-led intervention indicates that sustained capacity-building and creation of network structures contributed to the development of a “culture of rights,” the increased agency of community leaders, and collective action that effectively promoted and protected the SRHR of WLHIV. The development of critical consciousness and the collective action frame of promoting and protecting the SRHR of WLHIV strengthened bonding and bridging social capital among diverse groups of WLHIV, women affected by HIV, and feminist allies. These relationships mobilized technical, financial, and organizational resources to defend the SRHR of individual WLHIV and to influence the legislative and policy environment. Flexible and renewed funding over the five-year period allowed the initiative to be truly community-led and participatory by adapting to evolving priorities and supporting collective processes.

The participatory generation of evidence through community-led research deepened community leaders’ understanding of and motivation to defend the SRHR of WLHIV and was described as central for internalizing, adapting, and adopting human rights concepts. Community leaders reported changes in their health behavior and thinking about SRHR, which suggests that knowledge and skills development benefited them personally and started to permeate through their social networks. WLHIV also reported that the intervention began to create a “culture of rights” in which the normalization of SRHR violations and taken-for-granted discrimination based on HIV status began to be questioned. As a consequence, both individuals and networks of WLHIV began to raise their voices in protest. Having credible evidence about SRHR violations and scientific knowledge was perceived by participants as critical for positioning themselves as experts, engaging in dialogue and policy advocacy with decision-makers, and using national, regional, and international human rights mechanisms. In agreement with community leaders’ reports about their increased capacity and collective action to defend SRHR because of this intervention, a 2016 survey of 343 WLHIV and 101

external stakeholders identified SRHR and other human rights of WLHIV as the thematic areas in which ICW-Latina has had the greatest influence and advocacy success.²⁹

Actions by participating community leaders improved immediate access to SRHR for individual WLHIV and resulted in legal decisions, guidelines, policies, and legislation that promoted the SRHR of WLHIV in alignment with international human rights law. This analysis indicates that community mobilization interventions that foster critical consciousness, social cohesion, and organizational linkages increase the capacity of community leaders to hold governments to account for meeting national, regional, and international human rights standards and can make broad contributions to the health and well-being of society by supporting health policy and systems improvements.

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The Right to Health in Times of Pandemic: What Can We Learn from the UK's Response to the COVID-19 Outbreak?

LISA MONTEL, ANUJ KAPILASHRAMI, MICHEL P. COLEMAN, AND CLAUDIA ALLEMANI

Abstract

The UK's response to COVID-19 has been widely criticized by scientists and the public. According to EuroMOMO, a European mortality monitoring initiative, the excess mortality that may be attributable to COVID-19 in England is one of the highest in Europe, second only to Spain. While critiqued from a public health perspective, much less attention is given to the implications of the pandemic outbreak for the right to health as defined under international human rights law and ratified by member states. Using the UK as a case study, we examine critically the extent to which the government's response to COVID-19 complied with the legal framework of the right to health. We review further key states' obligations on the right to health and assess its suitability in times of pandemic. Finally, we offer some recommendations for an update of the right to health. This paper adds to the body of literature on the right to health and human rights based-approaches to health.

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Introduction

On April 22, 2020, the European Committee of Social Rights, the body responsible for overseeing the implementation of the European Social Charter, issued its *Statement of Interpretation on the Right to Protection of Health in Times of Pandemic*.¹ This statement emphasizes the interrelation of the right to protection of health with other rights enshrined in the European Social Charter, such as the right to social and medical assistance, the right to housing, the right to freedom from poverty and social exclusion, and the right to safe and healthy working conditions. States' obligations to realize further the right to health in response to COVID-19 were also addressed by UK experts in a submission to the Parliamentary Joint Committee of Human Rights in July 2020.² The submission includes recommendations for the protection of vulnerable groups, preparedness, essential medical goods, testing and tracing, lockdowns, vaccines, the right to access other health services, long-term care for COVID-19 patients, international cooperation, and accountability.

These statements show the importance of systematically applying the right to health to public health policies when addressing the COVID-19 pandemic. This has also been reiterated by the United Nations (UN), the World Health Organization (WHO), and the UN Special Rapporteur on the right to health.³

The UK's response to the pandemic has been widely criticized by experts in human rights and the public health community.⁴ Analyses from EuroMOMO, a European mortality monitoring project, show that England has the second excess mortality in Europe.⁵ This, despite the fact that the UK is a signatory to several UN and regional treaties protecting the right to health, including the European Social Charter and the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁶

In this context, we take the UK as a case study to evaluate its early response to the pandemic and to assess the extent to which it fulfilled its obligations arising from the right to health. We use the Committee on Economic, Social and Cultural Rights' General Comment 14 as the legal reference

to assess five of the UK's core obligations arising from the right to health: (1) to ensure the right of access to health facilities, goods, and services on a non-discriminatory basis; (2) to ensure access to the minimum essential food; (3) to take measures to prevent, treat, and control epidemic and endemic diseases; (4) to provide education and access to information concerning health; and (5) to provide appropriate training for health personnel.⁷ We choose to rely on General Comment 14 because, although not legally binding, it constitutes a global understanding of the normative content of the right to health.⁸ We build on the analysis of General Comment 14 to reflect on the legal framework of the right to health and offer some recommendations to adapt it further to the context of pandemics.

This article contributes to the robust international legal framework for the right to health. So far, the literature has explored various areas, including health rights in HIV/AIDS and maternal health, as well as policy issues such as patent rights and access to medicines. To that effect, Covid-19 presents itself as another opportunity to examine and discuss the right to health in times of pandemic.

The UK and the right to health

The UK has signed and ratified both the 1961 European Social Charter and the 1966 ICESCR, which protect the right to health in their articles 11 and 12, respectively.⁹ It is also a signatory to other UN treaties that protect the right to health of specific groups, including the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of Persons with Disabilities, and the Convention on the Rights of the Child.¹⁰

We assess the extent to which the UK respected its obligations under the right to health when it responded to the onset of the pandemic, from February to May 2020. This period was crucial for preparedness and the adoption of principles such as availability, accessibility, acceptability, and quality of health services, as well as non-discrimination, participation, and accountability of the state in its public health response.

During these four months, the government took decisions on triaging patients in primary health care, testing and tracing, the provision of essential medical goods and personal protective equipment (PPE), lockdown measures, and the communication of data on incidence and mortality for epidemiological research. All of these decisions had an impact on the right to health of its people, including their access to health services, equal access to treatment, the right to access health information, and the right to be treated for diseases other than COVID-19.

The right to health requires states to take positive action and engage their financial and human resources. As a result, they are subject to the principles of progressive realization and maximum available resources—in other words, states must take steps to realize the right to health gradually and continuously over time, and they must not take any retrogressive action.¹¹ To that effect, however, there are some core obligations that each state must fulfill immediately to realize the right to health, regardless of its economic and human resources. Such obligations are outlined by the Committee on Economic, Social and Cultural Rights in General

Comment 14 (Box 1).¹² Because the core obligations must be applied immediately and are not subject to the availability of resources, we chose to assess the UK's adherence to five of these obligations that we found relevant in the context of its early response to the pandemic.

The UK's response to COVID-19

To tackle outbreaks of infectious diseases, WHO recommends containing their spread by testing persons for the presence of disease, tracing their contacts, quarantining suspected cases, and treating confirmed cases. If the disease has spread in the community, the government must ensure that health facilities can cope with the patients who require hospital care.¹³

On December 31, 2019, WHO's China Country Office received a report about an unknown virus behind a number of pneumonia cases in Wuhan.¹⁴ On January 12, 2020, the Chinese government made the genetic sequence of the virus publicly available.¹⁵ This was to facilitate international efforts to develop diagnostic tools, to speed up research for a vaccine, and to ensure preparedness in case of an outbreak.

Box 1. Key obligations from General Comment 14 on the right to health

<p>Core minimum obligations</p> <p><i>a. To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;</i></p> <p><i>b. To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone;</i></p> <p><i>c. To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;</i></p> <p><i>d. To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;</i></p> <p><i>e. To ensure equitable distribution of all health facilities, goods and services;</i></p> <p><i>f. To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population [...]</i></p> <p>Obligations of comparable priority</p> <p><i>a. To ensure reproductive, maternal [...] and child health care;</i></p> <p><i>b. To provide immunisation against the major infectious diseases occurring in the community;</i></p> <p><i>c. To take measures to prevent, treat and control epidemic and endemic diseases;</i></p> <p><i>d. To provide education and access to information concerning the main health problems in the community, including methods of preventing and controlling them;</i></p> <p><i>e. To provide appropriate training for health personnel, including education on health and human rights.</i></p>

Source: Committee on Economic Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, UN Doc. E/C12/2000/4 (2000), paras. 43–44.

Meanwhile, the situation degraded rapidly, and on January 30, 2020, the WHO director-general declared a “Public Health Emergency of International Concern.”⁶ WHO’s Emergency Committee issued temporary recommendations: “All countries should be prepared for containment, including active surveillance, early detection, isolation and case management, contact tracing and prevention of onward spread of 2019-nCoV infection, and to share full data with WHO.”⁷ This coincided with the UK reporting its first lab-confirmed case of COVID-19. Figure 1 presents a timeline of key responses in the UK.

Obligation 1: Ensure the right of access to health facilities, goods, and services on a non-discriminatory basis, especially for vulnerable or marginalized groups

Ensuring non-discriminatory access to health care demands that attention be given to specific vulnerable groups. In the context of COVID-19, early analyses revealed that social inequalities exacerbate risks of COVID-19 and highlighted key vulnerable groups. These include elderly persons with chronic conditions, minority ethnic populations, persons from the lowest wealth quintile, and non-COVID patients with another serious illness.¹⁸ The failure of the UK government to tackle these vulnerabilities and to make specific provisions for vulnerable groups resulted in higher case fatalities among Black, Asian, and Minority Ethnic (BAME) groups in comparison to white population in deprived regions as well as in care homes.¹⁹ This marks a violation of their right to health.

Generally, access to primary health care in the UK was severely disrupted. From mid-March, general practices implemented triage by phone, thus limiting the number of patients allowed to visit their primary care physician in person or be referred to another health professional.²⁰ The health impacts on primary care disruption have yet to be estimated but will have mid- to long-term implications for the National Health Service (NHS), with some chronic conditions worsening, new conditions diagnosed too late, and referrals to special services such as cancer and mental health being postponed or canceled. Because of the long queuing

time over the phone and the digitalization of health consultations, phone triages may be discriminatory toward poorer households whose phone contracts may limit communication time each month and toward older patients who may find the use of technologies challenging.

Access to acute secondary care services was also severely affected. On March 17, 2020, hospitals were instructed to suspend all elective surgical procedures for at least three months.²¹ NHS trusts were instructed to redesign their services to free up capacity for COVID-19 patients.²² Yet it is estimated that 50% of elective procedures can inflict significant harm to the patient if postponed or canceled.²³

Several guides were published by NHS England to propose a system of priority levels for surgical procedures for cancer patients.²⁴ On March 30, it advised maintaining cancer treatment during the COVID-19 response.²⁵ However, the non-compulsory nature of the document meant that the responsibility lay with local health trusts, which introduced inconsistency in implementation.²⁶ As a result, some high-risk cancer patients faced delays in their treatment.

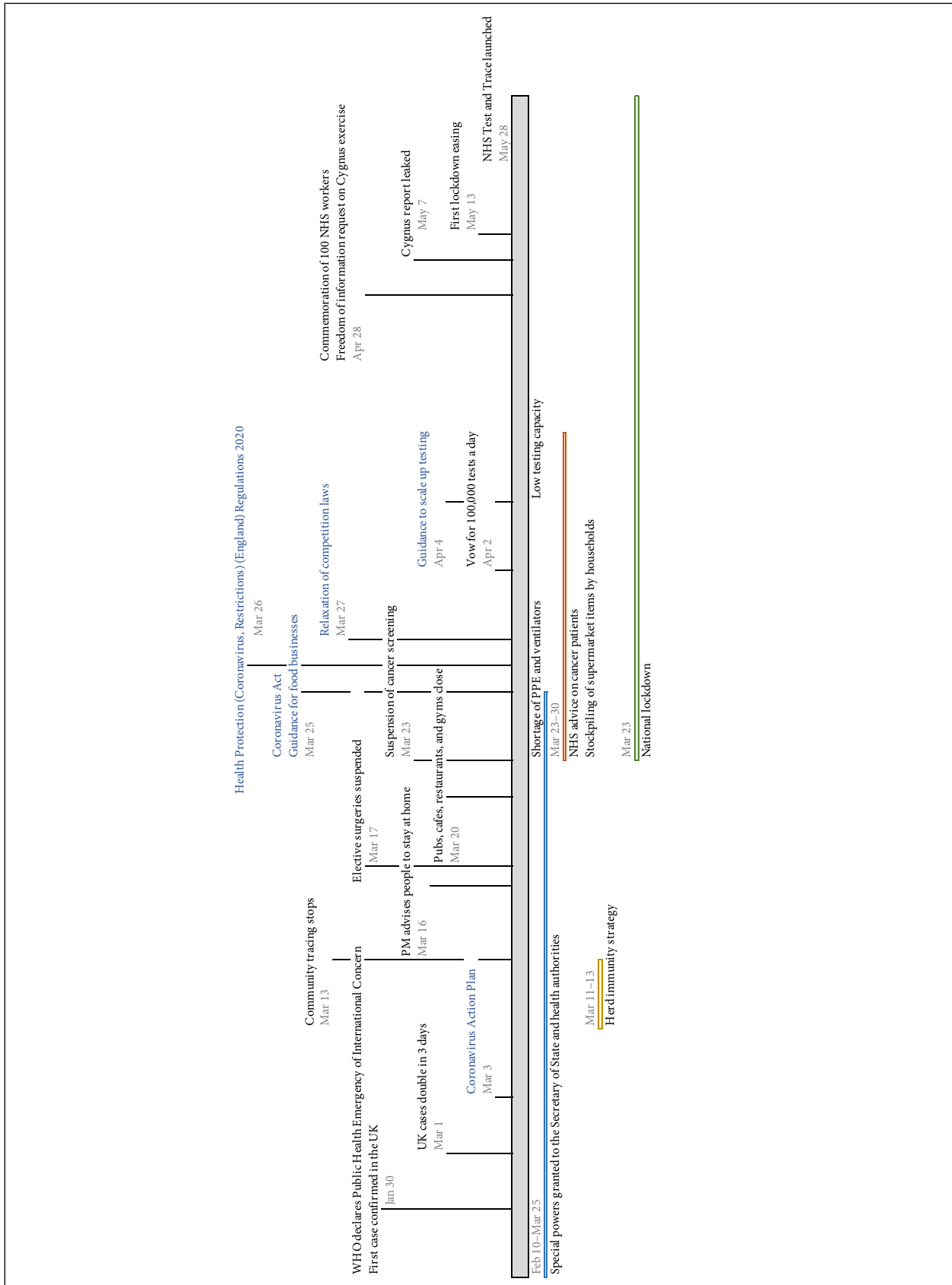
In addition, national cancer screening was suspended to allow the deployment of frontline health workers for COVID-19.²⁷ The number of high-risk patients being referred by their general practitioner for a possible cancer diagnosis dropped by roughly 70% in Scotland and Northern Ireland.²⁸

While the government prioritized the treatment of COVID-19 patients, it failed to ensure that other serious health conditions could be diagnosed and treated promptly. By publishing soft guidance for local NHS trusts, the state delegated its responsibility to ensure access to health services and facilities to everyone, which created inequalities in access between geographical regions.

Obligation 2: Ensure access to the minimum essential food

This obligation means that the government must take action, if necessary, to ensure that persons on a low-income or homeless have access, on a daily basis, to the minimum essential food that is nutritionally adequate and safe.²⁹

FIGURE 1. Timeline of the key early responses to the COVID-19 outbreak in the UK, February–May 2020



On March 21–22, 2020, the weekend preceding the lockdown, many people rushed to supermarkets and started stockpiling supplies such as food and antibacterial handwash. In its official guidance, the UK government focused on food hygiene, social distancing, and employee sickness, but did not include any advice for supermarkets on how to regulate the flow of supplies.³⁰ Nor did it advise citizens to shop responsibly.³¹ As a result, the week running up to and the first few weeks of the lockdown witnessed a scarcity of fresh fruit, vegetables, milk, and bread in supermarkets. More affluent households were able to stockpile, while poorer households found themselves unable to procure essential items due to their scarcity.

The government appeared to leave the burden of decision-making to private actors—namely supermarkets—to ensure that there was an adequate food supply. Partial regulation was seen at some point, when the government relaxed competition laws to allow supermarkets to exchange otherwise competitively sensitive information.³² The aim was to allow supermarkets to shift the priority from competing with one another toward ensuring that enough essential items would be available everywhere in the country. The Coronavirus Act 2020 on food supply provided only a monitoring power to the government through the requesting of information from businesses or persons working in the food industry.³³ One may argue that the state had a duty to regulate supermarkets in order to ensure the availability of food for the entire nation in these special circumstances.

The lack of strong government intervention meant that existing inequalities in access to food widened. People living on low wages or who had lost their job during the lockdown increased the demand on food banks. At the same time, donations to those food banks decreased, because of stockpiling. Families relying on school meals for their children also found themselves in strenuous situations.³⁴ This represented a violation of the state's core obligation to ensure access to minimum essential food and the right to food, as protected by article 11 of the ICESCR.

Obligation 3: Take measures to prevent, treat, and control epidemic and endemic diseases

A state can prevent and control an infectious disease by providing vaccination at the population level. With no vaccine available for the SARS-CoV-2 virus, states are left with the test-and-trace strategy, as well as scaling up their health care system's capacity to treat new cases.³⁵

On March 1, 2020, the UK recorded its highest surge in new cases, which represented a doubling of the number of cases in just three days.³⁶ The government had had one month since the WHO's declaration of the Public Health Emergency of International Concern before that first surge in cases to prepare its response to spread of the novel coronavirus. During this period, the official strategy was unclear, and communication to the public was inconsistent.

On March 3, 2020, the official strategy from the government's Coronavirus Action Plan was to contain, delay, research, and mitigate.³⁷ However, in mid-March, the government contemplated achieving herd immunity by allowing a large proportion of its population to become infected and then recover.³⁸ At the time, estimates suggested that up to 260,000 deaths could have been expected.³⁹ This approach came under scrutiny for lack of evidence on immunity, and uncertainty around the epidemiology of the virus and the disease it causes.

Following substantial criticism from the scientific community at home and abroad, as well as media scrutiny, the government shifted its strategy on March 16.⁴⁰ People were strongly advised to stay at home, but the decision to travel to work remained with employers. Social venues remained open until March 20, and it was not mandatory for major events to be canceled. On March 23, a national lockdown was finally announced, and a few days later it went into effect.⁴¹

Although the government's new strategy followed WHO's advice, it came too late.⁴² The incubation period for COVID-19 meant that the effect of the lockdown would be seen only after about two weeks. Meanwhile, the NHS was faced with a rapid increase in the number of patients who needed treatment in intensive care units, including

artificial ventilation for lung failure.

Despite the government's strategy to prioritize strengthening the capacity of the health care system and maintaining the functionality of tertiary services, it failed to equip health care workers adequately with PPE and to provide enough ventilators for seriously ill patients.⁴³ For instance, on March 17, the UK failed to take up an offer from the European Union to participate in a joint procurement call to buy ventilators for 25 member states.⁴⁴ The significant shortage in PPE also meant that NHS staff on the front lines were risking their lives. When NHS staff developed COVID-19 symptoms, they had to self-isolate for 14 days, thus reducing the workforce further.⁴⁵ The government also failed to enforce guidelines to reduce transmission to residents and workers in care homes, among whom the proportion of new cases and deaths was later shown to be much higher than in other population groups.⁴⁶

Community testing stopped on March 13, 2020. On May 28, the new NHS Test and Trace service was launched, after the peak of the epidemic had passed and after the first easing of the national lockdown had been implemented.⁴⁷ During the peak of the epidemic, the government attempted to scale up testing capacity but failed.⁴⁸ In late April, it was reported that the government met its target of carrying out 100,000 tests a day, but the methods used for reporting artificially inflated the numbers.⁴⁹

The lack of a clear national strategy based on transparent epidemiological evidence and the lack of clear official communications, including on the number of tests performed, mark a failure to prepare for the epidemic. The reliance on self-isolation while pubs, offices, and major events remained open; the delay in implementing a national lockdown; the decision to stop community testing mid-March coupled with the late launch of the Test and Trace service late May constitute a failure by the UK government to take strong action to contain and control the spread of the virus. The lack of sufficient PPE for NHS workers and people in social care homes, and of ventilators for seriously ill patients, represents a failure to treat and control the epidemic.

Obligation 4: Provide education and access to information concerning health

Two obligations can be distinguished in relation to information. First, states must report on their progress to fulfill the right to health and publish reliable data on indicators such as incidence and mortality. Second, states have a duty to ensure that health information of sufficient quality is circulated to the public.⁵⁰

Data about COVID-19 are questionable everywhere, including the UK. It is impossible to know the true incidence rate because some infections produce few or no symptoms. While the effects of the disease range from mild to severe to fatal, the UK was not initially testing people outside hospitals. Even calls to NHS 111, the national helpline, from people with COVID-19 symptoms were not systematically registered. Deaths due to COVID-19 outside hospitals were not routinely reported by government agencies, therefore underestimating the death toll. Deaths in hospitals that are attributed to COVID-19 among patients with underlying conditions lack clarity because the cause of death may not necessarily be COVID-19. The curve of deaths may also not be reliable because deaths were being reported at the time of registration, not in relation to the date of death. Reporting times vary between health centers.⁵¹ Without reliable data, public policy cannot be properly informed. For these reasons, scientists recommend relying on the number of excess deaths for international comparisons of COVID-19-related deaths.⁵²

The WHO director-general used the term "infodemic" to describe an excessive amount of information about the COVID-19 pandemic, which makes it difficult for the general public to identify reliable information and act responsibly.⁵³ The "infodemic" has caused both health-related and economic damages in the UK, partly because the government failed to prevent and control misinformation. For instance, some conspiracy theories fueled the belief that SARS-CoV-2 was made in a lab, or that it was spread through the 5G communications network, resulting in attacks on telecom engineers and the burning of cell phone towers.⁵⁴ Official communication on the country's testing

capacity was unclear, with numbers on testing capacity artificially inflated and the number of COVID-19 cases deflated.⁵⁵ Communication around herd immunity sent the wrong signals to the population, days before the government announced that everyone should voluntarily self-isolate. These examples show a failure of the UK government to uphold its duty to provide clear and reliable information so that members of the public have the necessary tools to make informed choices regarding their health and to protect the health of others.

Obligation 5: Provide appropriate training for health personnel

A key function of the health system is to train its workers and ensure that they are ready to handle outbreaks of diseases.⁵⁶ The situation late March 2020 in the UK, about one month after the start of the COVID-19 outbreak in the country, showed inadequate training of health workers to respond to such an emergency.⁵⁷

In 2016, Exercise Cygnus, a simulation exercise, was conducted to evaluate the capacity of the NHS in the event of a pandemic. The final report was kept secret, with some commentators arguing that it would have revealed that the NHS was unprepared for a pandemic.⁵⁸ It culminated in a freedom of information request from an NHS doctor in April 2020.⁵⁹ The report was eventually leaked to the *Guardian*, which published it in the interest of the public on May 7.⁶⁰

One of the report's key findings was that "the UK's preparedness and response, in terms of its plans, policies and capability, [was] not sufficient to cope with the extreme demands of a severe pandemic that [would] have a nationwide impact across all sectors."⁶¹ In addition, the report identified a need to develop a "methodology for assessing social care capacity and surge capacity during a pandemic," as well as to examine "the possibility of expanding social care real-estate and staffing capacity."⁶² These recommendations were not communicated to key stakeholders, as the Chief Executive of Care England testified.⁶³

The lack of appropriate training for health personnel also comes from a more structural issue

within the UK's health system. The social care sector in England, as well as the NHS, have seen drastic financial cuts for the past ten years, in addition to privatization. Working conditions for social care workers are deplorable, with low-pay and zero-hours contracts.⁶⁴ Junior doctors also work very long hours. The social care sector is now almost exclusively in the private sector and isolated from the NHS. Because of these structural issues, the current public health crisis has further amplified the problems faced by a tired and deficient workforce.⁶⁵

The state's failure to implement the recommendations from the pandemic preparedness exercise, its efforts to keep the final report confidential, and the fragmentation and privatization of the NHS and social care sector over the past ten years, mark a collective failure to comply with the obligation to train health workers and prepare the health sector to respond to outbreaks of diseases.⁶⁶

This brief examination of the UK government's early response to COVID-19 reveals four types of consequences from the failure to respect, protect, and fulfill the right to health, as illustrated in Table 1. The first type concerns direct health consequences—for example, people dying as a result of COVID-19, people losing family members to the disease, or people left with long-term sequelae after surviving an infection with the virus. The second concerns direct economic consequences—for example, people losing their jobs or homes, people being dragged into poverty, or children being unable to access school meals. The third category includes indirect health consequences, particularly for non-COVID patients with another serious health condition serious health conditions. For instance, the diagnosis, management, and follow-up of cancer patients was greatly affected, which will almost inevitably lead to worse cancer outcomes.⁶⁷ This category also includes consequences stemming from the psychological impact of the lockdown. Finally, the fourth type concerns indirect economic consequences—for example, people bearing the costs of more expensive treatment for pre-existing health conditions or the loss of their job due to health complications after a late cancer diagnosis. Other indirect consequences stemming from the

government's failure to provide reliable information about the virus include property damage to 5G towers. All of these consequences have an impact on one another; for example, people dragged into poverty due to the pandemic are more likely to experience worse health later in life, since poverty is a social determinant of health.⁶⁸

While late action from the government is to blame, the inadequacy of national responses worldwide also brings under scrutiny the utility and appropriateness of international legal provisions regarding the right to health. Are these legal texts adequate to address preparedness, surveillance, and promotion of the right to health for everyone in times of pandemic?

The international legal framework on pandemics and the right to health

We find that references to pandemics or public health crises are limited in human rights law documents.

General Comment 14 encourages “the creation of a system of urgent medical care in cases of accidents, epidemics and similar health hazards, and the provision of disaster relief and humanitarian assistance in emergency situations.”⁶⁹ This is supplemented by the European Committee on Social Rights' *Statement of Interpretation on the Right to Protection of Health in Times of Pandemic*, which outlines states' obligations to test, trace, and impose measures of physical distancing or lockdown and to ensure the availability of hospital beds, intensive care units, and PPE for health workers.⁷⁰ Of particular relevance to the UK, the European Committee on Social Rights emphasizes the need for states to act as soon as preliminary scientific evaluation in-

dicates reasonable grounds for concern regarding potentially dangerous effects of a virus or other factors on human health.⁷¹ The UK's delay in implementing a national lockdown and the confusion generated by the government's communications concerning the official public health strategy reveal the importance of such obligations. They all point toward states' duty to prepare adequately for a pandemic and to ensure the availability of sufficient material and human resources to treat a large number of patients at any one time.

Further, international human rights law points toward a “collective responsibility” of the international community with regard to outbreaks of infectious diseases.⁷² In the present context, the Committee on Economic, Social and Cultural Rights clarified that international cooperation means sharing medical equipment and best practices to combat the virus, sharing knowledge for the development of a vaccine, and engaging in joint action to minimize the economic and social impacts of the public health crisis.⁷³ International cooperation around COVID-19 seems to have been weak at first, with, for instance, Italy's call for help met with silence from other European countries.⁷⁴ The President of the European Commission, the UN Secretary-General, and the WHO called for solidarity among countries.⁷⁵ At the global level, many countries contributed to the COVID-19 Solidarity Response Fund.⁷⁶ However, this generosity was soon overshadowed by the withdrawal of the United States from WHO funding. International cooperation has not been satisfactory, and the pandemic response has emerged as a turf war between different polities, with some country leaders blaming China or banning exports of medicine.⁷⁷

We did not find further mentions of pandem-

TABLE 1. Examples of health and economic consequences of the failure to respect, protect and fulfill the right to health in times of pandemic

	Health	Economic
Direct	<ul style="list-style-type: none"> • COVID-19 deaths and long-term sequelae 	<ul style="list-style-type: none"> • Job losses • Homelessness • Child poverty
Indirect	<ul style="list-style-type: none"> • Worse cancer outcomes • Psychological impact of the lockdown 	<ul style="list-style-type: none"> • Costs of worse cancer outcomes • Property damage on 5G masts

ics or public health emergencies in international human rights instruments. The closest we found was the inclusion in these instruments of a duty for states to engage in international cooperation and to create systems of urgent care. However, as illustrated by the example of the UK in the COVID-19 pandemic, many other issues require attention, such as the training of medical staff in infection prevention and control, the prompt response and planning by the government as soon as scientific evidence becomes available, the transparency of the government's response based on scientific evidence, the accuracy of data collected and communicated, the provision of continuing care for everyone (including patients with conditions other than COVID-19), the management of intensive care services, and the regulation of food supplies, to name but a few. In this regard, the *Statement of Interpretation on the Right to Protection of Health in Times of Pandemic* from the European Committee on Social Rights constitutes an encouraging development, because it extends states' obligations to include the adoption of public health measures to prevent, contain, and control the spread of viruses, as well as to treat the diseases they cause.

The binding 2005 International Health Regulations and the non-binding 2011 Pandemic Influenza Preparedness Framework are key international documents that apply to all WHO member states with regard to preparing for outbreaks of infectious diseases.⁷⁸ While they are of critical importance from a public health perspective, and despite referring to human rights principles, we argue that they are not sufficient for the protection of the right to health in times of pandemic because they do not propose a rights-based approach to public health emergencies. They should, however, inform future development of the right to health.

Recommendations

International human rights law on the right to health needs updating. The inadequacy of responses to the COVID-19 pandemic that should have protected and safeguarded the right to health signals an urgent need for the firm grounding of pandemic

preparedness plans in human rights principles. The suitability of human rights instruments in the context of a health emergency also needs urgent reviewing.

The example of the UK shows that the public health response must explicitly address vulnerable groups in the general population—including older patients with chronic conditions, ethnic minorities, non-COVID patients with another serious health condition (such as cancer), people with mental or physical disabilities, people living in deprived areas and crowded households—to ensure universal access to health services and facilities.

Addressing human rights is especially needed during lockdown, because such measures disproportionately affect vulnerable groups, including women experiencing abuse.⁷⁹ Early studies suggest that people in BAME communities are more likely to die of COVID-19 than white people.⁸⁰ This may be due to the increased pressure faced by BAME doctors and nurses to see infected patients in settings without PPE, the fact that people from ethnic minorities are more likely to live in severely affected areas, and BAME individuals' greater likelihood of having underlying health conditions.⁸¹ Either way, states must implement measures that will protect groups at higher risk of dying from the disease, including those in social care homes.

Protecting vulnerable groups extends beyond access to health care. In the UK, many households are now affected economically by the crisis, as observed with the increased demand on food banks.

Experience in the UK also shows the need for a clear national strategy from the outset, as soon as a risk is reasonably identified through scientific evidence. Political action must be prompt, based on scientific evidence, transparent, and communicated clearly to the population. A soft approach like the one adopted by the UK in the weeks preceding the lockdown, where private actors with economic power remained in charge of deciding whether people should travel to work and whether events would be maintained, should be avoided.

Further, communication around the pandemic necessitates a minimum level of control by the state, especially in times of mass misinformation

and spread of fake news through social media channels. While it is important to maintain freedom of the press and freedom of expression, the state must guide the public toward reliable sources of information that are transparent and based on science. Data on the virus must be published using a clear method so as not to mislead the public, as pointed out by the UK Statistics Authority when criticizing the misuse of statistics by the Secretary of State for Health on June 2, 2020.⁸²

Because in the UK, as in many other countries, health workers initially lacked PPE in sufficient number and quality, the provision of essential medical goods must be at the forefront of a state's response to a pandemic—without, however, depriving other countries of such goods.

Based on the UK example of a state's response to COVID-19, we call on international experts in human rights, health systems, infectious diseases, non-communicable diseases, emergency care, and humanitarian disasters to develop a robust framework of protections that would be applicable in times of pandemic. This framework should include the following:

- A universal right to access urgent medical care on a non-discriminatory basis
- A universal right to screening, prompt diagnosis, treatment, and continuing care for non-communicable diseases in order to continue progress towards Sustainable Development Goal 3.4, i.e. to reduce by one-third premature mortality for non-communicable diseases by 2030
- The duty of states to act promptly and prepare for a disease outbreak as soon as scientific evidence indicates reasonable grounds for concern regarding potentially dangerous effects of a virus or other factors on human health
- The duty of states to adopt a national response plan based on scientific evidence available to the public
- The duty of states to ensure accurate data collection and dissemination by public agencies or universities, without political interference
- The duty of states to publish disaggregated data

that would help identify discrimination on grounds such as ethnicity, and socioeconomic status

- The duty of states, using an intersectionality lens, to monitor risks of infection and access to health care among vulnerable groups
- The duty of states, in collaboration with WHO and social media platforms, to control the spread of misinformation, fake news, and rumors about viruses and the diseases they cause, including racial blame and victimization
- The duty of states to ensure the regular flow of food supplies everywhere in their territories, with particular attention to deprived households
- The duty of states to ensure that medical staff have the necessary resources to work, including PPE, disinfectant, and medical supplies of adequate quality relevant to the disease being treated

In addition, the right to health as enshrined in international human rights law should be updated to include the following provisions:

- A core minimum obligation to ensure access to emergency care on a non-discriminatory basis
- The duty of states to build and support robust and resilient health systems based on scientific evidence, on WHO's six building blocks (governance, financing, workforce, products and technologies, information and research, and service delivery), and on human rights principles
- The training of health and social care professionals in infection prevention and control, in both the public and private sectors

Such provisions could either be added to a revised version of General Comment 14 or be included in a new general comment on the right to health in times of pandemic. Regional human rights bodies such as the European Committee on Social Rights, the African Commission on Human and Peoples' Rights, the Inter-American Commission on Human Rights, the Arab Human Rights Committee, and the South Asian Association for Regional Co-

operation should adopt recommendations on the right to health in times of pandemic and consider including the above provisions.

Conclusion

The risk of pandemics from new viruses is likely to increase due to a growing world population, urbanization, and frequency of international travels, together with the presence of live animal markets in densely populated areas. The *Statement on the Right to Health in Times of Pandemic* from the European Committee on Social Rights builds on the robust international legal framework for the right to health and constitutes an encouraging basis to develop it further.

In this article, we observe the UK's response to the COVID-19 pandemic and identify some issues that have emerged in such exceptional times. We argue that the right to health as enacted today is not sufficient to address these issues. The current international human rights framework is robust, but states' obligations should be clarified so they can be adapted to public health measures in times of pandemic. At the same time, international public health documents to prepare for pandemics are not sufficient on their own to protect the right to health of everyone. We offer some recommendations to that effect.

Writing about issues as we witness them allows us to construct reliable historic memory. The COVID-19 pandemic has caused many deaths that could have been avoided had we been better prepared with strong rights-based provisions. These are essential lessons to be learned, and the human rights community has a crucial role to play to ensure that future responses to pandemics are grounded in human rights law.

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A Health-Based Case against Canadian Arms Transfers to Saudi Arabia

RHONDA FERGUSON AND ZARLASHT JAMAL

Abstract

Under the Arms Trade Treaty, state parties must assess the extent to which the export of conventional arms might contribute to, *inter alia*, serious violations of human rights or international humanitarian law. The stated aims of Canada's arms export licensing decision-making process are, similarly, to assess such risks on a case-by-case basis. This paper examines Canada's ongoing arms transfer arrangements with Saudi Arabia in light of health-related international humanitarian and human rights law considerations enumerated in the Arms Trade Treaty. It assesses available information suggesting serious violations that implicate acts of commission by the Saudi-led coalition in the conflict in Yemen. The article centers on questions about the potential health-related consequences of Canadian-made, Saudi-coalition-used arms for people in Yemen and how risks are being assessed in export decision-making processes. Ultimately, it argues that Canada is failing to meaningfully take into account the possible negative impacts of its arms exports on people's health and health care in Yemen. It counters the government's approach to risk, which it argues is serviceable to exporter interests, with a health-based precautionary approach to exports.

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Introduction

Canada's accession to the Arms Trade Treaty (ATT) in 2019 heralded a new era of oversight of its export-permitting regime. Pursuant to the aims of the ATT, including the reduction of suffering, state parties must, *inter alia*, assess the extent to which the export of conventional arms might contribute to serious violations of international human rights law (IHRL) or international humanitarian law (IHL).¹ Canada's amended Export and Import Permits Act includes a similar assessment.² However, the assessment criteria used by licensing authorities and the information provided by intended importers remains unavailable to the public. This paper examines Canada's health-related IHL and IHRL obligations as set forth in the ATT, in light of its ongoing arms transfer arrangements with Saudi Arabia. It highlights available information on violations that implicate acts of commission by the Saudi-led coalition in the conflict in Yemen. This research stems from questions about the human consequences of Canadian-made, coalition-used arms for people in Yemen and the effectiveness of Canada's transfer decision-making process. Ultimately, it argues that Canada is failing to meaningfully take into account the possible negative impacts of its arms exports on people in Yemen. It counters the government's approach to risk—which is serviceable to exporter and economic interests—with a health-based precautionary approach to exports.

To undertake this analysis, we first present an overview of the relevant obligations under the ATT and Export and Import Permits Act, particularly obligations to assess the potential of arms transfers to facilitate serious violations of health-related norms in IHL and IHRL. Second, we outline Canada's arms transfer arrangements with Saudi Arabia. Third, to demonstrate the risks of Canadian arms exports for people, we discuss the known impacts of arms import, accumulation, and use on population health. This includes the available information on the health implications of arms use by the Saudi-led coalition in Yemen. Finally, we argue that health-related risks to people in Yemen do not adequately inform Canada's arms transfer decisions.

State party obligations under the Arms Trade Treaty

Included in the purposes of the ATT are contribution to international peace, reduction of human suffering, and increased transparency and responsibility in the arms trade.³ State parties are obligated to “assess the potential that the convention arms or items ... could be used to commit or facilitate a serious violation” of IHL or IHRL.⁴ According to article 7, states are to refrain from authorizing export if there is a significant risk of violations and available mitigating measures are inadequate.⁵ To understand what is encompassed by these particular obligations, a number of phrases must be unpacked.

The nature of the assessment itself should be emphasized; states are obligated to consider *the potential or risk* for something to happen, and not to prove that a violation has or will definitively happen.⁶ This distinction is significant in that the potential risk does not have to meet the threshold of an international crime, as Andrew Clapham et al. note in their commentary to the ATT.⁷ They also assert that the requirement of states to assess the potential for the arms to “commit or facilitate” serious violations of IHRL or IHL “means that the weapons may be one or more steps removed from the actual violation.”⁸ As a result, we must be concerned with the ways in which weapons might support activities that lead to violations. While a degree of deference to state parties' determination of risk is expected, article 7 is essentially a preventative provision that instructs states to consider the possibility and potential and not wait for evidence that items will definitively be used to violate international law.

The ATT obligates parties to conduct assessments, though it is up to each country to determine the format. Canada's amended Export and Import Permits Act employs the “substantial risk test,” as established through Canadian jurisprudence.⁹ Substantial risk is found where there is a “direct, present and foreseeable risk that a specific good or technology proposed for export would result in one or more of the negative consequences specified in subsection 73(1) of the [Export and Import Permits Act],” which encapsulates the ATT criteria on vi-

olations.¹⁰ The risk must be grounded in evidence and amount to more than a possibility.¹¹ The empirical emphasis suggests a narrow interpretation of the treaty's obligations, and a departure from the commentary authors' interpretation. This also runs counter to the preventative objective of the treaty and Canada's Export and Import Permits Act. Indeed, if we are concerned with human suffering, as the ATT states it is, then the potential for such "negative consequences"—even if falling short of IHRL or IHL violations—should be a compelling factor in risk assessments.¹² Yet, as Anna Stavrianakis writes of permit issuances in the United Kingdom, risk assessments become "an elaborate process of constructing an infrastructure that ostensibly assesses risk but inevitably has the outcome that the risk is not clear, and exports will continue."¹³ Consequently, she finds that "risk is mobilized as a permissive technology."¹⁴ This is further accomplished by a reductive approach to potential harms, which encompasses only those that constitute violations, with an emphasis on their gravity.

States must also create guidelines for consistent decision-making processes. Although the details of the process are not public, the Canadian government's Backgrounder document provides some indication of what factors might be taken into account. For example, there are questions about the importer's human rights record and the existence of "substantiated information" that similar items might be used to commit serious violations.¹⁵ A footnote to the Backgrounder reminds us that "serious violations" of IHL or IHRL are undefined in the ATT. It asserts that "[t]his is a legal question, to be assessed in light of the factual circumstances of each specific case," which may therefore require a legal challenge of permits issued.¹⁶ Yet, as discussed in the next section, legal challenges to date have been dismissed without consideration of the factual circumstances inside Yemen. The Backgrounder cites attacks against medical personnel as an example of a serious violation. The International Committee of the Red Cross's guidelines on the implementation of the ATT list serious violations, including "directing attacks against hospitals, ambulances, or medical staff using the distinctive emblems of the

Geneva Conventions."¹⁷ The committee notes that the meaning of the term "serious violations" differs according to the body deploying such language; a serious violation in international criminal law refers to crimes against humanity, while human rights monitoring bodies use the term more liberally, including for violations of socioeconomic rights.¹⁸ It is worth noting that the ATT's *travaux préparatoires* indicate that multiple countries expressed the importance of considering violations of rights under the International Covenant on Economic, Social and Cultural Rights (ICESCR) vis-à-vis the arms trade.¹⁹ Still, socioeconomic rights appear to be secondary considerations in Canada's arms exports decisions and reviews.²⁰

Only the International Committee of the Red Cross's guide to the ATT definitively encompasses socioeconomic rights. A guide by Amnesty International offers few comments on how socioeconomic rights such as the right to the highest attainable standard of physical and mental health (the right to health) should be incorporated into assessments.²¹ Notwithstanding the limited discussion on socioeconomic rights with regard to arms transfers, the rights enumerated in the ICESCR form an integral part of IHRL, and Canada thus has an obligation to consider how arms exports might threaten them, including the right to health.²² The Committee on Economic, Social and Cultural Rights espouses a wide definition of health; it finds that health is affected not only by genetics and access to facilities, goods, and services but also by access to the underlying determinants of health and the social context, including armed conflict.²³ Serious violations of the right to health include attacks on hospitals and a failure to provide basic services.²⁴

Two of the main challenges in considering socioeconomic rights violations in assessment criteria are that violations of this subcategory of rights are less likely to be labeled "serious" (or gross for that matter) and that attribution of deprivations to an act or omission of the state can be difficult. These issues stem from the formulation of the ICESCR, which is more indeterminate than its civil and political rights counterpart. The obligation to realize rights progressively, according to "available

resources,” creates flexibilities that complicate the determination of violations and underlies arguments against the justiciability of socioeconomic rights.²⁵ However, the small but growing body of case law involving socioeconomic rights such as the right to health, particularly in the Global South, proves their justiciability.²⁶ Although Saudi Arabia has not ratified the ICESCR, this does not preclude an analysis based on IHRL and IHL norms, which are commonly said to be universal, especially considering that it is party to the Convention on the Rights of the Child and the Arab Charter on Human Rights, both of which enshrine the right to health.²⁷

The Canadian government’s *post facto* review of export permits to Saudi Arabia and its halting and subsequent reissuing of permits (discussed in the following section) suggest that risk assessments are limited in scope and hinge on proven IHRL or IHL violations. As Stavrianakis finds, decision-making processes tend to rely on “keeping open the possibility that the future will not involve IHL violations, such that exports can be allowed.”²⁸ This approach to permit issuance does little to effectively reduce human suffering, particularly that which does not fit neatly within the legal categorizations created by IHRL or IHL. Adopting a preventative or precautionary approach re-centers the assessment around potential threats to people. It places the onus on state actors to demonstrate that weapons will not be used in contravention of international law. According to the precautionary principle, “persuasive evidence of harm does not have to exist before measures are taken to protect individuals and society from the harm.”²⁹ Notwithstanding the continued disagreement about what exactly the precautionary principle entails, it is part of customary international law, as recognized by various international adjudicative bodies.³⁰ In 2013, the United Kingdom appeared to act preventatively (albeit under pressure from rights organizations) when it temporarily suspended 48 arms export permits to conduct further review (17 of which were ultimately denied).³¹

IHRL governs the relationship between individuals and the state, and consequently it might be argued that only the acts or omissions of the

importing state toward people within that state must be included in the exporting states’ assessment. However, as argued by commentators, an actual violation of the law is not necessary to halt export permits. Understanding IHRL as a set of standard-setting norms (which create obligations *erga omnes*) can bring assessment processes in line with the express objective of the ATT and Canada’s permitting regime—to “reduce human suffering.”³² Instituting a precautionary approach to permit issuance would enrich the preventative character of ATT article 7(1)(b)(i) and (ii) and would better respect the rights of people in importing or third-party countries.³³

The stringent focus on the risk of IHRL and IHL violations, interpreted narrowly (and excluding socioeconomic rights considerations) rather than on harm, serves to “structure out certain key concerns before the process of risk assessment even begins.”³⁴ Ultimately, questions must be asked about the role of the assessment within the arms transfer decision-making processes; if assessments are intended to protect people, then the potential impact on the lives and health of the people in Yemen must be foregrounded—even when formal obligations of the ATT fail to ensure it. In other words, what is the *risk* that parties must assess? Is it the risk to lives and health? Or is it merely the risk that a legal rule might be broken?

The socioeconomics of the deal in the context of the global arms trade

Some facts about the global conventional weapons trade are useful at the outset. The most recent estimate values the trade at over US\$95 billion, and the trend shows that the volume of weapons being transferred is increasing annually, with the exception of 2018.³⁵ According to the Stockholm International Peace Research Institute, purchases from countries in the Middle East account for the largest share of imports in 2015–2019, a 63% increase from the previous four years.³⁶ Saudi Arabia alone increased its arms imports by 130% during this same period, importing the largest share of arms in the world.³⁷

The expected profit and employment opportunities generated by arms production are often invoked as the political rationale behind morally questionable arms transfer decisions.³⁸ But economic rationalization efforts tend to omit from their calculations the causal linkages between weapons and the harms caused by their use throughout their life cycle. As a result, the economic benefits for arms-producing (and assembling and training) communities tend to dominate political discourse about production and export.³⁹ Absent from such calculations are the findings showing relationships between arms availability and the duration and severity of conflict, mortality, and morbidity, as discussed in the next section.

In 2014, a deal was reached between Canada and Saudi Arabia whereby General Dynamics Land Systems, a weapons manufacturing company based in Ontario, would sell an undisclosed number of light armored vehicles (LAVs) and other items to Saudi Arabia for CAD15 billion.⁴⁰ The details of the arrangement were not made public and the items to be transferred were initially described as “trucks” and “jeeps,” thereby obscuring their military capabilities.⁴¹ It was later revealed that 928 LAVs with “heavy assault,” “anti-tank,” and “direct fire” capabilities were included in this deal.⁴²

In 2016, amid the escalating violence in Yemen and repression of rights in Saudi Arabia, the newly formed government granted six additional permits instead of reevaluating the deal signed by its predecessor.⁴³ A 2016 Global Affairs Canada memo explains that a consultation took place to examine the possibility that exported arms would be used to commit human rights violations in light of reports of Canadian-made weapons in Yemen.⁴⁴ However, the consultants found no connection between the exports and human rights violations and recommended approving the six permits.⁴⁵ Important parts of the memo are redacted—for instance, the number of LAVs exported and the type of weapons systems included.

In 2017, a request for legal review of Canada’s arms export permits for Saudi Arabia was filed based on concerns of the latter country’s human rights record and adherence to IHL.⁴⁶ Applicant

Daniel Turp argued that “the issuance of the permits to export LAVs to Saudi Arabia runs counter to the objectives of the [Export and Import Permits Act] and the Geneva Conventions Act.”⁴⁷ He asserted that there was sufficient evidence to establish a “reasonable risk” that the exported items would be used to violate human rights or threaten peace in the Arabian Peninsula, citing the country’s involvement in the conflict in Yemen specifically. He argued that the minister responsible for permit issuing applied the wrong test in dismissing the fundamental rights concerns, noting that

[a]ll that is required is a reasonable risk that the arms will be used in a prohibited manner, there does not have to be evidence demonstrating that the arms have been so used. Saudi Arabia’s past and present conduct were sufficient to establish that risk.

The Federal Court of Canada found that the minister had acted within his powers and adhered to all relevant obligations, noting that it could not pass moral judgement on the matter.

In 2018, Canada reviewed its export arrangements with Saudi Arabia again in light of reports of international law violations in Saudi Arabia and Yemen where the Saudi-led coalition is active. The review found “no evidence or credible reporting that would link any Canadian exports (e.g. ground vehicles, sniper rifles) to contraventions of international humanitarian law in Yemen.”⁴⁸

Again, these findings ignore the nature of Canada’s obligations under the ATT and the amended Export and Import Permits Act, which do not require a determination of a direct link between the specific items exported and a violation. As Turp suggests, given Saudi Arabia’s past activities in contravention of IHRL and IHL norms, there is a possibility of misuse of transferred arms.

The Federal Court of Appeal dismissed Turp’s appeal, and his application for leave to appeal to the Supreme Court of Canada was not granted.⁴⁹ However, a new application is pending before the Federal Court of Canada.⁵⁰

In response to the murder of journalist Jamal Khashoggi in 2018, Canada put a moratorium on the issuance of new permits to Saudi Arabia.⁵¹ That

it was a single murder in contravention of international law that prompted the Canadian government to act—and not the continued attacks on and widespread suffering of civilians in Yemen—illustrates the subordination of socioeconomic rights considerations in arms export decisions.⁵² In April 2020, during the COVID-19 pandemic and unfolding economic crises, including record-low oil prices that were damaging Canada’s export revenue potential, Canada announced the resumption of application reviews under a “renegotiated” deal.⁵³ Foreign Affairs Minister Chamberlain denied that the decision had any connection to Canada’s struggling oil industry.⁵⁴ A group of human rights organizations condemned the lifting of the moratorium in an open letter to Prime Minister Trudeau.⁵⁵ They noted the hypocrisy of the decision just days before the government released a statement calling for a global ceasefire on conflicts in order to cope with the COVID-19 pandemic. Furthermore, the \$15 billion deal illustrates inconsistencies with Canadian foreign policy rhetoric and reality. While Canada considers itself a champion of human rights, and the Trudeau government has explicitly expressed its commitment “to advancing feminist foreign policy objectives,” its arms exporting decisions to Saudi Arabia fail to uphold these values.⁵⁶ The resumption of export permit application reviews (and the deal itself) points to the calculated risk the government takes to maintain the Canadian defense industry by promoting violence abroad, even while acknowledging findings that the supply of weapons by third parties perpetuates and prolongs the suffering of people in Yemen.⁵⁷

Global Affairs Canada’s 2019 memo and 2020 final report provide insight into the most recent review of export permits to Saudi Arabia. They conclude that based on a “robust” risk assessment process and taking into account the conflict in Yemen, current military exports to Saudi Arabia do not violate Canada’s obligations or create a substantial risk of violations.⁵⁸ Addressing recorded images of Canadian LAVs on Yemen’s border, it found that the images depict older LAVs stationed there for security purposes.⁵⁹ It must be noted, however, that the \$15 billion deal includes upgrade

packages for older model LAVs.⁶⁰ Other images of LAVs inside Yemen suggest that the LAVs are not confined to the Saudi-Yemen border.⁶¹ On June 12, 2018, a video uploaded to Twitter showed a number of Canadian-made LAVs on Yemini territory in Hajjah Governorate.⁶² The government views Saudi Arabia as an ally in “countering instability in Yemen” and believes that “the acquisition of the state-of-the-art vehicles will assist Saudi Arabia in these goals.”⁶³ Global Affairs Canada’s final report also claims that Canada’s arms exports to Saudi Arabia “are more likely to help ensure the stability of a key region for the global economy than to destabilize the region.”⁶⁴ The narrative that Canada’s arms exports to Saudi Arabia promote peace (rather than undermine it) is bolstered by United Nations Security Council Resolution 2216, which has been understood as affirming Saudi Arabia’s intervention in Yemen.⁶⁵

The lack of publicly available information on arms transfer arrangements, even six years after the \$15 billion deal was signed, prevents a comprehensive critique of the assessment criteria. As Luca Ferro maintains, the “high standards” of export controls touted by governments are of little use if they are misapplied or unchallengeable as a result of the secrecy that surrounds decision-making processes.⁶⁶ While the federal government denies that Canadian-made weapons are contributing to violations in Yemen, the evidence of the human toll caused by arms use in the country continues to mount. In response to the documented human rights abuses in Yemen, other countries, including Germany, Denmark, and Finland, have halted arms sales to Saudi Arabia.⁶⁷ In a 2019 legal challenge brought by the Campaign Against Arms Trade, the UK Court of Appeal found that the United Kingdom’s decision-making process regarding arms exports to Saudi Arabia was “unlawful” and “irrational” because it had not assessed the importers’ history of IHRL violations.⁶⁸

Direct and indirect health consequences of arms transfers

The ATT’s preamble recognizes a direct link

between human suffering and arms flows: state parties “bear[] in mind that civilians, particularly women and children, account for the vast majority of those adversely affected by armed conflict and armed violence” and “recogniz[e] the challenges faced by victims of armed conflict and their need for adequate care, rehabilitation and social and economic inclusion.”⁶⁹

Although arms build-up is only one of many factors that lead to the onset of conflict—and increased military capacity might even be argued to deter violence directed from external threats—the simple fact remains that when weapons are discharged at human targets, the immediate consequences for human health and life are entirely negative. That the majority of transfers flow from the Global North to the Global South, where nearly all modern-day conflict occurs, often with devastating consequences, points to the disproportionately negative experience of those in importing and end-use countries.

In 2018, approximately 76,000 people died from armed conflict, although more people die from indirect effects than from bullets and battle wounds.⁷⁰ Indirect deaths occur when preventable diseases emerge from conflict-related disruptions of everyday life.⁷¹ Although it is difficult to separate conflict-related mortality and morbidity from existing structures of ill health, it is estimated that for every direct conflict-related death there are an additional four indirect deaths.⁷² The destruction of key institutions and infrastructure during conflict can make physical access to health care difficult or impossible; displacement relocates people away from key health care facilities; the loss of livelihoods or assets imperils financial access to health care; the erosion of the social determinates of health jeopardizes long-term health; and conflict encourages skilled practitioners to emigrate.

The spread of otherwise easily preventable diseases reflects the breakdown of health care services and supporting public infrastructure in Yemen and other areas experiencing conflict. Armed conflicts create subpar living conditions, such as cramped camps for forcibly displaced people, and unsafe water, both of which increase the risk of infectious

diseases. During armed conflict, people (especially women and girls) are also more susceptible to malnutrition.⁷³ The Food and Agricultural Organization recognizes a causal relationship between violent conflict and food (in)security.⁷⁴ Indeed, the largest human-made food crisis is currently taking place in Yemen. Conflict undermines the accessibility and availability of food: agricultural production declines due to loss of capital and damage to farmland, market disruptions lead to higher prices, and loss of livelihoods limit economic access to food.⁷⁵ Even in the absence of an armed conflict, increased arms imports and military spending are positively correlated with increased food insecurity.⁷⁶

There are gender and age dimensions to the health effects of conflict as well, with women and children disproportionately affected. David Southhall points to the great disparities in child and maternal mortality between low-income countries experiencing armed conflict and the rich countries that supply them weapons, arguing that arms transfers can be considered a form of child and maternal abuse.⁷⁷ He asserts that it is not exclusively the use of arms but the indirect effects of their use—such as food deprivation, disability, and infrastructural damage—that cause most fatalities.⁷⁸ Conflict breaks down existing support and protection mechanisms and places women and girls in vulnerable situations (for example, internal displacement camps, where they are at risk of gender-based violence).

Violations of the right to health are consequences of the conditions that armed conflict produces: loss of livelihood, destruction of housing or shelter, food insecurity, unsanitary living conditions, lack of safe water and sanitation, and limited access to health services.⁷⁹ The indirect effects of arms imports tend to be widespread and long term. Zachary Wagner et al. find that mortality risk is increased for people up to 100 kilometers away for a period of eight years after the conflict ends.⁸⁰ The destruction of infrastructure and health systems has long-lasting effects and requires a significant amount of funding to reverse. Arms purchasing reallocates resources within public budgets, diverting resources away from social services such as health

care. Given these points, there is a clear imperative for arms-exporting countries to conduct risk assessments that ensure that exported arms do not have a role in the violation of human rights or humanitarian norms.

The known health-related consequences of arms use in Yemen

Most direct and indirect health-related consequences of conflict are exemplified in Yemen. As one of the most impoverished nations in the Middle East, Yemen is undergoing a human-made, protracted crisis resulting from armed conflict. Approximately 80% of the population requires humanitarian assistance.⁸¹ Notwithstanding the accusations against all parties to the conflict, this section examines the activities of Saudi Arabia and eight other coalition member states that are detrimental to health and health care to illustrate that Saudi Arabia is a risky destination for Canadian arms.⁸² (A longer list of IHRL and IHL violations in Yemen has been compiled by David et al. to demonstrate the illegality of arms transfers to Saudi Arabia.⁸³)

The Yemen Data Project has gathered data on 20,528 coalition air raids, a quarter of which have targeted civilians in residential dwellings, markets, funerals, weddings, and hospitals.⁸⁴ Over 17,500 civilians have been killed and injured in Saudi-led coalition bombing.⁸⁵ Human rights organizations warn that civilians are targeted by the Saudi-led coalition. One of the deadliest civilian bombings occurred in 2016, when 137 civilians were killed and 695 injured in a coalition-led airstrike on Al-Kubra Hall in Sana'a during a funeral.⁸⁶ In 2018, 40 Yemeni fishermen and seven children died as their fishing boats were attacked by Saudi-led coalition naval forces and helicopters.⁸⁷ Human Rights Watch argues that the coalition forces were close enough to see that the fishermen were waving white cloths and were in fact civilians.⁸⁸ A group of experts appointed by the United Nations High Commissioner for Human Rights, analyzing the violation of international human rights and humanitarian law in Yemen, concluded that parties to the conflict, including the Saudi-led coalition, "are responsible for ... serious violations of freedom of expression and

economic, social and cultural rights, in particular the right to an adequate standard of living and the right to health."⁸⁹

Attacks on medical staff and facilities

Attacks on medical facilities and staff have devastating repercussions for the health of an already vulnerable population. These attacks violate the principle of medical neutrality—that is, the "non-interference with medical services in times of armed conflict and civil unrest."⁹⁰ The International Rescue Committee and the United Nations Office for the Coordination of Humanitarian Affairs estimate that 50% of Yemen's health care infrastructure has been destroyed, closed permanently, or partially affected. For instance, in Taiz Governorate, only four out of the ten medical facilities are in operation.⁹¹ Human Rights Watch, Amnesty International, and Physicians for Human Rights have continuously criticized the Saudi-led coalition's bombardment for breaches of medical neutrality.⁹² The coalition's indiscriminate bombing and targeting of health care facilities and infrastructure effectively weaponizes health, as part of a "strategy of using people's need for health care as a weapon against them by violently depriving them of it."⁹³

Examples of the weaponization of health by the Saudi-led coalition include an attack on a hospital operated by the country's Ministry of Health and supported by Médecins Sans Frontières and UNICEF in Abs District in northwestern Yemen (August 15, 2016); the bombing of a Médecins Sans Frontières medical clinic (June 11, 2018); and a missile attack on Kitaf hospital that killed eight people, including five children and a health worker (March 26, 2018).⁹⁴ The Kitaf hospital was located in a densely populated civilian area, and the facility's coordinates were shared with the coalition beforehand.⁹⁵ Evidence suggests that the coalition was behind another attack on a hospital supported by Save the Children in rural northwest Yemen (March 26, 2019). Attacks on health facilities place the lives of millions of Yemeni people at risk, for they have caused many health care staff to leave already overcrowded and under-resourced hospitals and have led patients to avoid going to hospitals.⁹⁶

The Saudi-led coalition's bombardment of the few operating health facilities deprive 19.7 million Yemenis who require access to health care.⁹⁷

Attacks on public infrastructure and naval blockade

The effects of the armed conflict are compounded by the Saudi-led coalition's destruction of the health care system and its supporting infrastructure. One example of the negative health consequence is the cholera outbreak in Yemen. In the year between April 2017 and March 2018, a total of 1,111,653 cholera cases and 2,400 deaths were reported; between January 2019 and September 2019, another 696,537 cases and 913 associated deaths were reported.⁹⁸ Cholera is an easily preventable and treatable waterborne disease; however, without treatment, it can be fatal.⁹⁹ The deadly outbreak of cholera in Yemen has a direct relationship to the destruction of infrastructure during conflict.¹⁰⁰ For instance, in January 2016, the Saudi-led coalition destroyed a water desalination plant in the city of Mokha.¹⁰¹ In June 2018, coalition airstrikes destroyed a water station that provides the majority of the water to the city of Hodeida.¹⁰² Adding to the problem, Yemen experiences chronic water scarcity and sanitation issues, with 50% of the population requiring assistance in accessing safe drinking water and adequate human waste disposal.¹⁰³ Attacks on water supply, sanitation systems, and health care facilities fuel cholera outbreaks and violate international law.¹⁰⁴

A further indirect consequence of Saudi coalition arms use is the naval blockade and resulting import restrictions on food, fuel, and humanitarian aid, which impede access to essential goods. The Food and Agriculture Organization reports that 15.9 million people (over half the population) are in urgent need of food and livelihood assistance, and approximately 63,500 Yemenis are facing famine.¹⁰⁵ The blockade is ostensibly aimed at restricting weapons inflows.¹⁰⁶ However, Yemen relies on imports for 90% of its food, and therefore the blockade and associated import restrictions on essential goods place millions of lives at risk.¹⁰⁷ There are reports that cargos carrying medicine and food cleared by the United Nations have been blocked.¹⁰⁸

Similarly, Human Rights Watch reports seven cases of Saudi-led coalition forces "arbitrarily divert[ing] or delay[ing]" fuel tankers.¹⁰⁹ In turn, increasing transport costs due to fuel shortages have driven up food prices 137% (compared to their pre-conflict cost).¹¹⁰ Increased fuel prices—along with damage to water systems and the aerial bombing of rural infrastructure—have also resulted in lower crop yields within the country.¹¹¹ Produced in part by coalition activities, the crisis in Yemen deprives people of their right to food and inflicts widespread harm on civilian health. In addition to causing food insecurity and hunger, if actions undertaken by parties to the conflict are intended to induce starvation, this constitutes a war crime, including in non-international armed conflicts.¹¹²

Moreover, the conflict in Yemen exacerbates gender inequality and has subjected approximately three million women and girls to gender-based violence.¹¹³ The abuse of women has increased by 63% since the onset of the conflict, as conflict-induced vulnerabilities such as displacement heighten the risk of gender-based violence.¹¹⁴ Kidnapping and sexual violence against displaced people by the 35th Armored Brigade (Yemen's armed forces) and by the Security Belt Forces (supported by the government of the United Arab Emirates) have also been documented.¹¹⁵ In 2015, women made up the majority of the 2.5 million internally displaced persons.¹¹⁶ The Group of Experts on Yemen has verified 37 cases implicating all parties to the conflict in the commission of gender-based violence, including sexual violence, rape, and the hostage-taking of women and girls.¹¹⁷

Conclusion: Calculating costs, considering lives

The calls from human rights and humanitarian organizations urging Canada to cancel arms shipments to Saudi Arabia are based on extensive research on the impacts of arms use in Yemen. Clear risks have been identified in numerous reports, including those by United Nations experts, which have found that "the continued supply of weapons to parties to the conflict is perpetuating

the conflict and prolonging the suffering of the Yemeni people.”¹⁸ Yet Canada has chosen to ignore these warnings, citing a lack of evidence that the specific items for export will contribute or have already contributed to violations.

The ATT is an imperfect instrument that may ultimately serve to legitimize the trade in certain arms.¹⁹ Indeed, as illustrated by Global Affairs Canada, the government hinges the legitimacy of its export decisions on the question of strict legality. If the relevant legal rules allow the export of weapons that contribute to the suffering of people in other countries—but just below the threshold of international crimes—the law itself must be called into question. For the moment, however, and notwithstanding the shortcomings of the existing framework, the ATT is the criteria against which an argument can be made to adopt a more careful approach to permit issuance and to halt the transfer of arms to Saudi Arabia and other countries engaged in hostilities. Adopting a robust interpretation of ATT provisions and implementing the precautionary approach to arms-export-permitting decisions will make Canada better positioned to achieve the stated aim of the treaty: to reduce suffering. The economic benefit that the arms sales provide to Canadians must not override the true cost to human lives in other countries.

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Underreporting of Violence to Police among Women Sex Workers in Canada: Amplified Inequities for Im/migrant and In-Call Workers Prior to and Following End-Demand Legislation

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Abstract

Sex workers globally face high levels of violence. In Canada, im/migrant sex workers who work in indoor venues may be uniquely targeted by police due to immigration policies, racialized policing, and the conflation of trafficking and sex work. In 2014, Canada passed end-demand legislation that purportedly encourages sex workers to report violence to police; however, little research has evaluated its impact. Using interrupted time series and multivariable logistic regression, we examined proportions of reporting violent incidents to police among sex workers who had experienced workplace violence (2010–2017), including potential changes prior to and following end-demand legislation. We then modeled the independent effects of im/migrant status and place of work on reporting violence. Among sex workers who experienced recent violence during the 7.5-year study ($n=367$), 38.2% of all participants and 12.7% of im/migrants reported violence to police, and there was no significant change in violence reporting after end-demand legislation. Our results suggest that end-demand laws do not remove barriers to justice faced by sex workers and instead actually perpetuate harms, particularly for racialized im/migrant and indoor workers. Policy reforms to decriminalize sex work, address discriminatory policing, and promote access to safety and justice are urgently needed.

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Background

Globally, sex workers face egregious human rights violations, including high levels of violence, which have been linked to health and social inequities such as an elevated burden of HIV and other sexually transmitted infections and poor reproductive and mental health outcomes.¹ A 2014 global systematic review identified a staggeringly high lifetime prevalence (45–75%) of physical, sexual, or combined workplace violence against women sex workers.² This violence is partly fueled by perpetrators' recognition of sex workers' devalued social status and by the fact that sex workers often hesitate to report incidents to police due to deep-rooted mistrust and fear of criminal charges, stigma, or further abuse.³ Importantly, research has shown that sex workers' inability to contact police for support after experiencing violence enables perpetrators to abuse sex workers with impunity, perpetuating high levels of violence.⁴

Criminalization, violence, and access to police protections

The criminalization of sex work shapes the prevalence of workplace violence, as well as sex workers' access to police protections.⁵ A *Lancet* review concluded that human rights violations against sex workers are most profound where aspects of sex work are criminalized, as sex workers fear reporting violence to police due to the risk of criminal charges.⁶ Globally, punitive policing of street-based and indoor sex work locations has been documented to displace sex workers to isolated environments where they are more vulnerable to violence and coercion into unprotected sex.⁷ Criminalization also enables police abuses against sex workers (for example, harassment, physical and sexual assault, and forced sex under threat of arrest), which have been documented in diverse contexts and represent

a clear obstacle to sex workers' access to justice.⁸

Marginalization among racialized im/migrant and indigenous sex workers

In Canada, racialized sex workers—including black, indigenous, and other people of color, as well as visible minority immigrant and migrant (im/migrant) workers—face severe health and rights inequities, and concerns have been raised regarding racialized policing and barriers to reporting violence to police.⁹ Fear of authorities is amplified among racialized im/migrant sex workers, who often face discrimination, language barriers, privacy concerns, and precarious legal status.¹⁰ Importantly, sex work is explicitly criminalized among temporary residents and im/migrants with open work permits (permits legally authorizing the holder to work in any type of employment, except for sex work) under Canadian immigration policy.¹¹ Im/migrant sex workers in Canada are also more likely to work in in-call sex work venues (for example, massage parlors and micro-brothels) than in outdoor and public spaces (for example, streets and parks), and venue raids by authorities have been documented to enhance sex workers' vulnerability to violence and further undermine their access to recourse.¹² Emerging evidence from Europe suggests that racialized im/migrant sex workers in in-call venues may be targeted by authorities under end-demand legislative models (also known as the Nordic or neo-abolitionist models). End-demand ideology represents sex workers as victims of gender-based violence by conflating sex work (defined as the consensual exchange of sex services) with victimization and sex trafficking (defined as forced sexual labor). As a result, end-demand legislative models criminalize sex work clients and third parties, such as venue owners and managers, which has contributed to punitive policing of indoor sex work venues.¹³ While community reports have highlight-

* The term “migrant sex worker” often refers to individuals who do not hold citizenship or permanent residency (for example, temporary or undocumented workers) in a country. Community-based organizations (such as SWAN Vancouver) have proposed “im/migrant sex worker” as a broader term that is more inclusive of the diverse persons (regardless of immigration status) who were born in another country and now work in sex work in Canada. Our study uses “im/migrant” to be inclusive of all possible forms of immigration status.

ed enhanced marginalization and policing among racialized im/migrant and indoor sex workers in Canada, quantitative evidence on access to violence reporting among these groups is needed, particularly given recent legislative reforms.¹⁴

In Canada, indigenous women face twelve-fold greater odds of being murdered or missing relative to non-indigenous women, and these odds are exacerbated among sex workers.¹⁵ Indigenous sex workers continue to report deep mistrust of Canadian law enforcement. This stems from colonial abuses, including racialized policing of and child apprehension among indigenous peoples, police failures to respond to missing and murdered indigenous women (including sex workers), and the historical legacy of the residential school system (that is, government-sponsored schools to assimilate indigenous children into Euro-Canadian culture from 1880 to 1996).¹⁶ While the severe structural violence affecting indigenous women in Canada remains the subject of a national inquiry and numerous reports, indigenous sex workers continue to face disproportionate violence, and their access to justice merits investigation.¹⁷

Canadian end-demand legislative framework

After Canada's previous sex-work laws were struck down by the Supreme Court in 2013 for violating sex workers' rights to security of person, end-demand legislation (the Protection of Communities and Exploited Persons Act) was enacted in 2014, leaving the sale of sex legal while criminalizing clients and third-party activities (such as gaining material benefit from the sale of others' sex services and advertising for others' sex services). This legislation emphasizes "the exploitation inherent in prostitution, and risks of violence posed to those who engage in it" and encourages sex workers to report violence to police.¹⁸ By representing all sex work as inherently exploitative and victimizing, this legislation also conflates consensual sexual labor with sex trafficking and intersects with prohibitive immigration policies to render racialized im/migrant sex workers susceptible to heightened scrutiny from authorities.¹⁹ Since 2014, anti-trafficking raids across Canada have resulted in the

arrest of, charges against, and detention and deportation of im/migrant sex workers.²⁰ Concerningly, im/migrant sex workers have avoided contacting authorities even after violent robberies due to fear of arrest, charges, police harassment, and discrimination.²¹ Im/migrant sex workers have reported that workers' inability to call police due to fear of criminal charges and police prejudice against sex workers promotes violence by predators.²²

Despite high levels of violence faced by sex workers in criminalized contexts and the implementation of end-demand legislative regimes in a number of countries, little quantitative research has examined sex workers' ability to report violence to police in the context of end-demand legislation or its structural determinants. This study aimed to (1) examine the proportions of sex workers in Vancouver who reported violence to police, including potential changes in reporting practices prior to and following the implementation of end-demand laws (2010–2013 vs. 2015–2017); (2) examine structural correlates of reporting violence; and (3) model the independent associations between im/migrant status and place of work, respectively, with the reporting of violence.

Methods

We drew longitudinal data from a community-based open prospective cohort entitled "An Evaluation of Sex Workers Health Access," which initiated recruitment in 2010 and is based on collaborations with community organizations serving women, sex workers, and people living with HIV.²³ Eligibility criteria include identifying as a cisgender or transgender woman, having exchanged sex for money in the last month at enrollment, and providing written informed consent. Time-location sampling was used to recruit youth and women aged 14+ through outreach to outdoor (for example, streets and alleys), in-call (for example, massage parlors, and micro-brothels), and informal indoor (for example, hotels and bars) locations and online solicitation spaces across Metro Vancouver. Women with lived experience (current/former sex workers) have occupied various roles (for exam-

ple, as interviewers, project nurses, researchers, and others) on the project team since the AESHA study's inception, and our interviewer and outreach team includes multilingual staff. After providing their informed consent, participants completed interviewer-administered questionnaires in English, Mandarin, or Cantonese on sociodemographics, work environments, structural factors, and health access, at baseline and semiannual follow-up visits. Participants received \$40 CAD upon each visit for their expertise and time. The study received ethical approval from the research ethics boards at Providence Health Care/University of British Columbia and Simon Fraser University.

Independent variables

To examine potential associations with reporting violence to police, we explored variables at the individual, workplace, and structural levels. Childhood trauma was a time-fixed variable measured via a modified 25-item version of the scale known as CTQ-SF and imputed with the sample median where missing.²⁴ Time-fixed structural factors included educational attainment (high school completion vs. less than high school), im/migrant to Canada (yes vs. no), and ethnicity (white vs. indigenous [First Nations/Métis/Inuit] vs. another visible minority [for example, Chinese]). All other variables were time updated at each semiannual follow-up, examining events occurring during the previous six months. Time-updated individual factors included age, non-injection substance use (for example, cocaine and hallucinogens, but excluding cannabis and alcohol), and ever receiving any mental health diagnoses. Structural factors included physical violence (having been strangled, beaten, locked or trapped in a car or room, assaulted with a weapon, drugged, or kidnapped) or sexual violence (rape or sexual assault) from a client or predator posing as a client; having been threatened or physically assaulted by residents or businesses near the workplace; experiencing homelessness or unstable housing (such as sleeping at a family member's or friend's); and the use of sex-worker support services (for example, drop-in spaces). Work environment factors included primary place soliciting clients

(in-call venue vs. independently off-street [self-advertising] vs. from a street or public space) and primary place serving clients (informal indoor venue [for example, a hotel or client's place] vs. in-call venue [for example, massage parlor] vs. outdoor or public spaces [such as a park or car]). A final structural variable was the time period surrounding the implementation of end-demand legislation (2010–2013 vs. 2015–2017). Given that the end-demand bill was introduced in January 2014 and passed into law in December 2014, we dropped 2014 from our analyses due to potential variation in law enforcement during this time. We also excluded the first three months of 2015 to account for exposure measures referring to the preceding six months.

Outcome variable

Our primary outcome was a time-updated measure of reporting verbal, physical, or sexual workplace violence to police in the last six months at each semiannual study visit. Workplace violence was defined as involving any of the following: verbal harassment or threats, stalking, abduction or kidnapping, rape or sexual assault, strangulation, physical assault, being locked or trapped in a car or room or thrown out of a moving car, assault with a weapon, or being drugged by clients or predators posing as clients. We measured the frequency of reporting violence to police using a Likert scale (“always,” “usually,” “sometimes,” “occasionally,” and “never” to such violence at each six month interval), which we dichotomized as yes (always/usually/sometimes/occasionally) vs. no (never). For interrupted time series analysis, the outcome was summarized as semiannual proportions based on interview date.

Statistical analyses

For objective 1, we used interrupted time series analysis to examine semiannual proportions of reporting violence to police and to evaluate the impact of end-demand legislation on these proportions. We divided the study period into pre- and post-end-demand law (2010–2013 vs. 2015–2017). To test for autocorrelation over time, we used the Durbin-Watson test and examined autocorrelation

and partial autocorrelation function plots.²⁵ No autocorrelation was detected, and outliers (N=2) were excluded from analysis. Finally, we used segmented linear regression analysis to evaluate any changes in level and trend following the introduction of end-demand legislation, controlling for preexisting trends.

For objective 2, we used descriptive statistics and bivariate logistic regression with generalized estimating equations (GEE) and an exchangeable correlation structure to investigate factors correlated with reporting violence to police, as well as any potential changes in the odds of reporting violence prior to or following the legislative shift.

For objective 3, we constructed two separate multivariable confounder models to examine the independent associations between im/migrant status and place of work, respectively, with reporting violence. All potential confounders identified through bivariate analysis were included in these models and the pre- and post-end-demand legislation variable. Using the variable selection process described by George Maldonado and Sander Greenland, confounders that altered the association of interest by <5% were systematically removed in a manual backward stepwise manner to determine the most parsimonious model.²⁶ The study period was January 2010–August 2017, excluding January 2014–March 2015, and the sample was restricted to observations where participants had experienced recent workplace violence. We used a complete case approach (in other words, we excluded study visits with any missing data). All analyses were performed using SAS version 9.4 and R version 3.5.0, and all p-values are two-sided.

Results

Our study included 367 participants (711 observations). In time series analysis, the median number of observations at each time point was 69 (IQR: 20–86).

Objective 1: Proportions of reporting violence to police

At the beginning of the study period, the prevalence

of reporting violence was estimated at 26.0% (95% confidence interval [CI] 17.9–34.1%), and no significant trends were observed before the legislative shift (-0.4% semiannually, 95% CI -2.2–1.4%) (Figure 1). Following the implementation of end-demand legislation, no immediate change in the prevalence of reporting violence was observed (level change 4.2%, 95% CI -11.1–19.4%), and there was no significant difference in the trend of reporting violence (0.0% semiannually, 95% CI -4.7–4.7%).

Objective 2: Correlates of reporting violence to police

Of 367 participants who experienced any verbal, physical, or sexual workplace violence incidents over the study period, 38.2% (n=140) of all participants and only 12.7% (n=7) of im/migrants reported violence to police during the last six months at any point over the seven-and-a-half-year study (Figure 2), contributing a total 195 reporting events out of 711 violent incidents. Over half of the sample (53.4%) experienced only one violent incident, 22.9% experienced two, and 23.7% experienced more than two. Of 131 events of rape and sexual assault, 57.3% (n=75) were unreported.

Among a subsample of 147 participants who answered questions about why they did not report violence, 34.0% reported not trusting police to help. Participants' reasons for not reporting to police were generally similar pre- and post-end-demand law (Table 1), with more participants reporting that they did not report violent incidents due to previous negative experiences with police after the implementation of end-demand legislation.

At baseline, participants' median age was 33.2 (IQR: 27.9–41.5). Nearly half (44.7%) were of indigenous ancestry, 17.2% identified as another visible minority, and 15.0% were im/migrants born outside of Canada. Among im/migrant participants, most represented racialized backgrounds, with 54.6% identifying as Chinese, 9.1% as indigenous (that is, First Nations, Inuit, or Métis born outside Canada), 3.6% as Filipina, and only 10.9% as white.

Almost half (46.6%) of participants worked primarily in outdoor or public spaces; 35.7% worked in informal indoor spaces, and 14.7% worked in in-

call venues (Table 2).

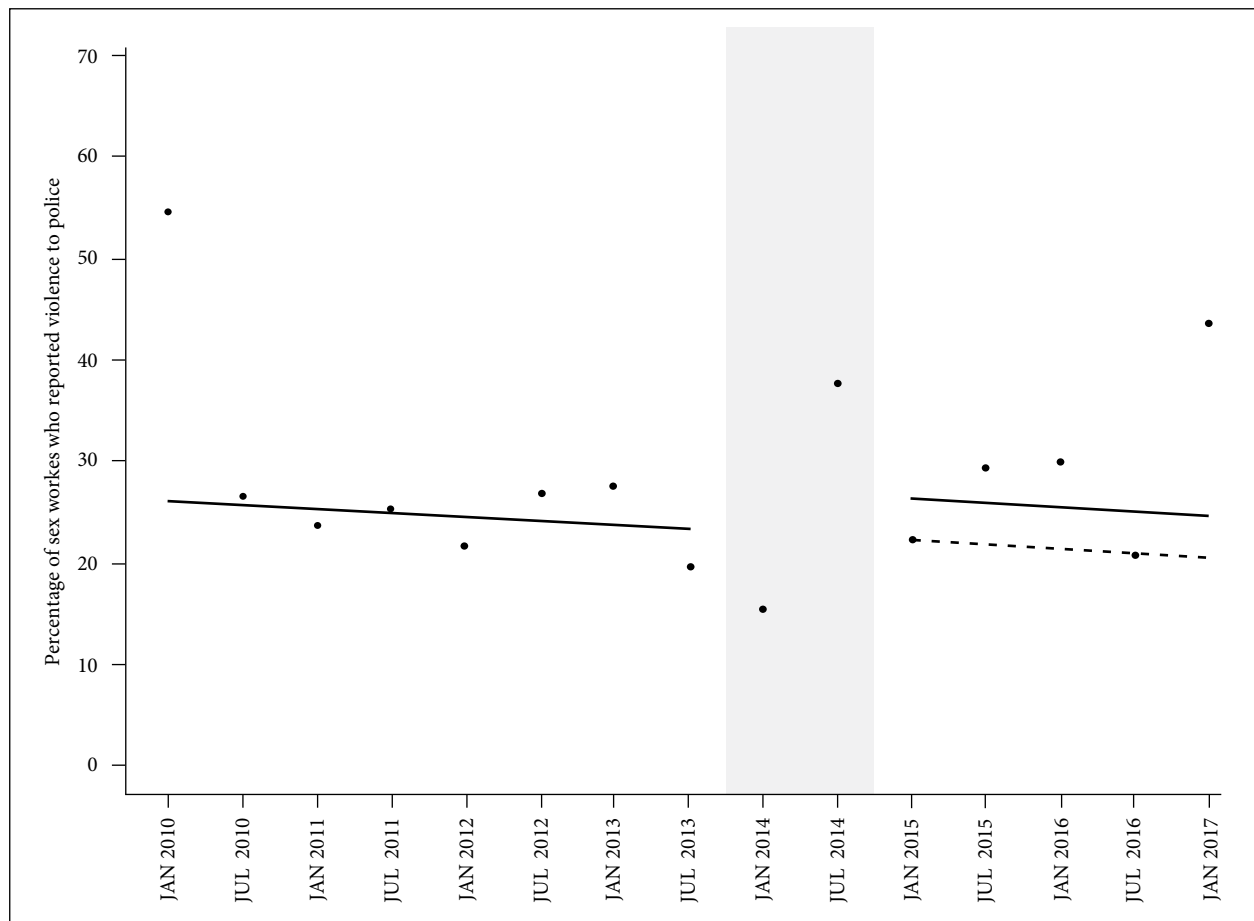
In bivariate GEE analyses, reporting violence to police was negatively associated with im/migrant status (odds ratio [OR] 0.25, 95% CI 0.12–0.54), identifying as a non-indigenous visible minority (vs. white) (OR 0.33, 95% CI 0.16–0.67), and working in in-call venues (vs. outdoor or public spaces) (OR 0.18, 95% CI 0.07–0.46); and positively associated with recent non-injection drug use (OR 2.81, 95% CI 1.45–5.45) and higher childhood trauma scores (OR 1.01/additional point on scale, 95% CI 1.00–1.02). There were no significant changes in odds

of reporting violence after the implementation of end-demand legislation (OR 0.93, 95% CI 0.53–1.63) (Table 3). Notably, no im/migrant participants and no in-call workers indicated that they had reported violence to police in the post-end-demand legislation period.

Objective 3: Independent effects of im/migrant status and place of work on reporting violence to police

In multivariable GEE confounder models, im/migrant status (adjusted odds ratio [AOR] 0.42,

FIGURE 1. Interrupted time series depicting proportions of reporting violence to police among sex workers who experienced recent workplace violence in Vancouver, 2010–2017 (N=367)



Note: Observed semiannual proportions of workplace violence reported to police are presented with dots; estimated semiannual proportions of workplace violence reported to police are presented with a solid line; and predicted semiannual proportions of workplace violence reported to police had end-demand legislation not been implemented are presented with a dotted line. Estimated and predicted rates represent estimates from our interrupted time series analysis. The gray box represents the legislative transition period between January 2014 (after Canada's previous sex-work laws were struck down by the Supreme Court as unconstitutional) and December 2014 (when end-demand legislation was officially implemented). These data points are excluded due to variation in how the laws may have been enforced during this transition period. Source: AESHA study 2010–2017

95% CI 0.19–0.93) (Table 4) and working in an in-call venue (vs. outdoor or public space) (AOR 0.27, 95% CI 0.09–0.78) (Table 5) were independently associated with reduced odds of reporting violence after adjustment for confounders, including the implementation of end-demand laws and other key individual and structural confounders (such as substance use, mental health diagnoses, and types of violence experienced).

Discussion

In this seven-and-a-half-year community-based cohort study, 38% of all women and only 12.7% of im/migrant women who experienced violence reported any of these incidents to police, highlighting severe gaps in this aspect of sex workers’ access to police protections. Racialized im/migrant and indoor sex workers faced significantly lower odds

of reporting violence, and there was no significant improvement in reporting violence after the implementation of end-demand legislation, despite the law’s stated aim of “encouraging those who sell their own sexual services to report incidents of violence.”²⁷ This is a critical finding given that Canadian end-demand legislation centers on the protection of vulnerable communities, represents sex workers as victims needing protection, and explicitly purports to encourage sex workers to seek police protections. The fact that we observed no significant change in sex workers’ access to police protection is an unacceptable outcome of this legislation. Further, the association that we documented between racialized im/migrant status and lower odds of reporting violence is alarming given the ongoing human rights violations faced by sex workers who experience physical and sexual violence in Canada and elsewhere.

FIGURE 2. Percentage of Canadian-born and im/migrant sex workers who reported or did not report any violence to police among those who experienced workplace violence in Vancouver, 2010–2017 (N=367)

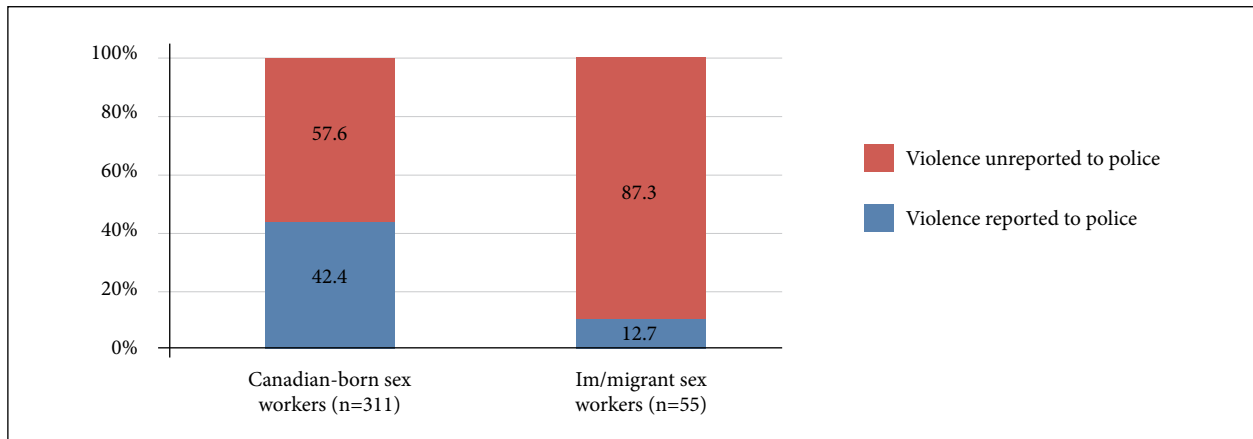


TABLE 1. Reasons for not reporting workplace violence to police prior to and following the implementation of end-demand legislation among sex workers in Vancouver, 2010–2017 (N=147)

Reason for not reporting	Before implementation of end-demand law (2010–2013)	After implementation of end-demand law (2015–2017)
Did not trust police	28.4%	26.4%
Felt the violence was “not a big deal” or not serious enough to report	38.3%	35.9%
Had negative past experiences when reporting violence to police	8.6%	15.1%

Source: AESHA study 2010–2017

Our findings are consistent with evidence from France, where, following the passage of end-demand laws in 2016, 70% of sex workers reported no improvement in or a deterioration of relationships with police, and 42% reported facing heightened violence.²⁸ In other places that have introduced end-demand models representing

sex workers as victims, sex workers continue to experience police harassment and stigma, and discrimination influences police officers' willingness to protect sex workers.²⁹ In Sweden, sex workers have faced police harassment and forced evictions from their homes despite laws stating that "victims of prostitution do not risk any legal repercussions,"

TABLE 2. Baseline individual and structural factors stratified by reporting violence to police among sex workers in Vancouver, 2010–2017 (N=367)

Characteristic	Total (N = 367) n (%)	Reported violence to police, Last 6 Months		P
		Yes (N=105) n (%)	No (N=262) n (%)	
Individual factors				
Age, median (IQR)	33.2 (27.9–41.5)	34.0 (29.0–42.0)	33.0 (27.2–41.0)	0.280
Non-injection substance use [†]	304 (82.8)	97 (92.4)	207 (79.0)	0.002
Mental health diagnosis, ever	226 (61.6)	78 (74.3)	148 (56.5)	0.002
Childhood Trauma Scale (CTQ-SF) score, median (IQR)*	53.0 (40.0–79.0)	57.0 (42.0–84.0)	52.0 (39.0–77.0)	0.137
Structural determinants				
Completed high school	173 (47.1)	46 (43.8)	127 (48.5)	0.419
Im/migrant to Canada	55 (15.0)	6 (5.7)	49 (18.7)	0.002
Ethnicity				
White	140 (38.2)	45 (42.9)	95 (36.3)	
Indigenous	164 (44.7)	52 (49.5)	112 (42.8)	
Other visible minority	63 (17.2)	8 (7.6)	55 (21.0)	0.009
Unstable housing [†]	317 (86.4)	99 (94.3)	218 (83.2)	0.005
Homeless or living on street [†]	146 (39.8)	49 (46.7)	97 (37.0)	0.104
Primary place soliciting clients [†]				
Street or public space	240 (65.4)	85 (81.0)	155 (59.2)	
In-call venue	54 (14.7)	3 (2.9)	51 (19.5)	
Independent off-street	72 (19.6)	17 (16.2)	55 (21.0)	<0.0011
Primary place serving clients [†]				
Outdoor or public space	171 (46.6)	63 (60.0)	108 (41.2)	
Informal indoor space	131 (35.7)	36 (34.3)	95 (36.3)	
In-call venue	54 (14.7)	4 (3.8)	50 (19.1)	<0.001
Accessed sex-worker support services [†]	282 (76.8)	84 (80.0)	198 (75.6)	0.364
Physical workplace violence [†]	169 (46.1)	66 (62.9)	103 (39.3)	<0.001
Sexual workplace violence [†]	132 (36.0)	57 (54.3)	75 (28.6)	<0.001
Threatened or physically assaulted by residents or business owners [†]	88 (24.0)	39 (37.1)	49 (18.7)	<0.001

Source: AESHA study 2010–2017

and Norwegian sex workers avoid reporting crimes due to fear of being evicted and facing stigma from police.³⁰ Our participants were no more likely to report violence under end-demand legislation, which is particularly concerning given strong evidence that sex workers' inability to access protection after experiencing violence enables impunity for perpetrators, thereby perpetuating ongoing human rights violations against sex workers.³¹ Our finding that nearly two-thirds of sex workers did not report recent violence is consistent with studies from Nairobi and Tijuana, which found that 85.5% and 86% of sex workers, respectively, did not report recent violence to police under various regimes of sex work criminalization and regulation.³²

In our study, im/migrant status was associated with 58% lower odds of reporting violence to police.

This finding is consistent with previous research from our group highlighting how racialized im/migrants often report heightened economic and legal vulnerability and how stigma, privacy concerns (such as police putting sex work on one's criminal record or one's family finding out), and risk of immigration status revocation (the loss of official immigration status and risk of deportation) represent powerful barriers to seeking police protections in the context of im/migrant sex work.³³ In Hong Kong, im/migrant sex workers fear reporting violence due to concerns of deportation.³⁴ Under end-demand legislation, undocumented sex workers in France face pressure to report clients and threats of deportation if they do not comply, and sex workers in Sweden, Norway, and the United Kingdom have faced surveillance and deportations,

TABLE 3. Correlates of reporting violence to police among sex workers in Vancouver, 2010–2017 (N=367)

Characteristic	Unadjusted odds ratio (95% CI)
Individual factors	
Non-injection substance use [†]	2.81 (1.45–5.45)‡‡
Mental health diagnosis, ever	2.07 (1.35–3.18)‡‡
Childhood trauma scale [CTQ-SF] score, per point higher [†]	1.01 (1.00–1.02)‡‡
Structural determinants	
Im/migrant (vs. Canadian born)	0.25 (0.12–0.54)‡‡
Ethnicity	
White	Ref
Indigenous	1.06 (0.73–1.55)
Other visible minority	0.33 (0.16–0.67)‡‡
Primary place serving clients[†]	
Outdoor or public space	Ref
Informal indoor space	0.78 (0.53–1.14)
In-call venue	0.18 (0.07–0.46)‡‡
Accessed sex-worker support services [†]	1.11 (0.69–1.79)
Physical workplace violence [†]	2.78 (1.90–4.07)‡‡
Sexual workplace violence [†]	2.81 (2.01–3.92)‡‡
Threatened or physically assaulted by residents or business owners [†]	1.68 (1.12–2.52)‡‡
Interview occurred after the implementation of end-demand legislation (April 2015–August 2017) (vs. 2010–2013)	0.93 (0.53–1.63)
[†] Time-updated measures (serial measures at each study visit using last six months as reference point) ^{**} Significantly associated with reporting violence at p <= 0.05 [*] With sample median imputation for missing values	

Source: AESHA study 2010–2017

contributing to their avoidance of authorities.³⁵ Further, the conflation of sex work and trafficking under the Norwegian end-demand law have resulted in media-accompanied anti-trafficking raids of massage parlors, in which racialized im/migrant sex workers' privacy was violated through their exposure on national television.³⁶ Our findings are consistent with evidence that fear of privacy breaches, criminal charges, or immigration status revocation present major barriers to racialized im/migrant sex workers' willingness to interact with authorities, which restricts their ability to report violent incidents to police.

Our study identified 73% lower odds of reporting violence among in-call sex workers (vs. workers in public or street-based locations). Canadian end-demand laws criminalize third-party material benefits, and this de facto criminalization of managed in-call sex work spaces has been linked to indoor sex workers' and venue owners'

avoidance of reporting violent robberies due to fear of criminal charges.³⁷ Our finding that in-call sex workers had lower odds of reporting violence is concerning given robust evidence that in-call venues with supportive management can provide critical health and safety supports to sex workers and are among the safest work environments.³⁸ Racialized im/migrants in particular are more likely to work in in-call venues and face discriminatory policing, which may further enhance their reluctance to report violence.

Alongside inequities in access to violence reporting for racialized im/migrants, other visible minorities were also significantly less likely to report violence to police. Previous work has documented barriers to violence reporting among ethnic minority women in Canada, suggesting that broader issues of racialization, barriers to accessing police protections, and outcomes of reporting violence warrant greater research and policy attention

TABLE 4. Independent effect of im/migrant status on reporting violence to police among sex workers in Vancouver, 2010–2017 (N=367)

Exposure	Outcome: Reporting violence to police [†] adjusted odds ratio (95% CI)
Im/migrant to Canada (yes vs. no)	0.42 (0.19–0.93)
[†] Time-updated measures (serial measures at each study visit using last six months as reference point) Note: Model adjusted for key confounders identified through bivariate analysis and retained in the model fitting process, including non-injection substance use and mental health diagnoses. The end-demand time period (2015–2017) was included as a potential confounder but was not retained in the final model.	

Source: AESHA study 2010–2017

TABLE 5. Independent effect of working in an in-call venue on reporting violence to police among sex workers in Vancouver, 2010–2017 (N=367)

Exposure	Outcome: Reporting violence to police [†] adjusted odds ratio (95% CI)
Works primarily in an out-call/informal indoor space [†] (for example, bar or hotel) (vs. outdoor or public space)	0.81 (0.54–1.22)
Works primarily in an in-call venue [†] (for example, massage parlor or body-rub studio) (vs. outdoor or public space)	0.27 (0.09–0.78)
[†] Time-updated measures (serial measures at each study visit using last six months as reference point) Note: Model adjusted for key confounders identified through bivariate analysis and retained in the model fitting process, including physical and sexual violence, non-injection substance use, and mental health diagnoses. The end-demand time period (2015–2017) was included as a potential confounder but was not retained in the final model.	

Source: AESHA study 2010–2017

for racialized and criminalized women.³⁹ While we also identified a high proportion of unreported violence among indigenous women, differences in violence reporting based on indigenous ancestry were not statistically significant. Indigenous sex workers are more likely to work outdoors in Vancouver's Downtown Eastside, a heavily policed neighborhood featuring a high density of social service organizations and bystanders who may call police. It is possible that this context contributes to more frequent reporting of violence to police among indigenous sex workers compared to non-indigenous participants. Indigenous sex workers in British Columbia report mistrust of authorities due to decades of harassment, neglect, and police inaction in responding to missing and murdered indigenous women, including sex workers. The majority of indigenous sex workers in Vancouver report recent police harassment and workplace violence, and indigenous sex workers with direct family members who experienced colonial violence (through attending government-sponsored residential schools created to assimilate indigenous populations) face higher rates of police abuse.⁴⁰ The high representation of indigenous women in street-based sex work, their continued exposure to violence, and ongoing barriers to justice suggest that sex work criminalization in Canada continues to reinforce the marginalization of indigenous women. In light of the National Inquiry into Missing and Murdered Indigenous Women and its calls to action, our findings underscore the urgency of policy reforms toward addressing colonial racialized and gendered violence to increase safety and access to meaningful justice among indigenous sex workers.

Our findings suggest that police mistrust is a pervasive factor in shaping whether sex workers report violence. Research from diverse criminalized contexts has documented inadequate police responses, ranging from neglect to enacting violence (for example, financial extortion and physical or sexual assault), which inform sex workers' distrust of police.⁴¹ Globally, arrest and intimidation by police fosters adversarial relationships, decreases sex workers' likelihood of reporting violence, and drives

sex workers to isolated environments, increasing their vulnerability.⁴² Concerningly, studies from Canada, Ivory Coast, and India have documented associations between police harassment and increased odds of violence among sex workers.⁴³ This evidence and our findings suggest that police abuses and stigmatizing treatment represent immense barriers for sex workers in reporting violence and enhance their vulnerability to aggressors.⁴⁴

Key recommendations

Our findings suggest that legislative changes are needed to remove the legal barriers and punitive policing that restrict sex workers' access to recourse and safer occupational conditions and to dismantle authorities' belief that sex workers are unworthy of protection.⁴⁵ While Canadian end-demand laws represent sex workers as exploited persons meriting protection, our study found no evidence of sex workers' increased access to police protections; rather, sex workers continue to face disrespectful treatment and threats of arrest when seeking assistance from police and thus attempt to avoid police interactions, as previously documented.⁴⁶ Scholars have asserted that end-demand legislation's dual goals of "ending demand" for sexual services and of protecting sex workers as a vulnerable community are at odds with each other.⁴⁷ These competing goals were captured by Conservative senator Donald Plett during initial hearings for the legislation, who said, "Of course, we don't want to make life safe for prostitutes; we want to do away with prostitution. That's the intent of the bill." This disconnect must be addressed through legislative changes to sex-work laws in Canada that prioritize sex workers' access to police protections, safety, and rights.

Given our study findings and other research demonstrating that criminalization restricts sex workers' ability to report violence to police, legislative reforms to fully decriminalize all aspects of sex work are urgently needed in Canada. Efforts must promote access to justice for racialized im/migrant and visible minority sex workers facing heightened structural vulnerability; community-based programs offering culturally safe, confidential labor and legal resources have been shown to gain im/

migrant sex workers' trust and promote their rights and should be expanded.⁴⁸ Interventions blending trauma-informed supports and links to services (for example, police sensitivity training and community liaisons to enable anonymous violence reporting) are also recommended.⁴⁹

Strengths and limitations

This study relies on observational data, which cannot be used to infer causality; additionally, our analyses rely on self-reported data, which may be subject to recall, social desirability, or misclassification biases. Our frontline team includes multilingual and experiential staff (current and former sex workers) who build rapport with participants through ongoing outreach, which is likely to mitigate social desirability bias. This study is unique in its use of prospective methods to examine proportions and correlates of reporting violence to police among sex workers, including through the use of an interrupted time series, which allowed us to control for secular trends within the data and was particularly well suited to evaluating the consequences of a "naturally occurring" intervention (such as a legislative shift).⁵⁰

Conclusion

Our study identified severe gaps in sex workers' ability to report violence to police, with no significant change in reporting violence after the implementation of end-demand sex work legislation, and with enhanced inequities documented for racialized im/migrant and in-call workers. These results suggest that end-demand laws that shift the focus of criminalization away from sex workers toward clients and third parties do not alleviate existing barriers to police protections for sex workers, particularly among im/migrant and in-call workers. Sex workers have the right to live and work free from violence, and addressing violence against sex workers should be prioritized by policy bodies in Canada and globally. Legislative reforms to fully decriminalize sex work and tailored efforts to promote access to police protections, particularly for racialized minority, im/migrant, and in-call work-

ers, are recommended as a means to upholding sex workers' human and labor rights. These changes are particularly vital within the current context of sweeping calls for enhanced attention to anti-racism efforts, as well as policy reforms to address police brutality and the harassment of marginalized and racialized communities.

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Regulating Conscientious Objection to Legal Abortion in Argentina: Taking into Consideration Its Uses and Consequences

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Abstract

Claims of conscientious objection (CO) have expanded in the health care field, particularly in relation to abortion services. In practice, CO is being used in ways beyond those originally imagined by liberalism, creating a number of barriers to abortion access. In Argentina, current CO regulation is lacking and insufficient. This issue was especially evident in the country's 2018 legislative debate on abortion law reform, during which CO took center stage. This paper presents a mixed-method study conducted in Argentina on the uses of CO in health facilities providing legal abortion services, with the goal of proposing specific regulatory language to address CO based not only on legal standards but also on empirical findings regarding CO in everyday reproductive health services. The research includes a review of literature and comparative law, a survey answered by 269 health professionals, and 11 in-depth interviews with stakeholders. The results from our survey and interviews indicate that Argentine health professionals who use CO to deny abortion are motivated by a combination of political, social, and personal factors, including a fear of stigmatization and potential legal issues. Furthermore, we find that the preeminent consequences of CO are delays in abortion services and conflicts within the health care team. The findings of this research allowed us to propose specific regulatory recommendations on CO, including limits and obligations, and suggestions for government and health system leaders.

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Introduction

In practice, the way in which conscientious objection (CO) is currently used is quite different from the use originally proposed by liberalism. CO was meant to protect citizens' autonomy and moral pluralism in society.¹ However, CO in health care has been expanding since 1970, particularly regarding euthanasia and abortion.² This broad use of CO has created and worsened barriers to accessing certain health services.³

The majority of countries in the Global North allow health care providers to invoke CO through "refusal" or "conscience" clauses. In some countries, policies allow for entire health care institutions to refuse to provide specific services (institutional CO).⁴ In the European Union, 21 countries formally recognize CO; in other parts of the world, including Latin America, policies regarding CO are less clear. Governments in Colombia, Uruguay, and Chile have passed specific regulations on CO, often alongside the liberalization of abortion laws.⁵

In Argentina, since the adoption of national laws on sexual and reproductive rights in 2002, CO has been explicitly included as a right belonging to health professionals. Ten years later, the Argentine Supreme Court ratified CO as a right in cases of legal abortion.⁶ During the 2018 debate to expand abortion rights, the discussion around CO was particularly contentious.

In this paper, we focus on an important legal and policy gap to be filled in the region—the need to better define and regulate CO to abortion—based on a more in-depth understanding of CO and its current uses, which we consider to be one of our main contributions to the literature on this subject.⁷ Argentina has no regulation that adequately addresses the use, abuse, and misuse of CO in the context of abortion services. Argentina is currently undergoing changes to further liberalize abortion laws. The 2018 debate on the liberalization of abortion rights was preceded by a significant national movement advocating for improved access to abortion services under the current law. Our exploration of the uses of CO among providers in Argentina led to our proposed regulatory language to ensure women's rights related to abortion access.

Although this study took place in Argentina, we believe it to be useful for advocates, legal professionals, and policymakers in other settings.

Methods

This study occurred in three phases. First, we reviewed jurisprudence and literature to understand the ways in which CO has and has not been addressed by Argentine law and global scholars. Questions that arose were discussed and clarified with experts in the fields of human rights law and medicine. This review informed the development of our survey and in-depth interview guides.

For the second phase, we developed a cross-sectional survey disseminated to a non-representative sample of sexual and reproductive health providers in Argentina's public health care system. The survey included 20 questions, 6 of which were open ended. Respondents were asked for demographic data and responded to questions about their participation in sexual and reproductive health and abortion services; definitions and understandings of CO; and the impact of CO on women and health services.

The survey was self-administered using the online survey platform SurveyMonkey. Networks of Argentine health professionals helped disseminate the survey to all people registered in their databases. Not all networks agreed to help disseminate the survey; six of eleven networks agreed, all of which lean pro-choice. Invitations to participate were sent to 641 providers between January and April 2018, and a total of 269 providers completed the survey, representing a response rate of 42%.

In the third phase, we conducted semi-structured interviews (n=11) between April and July 2018 with provincial managers of sexual and reproductive health programs and heads of health departments identified by the research team, none of whom self-identified as objectors. This was done with the aim of enriching survey data. Possible participants were identified using membership lists from pro-choice organizations in Argentina. Those who agreed to participate were also asked to identify others who might be willing to take the survey. We developed semi-structured interview guides

focused on participants' professional experience and current job responsibilities, their religious identity and practices, opinions on CO, causes or motivations for CO among health care professionals, and perceived consequences of CO for patients and health care teams. Interviews were carried out via Skype or in person and lasted for an average of 45 minutes. All interviews were conducted, recorded, and transcribed in Spanish. Interviews

were stored on password-protected devices, and IDs were created to protect anonymity. The first and last authors analyzed transcriptions using thematic analysis and developed a codebook using a priori themes. Other members of the research team reviewed the codebook; edits and clarifications were made as needed. This study received ethical approval from the institutional review board at the Hospital Británico in Buenos Aires.

TABLE 1. Characteristics of survey respondents

Respondents	Frequency (n=269)	Percentage	Respondents	Frequency (n=269)	Percentage
Age (n=251)			Profession of those who provide sexual and reproductive health services (n=218)		
20–29	13	5%	General practitioner or family physician	108	50%
30–39	98	39%	Ob-gyn or surgical gynecologist	70	32%
40–49	73	29%	Nurse	8	4%
50–59	49	20%	Social worker	18	8%
60–69	18	7%	Psychologist	14	6%
Sector (n=248)			Years working in profession, among those who provide abortion services (n=183)		
Public only	160	65%	<2	8	4%
Private only	22	9%	2–5	37	20%
Both	66	27%	6–10	30	16%
			11–20	56	31%
Provides legal abortions (n=250)			≥21	52	28%
Yes	185	74%	Religious affiliation (n=267)		
No	65	26%	Catholic	110	41%
Provides sexual and reproductive health services (n=251)			Christian or Protestant	22	8%
Yes	222	88%	Jewish	11	4%
No	29	12%	No religious affiliation	119	45%
Profession (n=249)			Other	5	2%
General practitioner or family physician	108	43%	Practices current religion (n=250)		
Ob-gyn or surgical gynecologist	67	27%	Strictly	5	2%
Nurse or obstetric nurse	29	12%	Somewhat	41	16%
Social worker	18	7%	Does not practice	58	23%
Psychologist	14	6%	Individually, without affiliation with a religious group and without worshipping at a religious center	57	23%
Other professions unrelated to legal abortion services (for example, lawyer, communications professional, political scientist, anthropologist, administrative assistant)	13	5%	No religious affiliation	89	36%
Years working in profession (n=251)					
<2	10	4%			
2–5	47	19%			
6–10	40	16%			
11–20	85	34%			
≥21	69	27%			

Results

Survey participant characteristics

Table 1 summarizes the characteristics of survey respondents. The age group with the highest proportion of respondents was 30–39 years old (39%). A large majority (92%) of respondents work in the public sector, and most (88%) provide sexual and reproductive health services. Of those who provide those services, 72% are physicians (general practitioners, ob-gyns, or surgical gynecologists). More than half of respondents who provide abortion services (59%) have been practicing medicine for over 10 years, with 28% having more than 20 years of experience. Nearly half of respondents (45%) have no religious affiliation, and among those that do, 41% currently practice their religion.

The Argentine legal context

Argentine legislation explicitly allows for CO in several reproductive health services.⁸

Regarding abortion, the *Guía nacional para la atención integral de personas con derecho a la interrupción legal del embarazo (National Guide on Comprehensive Care for People with the Right to the Termination of Pregnancy)* also allows individual health professionals to claim CO with some limitations. Further, the Supreme Court has authorized providers, including those working in the public sector, to request exemption from providing abortion on moral or religious grounds.⁹ Most of Argentina's 23 provinces have adopted similar guidelines. Currently, all provincial policies on abortion acknowledge CO, without clarifying its procedures or conditions, except for the provinces of Santa Fe, Mendoza, and San Luis, all of which have more specific legislation.¹⁰

In June 2018, the lower house of the Argentine National Congress passed a bill expanding abortion rights. The bill also granted individual CO and explicitly banned institutional CO. The Senate rejected this bill in August of the same year.

Conscientious objection in practice: Unexpected applications

Our analysis revealed that surveyed respondents believe that CO to abortion has been used by some health professionals to pursue political goals associated with traditional views on sexuality, gender roles, and family structures. Among all survey respondents, 47% believe that CO is used to resist policies favorable to sexual and reproductive rights.

This belief was supported by qualitative findings. Respondents expressed that hospital authorities (such as directors, chiefs of service, and faculty) have used CO to establish an ideological approach to sexual and reproductive health care in their departments. One of the sexual and reproductive health coordinators interviewed stated, “In hospitals, you find people saying ‘The CO [form] must be signed,’ and those orders came from department heads.” According to our literature review, CO is not so much a mechanism to which marginalized minorities resort but is instead leveraged by majorities and privileged sectors of society to resist social and legal changes. This appears to be especially true regarding abortion services, enabling these professionals to impose what they consider to be “right,” preventing patients from exercising their rights.¹¹

Our research also points to other, less obvious uses of CO. We call these “defensive uses of CO,” which occur when health professionals who, under especially challenging conditions for abortion provision, resort to CO. These professionals are often *not* driven by moral reasons, but instead wish to avoid inconveniences or criticism related to abortion stigma. For example, 60% of survey respondents believe that objection to abortion occurs out of fear of stigmatization. In the words of a one service provider:

In general, they argue that performing an abortion puts them in a stressful and uncomfortable situation, which exceeds their ability to perform the abortion. They do not want to be identified as abortionists.

In the survey and interviews, CO was also identified as being used as a protective mechanism. This often stemmed from misunderstanding or ignorance of the law or fear of potential problems that health professionals thought they would face after provid-

ing abortion services. In other cases, professionals simply use CO to avoid heavy workloads due to the small number of health professionals available to provide abortions: 54% of survey respondents believe that CO is used to avoid more work. As one health care administrator stated:

I remember one physician that said to me, “I signed it because we had the feeling people would come in droves to have abortions, and we would have to deal with all that.”

Conditions surrounding CO and its consequences

The majority of survey respondents (82%) identified delays in care or barriers in access to abortion procedures as the main effect of CO, followed by the stigmatization of reproductive health services (68%). According to the survey, in many cases, CO was seen as an excuse to abuse medical authority and even to mistreat patients.

Among our sample, others expressed that a lack of clear regulations on CO can affect freedom of conscience among abortion providers. These providers often work in environments where CO is the “norm.”¹² Although these professionals fulfill their obligations, they face stigma, marginalization, and harassment. Hence, they pay a very high price to exercise their freedom of conscience, as opposed to the professionals who refuse to provide abortion services. As one of the respondents shared:

One of the physicians who is a legal abortion provider has had many problems, and the others, who are hypocrites, make it difficult for him to work. They have denied him entrance to a clinic here. Even the head of the department admits [this situation].

As a result, many of these abortion providers—especially those who are isolated from a network of other safe abortion providers—do not speak openly about their work.¹³ One of the respondents stated:

I don't like receiving patients from other hospitals. I don't like our facility to be seen as a facility that receives cases that others are not willing to treat.

This paradox of *asymmetric legitimacy* creates an

imbalance between professionals who deny abortion services and those who provide them. This imbalance is driven by the decisions or omissions of department heads. One in three people surveyed (33% of respondents) consider that health care authorities influence the use of CO among younger professionals, and 30% of respondents believe that the lack of leadership and clear guidance increases the use of CO. In some cases, leadership directly affects health professionals' decision to use CO—38% of respondents believe that some colleagues resort to CO following mandates from their bosses. According to one respondent:

I believe the department head is not the same as a physician. I dare say that a requirement to be head of a department, for example of obstetrics and gynecology, should be not being a conscientious objector. I believe this cadre needs to safeguard certain issues, especially those related to medicine, which is such a hierarchical profession.

Many respondents believe that unclear regulations surrounding CO leads to an unfair distribution of tasks within health care teams. In this regard, 58% of survey respondents believe that CO creates a work overload for abortion providers, and 72% stated that this leads to tension within teams. As one respondent shared:

In general, from what I've seen, few cases are actual objections. They are false objections, either because providers don't know what CO really means, or because they do not want to be involved in a sensitive issue, since it is easier not to become involved. Of course, this results in work overload for those who do provide the service. The fatigue this causes often makes them want to become objectors as well ... due to the fatigue and stigma from their colleagues who are false objectors.

In fact, there is a status quo of impunity regarding the breach of professional duties, which supports the abuse of CO.¹⁴ As one respondent stated:

At this facility, there is a pharmacist who refuses to order contraceptives bi-monthly and distribute them ... Regarding legal termination of pregnancy, the same person tried to hinder that practice

and convince providers that it is wrong. All these attitudes are supported by the director of the facility, as she does not want to “create conflict.”

Legal acceptability

Although judicial cases in Argentina acknowledge CO as a legitimate concept, positions on its legal acceptability and limits differ. Some respondents believe that CO in health care is unacceptable, primarily because it negatively affects those who need health services and health care teams. As one survey respondent stated, “Objectors are, in fact, abandoning their patients.” Along similar lines, most respondents (70%) believe that the use of CO leads to a breach of professional duties.

In addition, some believe that the right to health and other rights have a veto effect on the acceptability of CO to abortion.¹⁵ As one respondent stated, “If a person chooses to practice medicine, they can never put their beliefs before patients’ rights.” Similarly, a slight majority of respondents (52%) believe that CO should not be allowed in health care contexts.

Likewise, many respondents believe that CO to sexual and reproductive health services is particularly discriminatory.¹⁶ Those with lower social or economic capital are especially unlikely to have resources to overcome barriers imposed by CO. Most respondents (74%) believe that CO is based on biases against women, and a majority (59%) believe that it is based on discrimination against some women in particular.

On the other hand, few respondents (7%) believe that CO is a fundamental right; therefore, its restriction must be exceptional and established by law. In general, these respondents relate CO with religious beliefs.

There are also those who hold more nuanced views, positioning CO as a conflict between individuals’ values and rights, for which they promote ways to resolve this conflict.¹⁷ They argue that the government must ensure both freedom of conscience and the right to health. In this regard, CO in health care contexts must always be limited by the institutions and individuals charged with ensuring access to health care. Forty-eight percent of provid-

ers surveyed believe that CO should be permitted. As one provider stated, “I’m okay with objectors as long as they are honest enough to always refer patients to someone who provides this service.”

Others see CO as a mechanism for managing some health professionals’ resistance to abortion in a way that still allows for access to this care. This was the vision of those who designed the pioneering CO policy in the province of Santa Fe in 2010.¹⁸ This position assumes that CO must be reviewed thoroughly in legal and public policy regulations. In this regard, some respondents expressed viewpoints like that of the following health professional:

Conscientious objection must be de-ideologized, and it should be taken seriously with all it entails as a barrier and comfort zone, and with all that it implies as a challenge for health policy to ensure coordination, control, governance, standardization, legitimization—in sum, everything a health policy should do.

Discussion

Liberalism justifies CO as a way of protecting the moral integrity of minority groups within a given society.¹⁹ However, this study shows that health professionals in Argentina have sought to extend the use of CO far beyond its standard definition. In practice, some health professionals weaponize CO as a way to deteriorate access to safe, legal abortion services.

In particular, our study highlights conservative political uses of CO in Argentina. This echoes previous work that shows that CO is used for reasons other than moral, religious, and ethical reasons. Our study indicates that CO has been used as a “Trojan horse” to derail Argentina’s progress on sexual and reproductive rights, a pattern that threatens the lives and safety of pregnant people.

The consequences of using CO to deny abortion services fall first on providers guided by their conscience, but they fall hardest on pregnant people requiring abortion services.²⁰ One of the most frequent and harmful consequences is the failure to hold objecting professionals accountable for ensuring patients’ access to care. On the contrary, in

many regions of Argentina, abortion providers are informally punished, while formal accountability mechanisms for those who hamper abortion services and abuse their power are scarce and weak in nature.²¹ Such is the case with one provider mentioned previously, who was unable to secure employment at private clinics after being labeled an “abortionist.” Often, conscience and moral reasons seem to be attached only to those denying services, obscuring the conscience and morality of abortion providers and rendering these providers as morally inferior.

As described by the authors of a 2015 study, abortion providers report that their work is referred to as “dirty work” and as having “little scientific value.”²² Recent studies show that these connotations create significant stress and anxiety among abortion providers.²³ Our analysis supports these studies, as denial of abortion services was partially explained by health professionals’ fear of stigmatization. Abortion providers interviewed refer to experiences of “loneliness,” “finger pointing,” “burnout,” and “work overload” when describing their work. Moreover, they fear that their job may lead to a lack of professional prestige or put them at risk for harassment.

Stigma and silence create a vicious cycle: when professionals do not disclose their role as abortion providers, or do not speak proudly about caring for those who need abortion services, their silence perpetuates stereotypes portraying abortion services as deviant care that “serious” physicians do not provide.²⁴ This contributes to the marginalization of abortion providers and exposes them to further harassment, fatigue, and other injustices. Thus, this cycle continues via what Lisa Harris et al. call “the legitimacy paradox”: providers of these services are still seen by many as illegitimate, substandard doctors.²⁵

Some sexual and reproductive health care providers in our sample believe that CO should not be permitted in health care facilities. Globally, only a few legal systems expressly prohibit the use of CO (Finland, Bulgaria, and Lithuania). This is based on the principle of legality and mandatory compliance with the law.²⁶ Governments that prohibit CO justify their decision by acknowledging the special

duties placed on health professionals and patients’ right to autonomy and nondiscriminatory services.

Comparative studies show that it is necessary to balance the decision that some providers make to refuse to provide abortion services on moral or religious grounds with the need to ensure access to abortion services and fairly distribute responsibilities within health care teams.²⁷ As made evident in this study, CO in Argentina is often used in response to professional environments where abortion is highly stigmatized, often characterized by a limited number of abortion providers, weak or nonexistent government oversight, or strong opposition to reproductive rights.

A regulatory proposal

Unfortunately, many existing regulations related to CO have focused on what, how, and when a health care professional may refuse to provide abortion services, leaving the task of ensuring access solely to providers. As one of our survey respondents stated:

The best way to deal with CO is focusing on legitimacy, legality, and governance, dealing with the conditions [necessary] to ensure the practice, not focusing on the issue of objection. Legitimizing and creating mechanisms and strategies that facilitate governance. Going beyond training and awareness-raising, adjusting them to the 21st century, [and] including them in a more complex package.

Comments like these and our survey findings led us to propose specific regulatory language pertaining to the use of CO to deny abortion access. We also propose language that will guide the implementation of this clause, with specific guidelines for ensuring access to abortion while allowing providers to deny abortion on moral or religious grounds. Finally, we describe our rationale for each article of the proposed clause.

The proposal

The suggested regulation covers four key areas pertaining to health professionals’ refusal to provide abortion services on moral or religious grounds:

1. the extent to which this refusal can be used by providers and corresponding duties:
 - (i) CO should be permitted only for individual providers (not for institutions)
 - (ii) CO must be based on moral or religious grounds, not on other motives such as ignorance of the law, workload issues, or fear of abortion stigma within institutions. Leadership needs to clearly differentiate and discourage other motivations to use CO and should be responsible for ensuring that objectors in their hospitals are not driven by other motivations through a review of their written refusal (see “How This Refusal Must Be Expressed” below).
2. the limits associated with this refusal:
 - (i) providers cannot refuse to make a referral to a legal service or to give information on the right to an abortion
 - (ii) objectors should not be in leadership positions, as their status as objectors can negatively affect abortion access
3. how this refusal must be expressed in order to be considered valid:
 - (i) CO must be expressed in writing to health facility authorities
 - (ii) the document used to record CO must include the moral or religious reasons and motives that underly the refusal to provide abortion services
 - (iii) the application must be reviewed and accepted by health authorities
4. institutional responsibility to ensure access to abortion:
 - (i) national or provincial coordinating and administrative bodies are responsible for ensuring access to abortion within existing legal regulations, while also allowing providers to deny this care on moral or religious grounds
 - (ii) health care institutions and administrators are responsible and accountable for ensuring

access to abortion services at all times

- (iii) people who occupy leadership roles in health care settings should support access to abortion services in accordance with the law

Arguments for the regulatory proposal

The extent to which health professionals can refuse to provide abortion on moral or religious grounds and corresponding duties. The refusal should be based solely on moral or religious grounds, as this refusal is grounded in democratic constitutional rights of freedoms of expression and conscience. Leadership needs to clearly differentiate and discourage other motivations to use CO, such as workloads or lack of legal knowledge.

CO should be limited to individual health professionals who are directly involved in abortion care and should not be extended to ancillary personal or health institutions, as they do not have a conscience.

Information on abortion services in Argentina is deficient.²⁸ This reality requires that all health professionals provide patients with the information necessary to access abortion. Accordingly, the proposed clause highlights the obligation to make good-faith referrals for abortion services so that refusals do not become a barrier to access.²⁹ Lack of adequate referral systems can subject patients to a sort of pilgrimage, during which they travel to various facilities and professionals, requesting abortion and losing crucial time as their pregnancy progresses.

Partial refusal to provide abortion services is permitted. As stated, the regulation of abortion must take a pragmatic approach. By allowing for partial refusal, health systems may increase the number of available providers in facilities where resistance would otherwise severely limit access. It is necessary to clarify that this partial exception does not allow for discrimination toward patients based on individual characteristics, including age, nationality, ethnicity, gender identity, marital status, and situations surrounding a pregnancy. In Portugal, for instance, though groups opposed to a regulatory framework that allows for partial refusal consider this to be a positive regulatory outcome,

many of those who support reproductive rights also view a nuanced gradation of objection as a positive development for abortion rights.³⁰

Limits on the refusal to provide abortion services.

The proposal includes two cases where the use of CO is prohibited. CO cannot be used by health care leaders, such as heads of health departments, health services coordinators, or chiefs of staff. According to our findings, health care leaders have a considerable influence on health care teams, both in terms of structuring services and organizational culture.³¹ In many cases, department heads have placed undue restrictions on the provision of abortion or have imposed illegal limitations on people with disabilities, adolescents, people with advanced pregnancies, and others. In other cases, the stance on abortion of those in leadership positions discourages health professionals under their authority from providing abortion.³² Therefore, leadership must commit to the provision of abortion services to ensure that professionals have no incentives to claim CO.

This restriction is reasonable for two reasons. First, the use of CO is available only to those providers who are tasked with directly providing abortion. Second, allowing health care leaders to formally refuse to provide abortion allows for the introduction of a moral position pertaining to these services and, potentially, at an institutional level.³³

The exclusion of health care managers and administrators from the right to refuse abortion services does not constitute workplace discrimination. It is not based on suspect classifications, such as religious affiliation, as it does not exclude any particular religious group. The restriction is justified by recognition of the need for abortion service provision as mandated by law. The exclusion of these professionals takes place due to the facility's needs and not as a result of individuals' religious choice.

How this refusal must be expressed in order to be considered valid. The proposal establishes that the refusal must be expressed in writing to the highest authority within the health care facility. This for-

mal expression must include motivations for said refusal. Acceptable explanations for permanently refusing to provide abortion are moral and religious in nature.

Our survey results show that CO is motivated primarily by reasons that are *not* moral or religious in nature, and may be identified and adequately addressed by ensuring that professionals submit, in writing, their motivations for refusal. The intention is not to question motivations or assess the religiosity or morality of any providers who submit objection on these grounds; rather, this policy makes clear to health professionals the legal reasons for the correct use of CO. Additionally, literature supports the submission of motivations for refusal in writing as important for promoting reflection among professionals who intend to formally refuse to provide abortions.³⁴ This reflection is necessary to address the complexity of the assumed conflict between abortion and protecting a gestating fetus. The written refusal should be made when first starting to work at the facility, encouraging continued reflection.

Overall, regardless of whether providers' moral or religious reasons are evaluated, it is necessary to distinguish other reasons for denying abortion services. As a result, the regulation explicitly mentions that reasons that stem from a lack of knowledge of scientific evidence or current legal standards, as well as those arising from discriminatory beliefs or practices, are unacceptable.

Formalizing the process for refusal provides two layers of assurance. On the one hand, it ensures that health care management has the necessary information to organize abortion provision. On the other, it allows refusing professionals to be exempted from the provision of abortion services. The proposal recommends allowing the exclusion of the refusal any time, as the professional becomes willing to provide abortion services.

Distribution of institutional responsibilities to ensure access to abortion services. The proposal establishes institutional responsibilities for each level of the health care system. Providers are the immediate guarantors of service access, local

authorities are considered health facility administrators, and national health authorities serve a coordinating role. Together, these three levels are responsible for ensuring equal access to abortion nationwide.

The responsibilities and mechanisms described at each level are aimed at guaranteeing patients' access to services. The proposal provides guidance on how to update policies pertaining to CO to ensure adequate availability of abortion. It also suggests ways for each level to implement supportive measures for abortion providers, acknowledging CO as an exception to a health system committed to providing abortion.

Limitations

Our study has a number of limitations. Findings from the qualitative component are not generalizable beyond Argentina or even within Argentina, given variation in abortion laws and access. However, our supplementation of qualitative findings with a quantitative survey helps increase our confidence in these results. Refusal by some professional networks invited to disseminate the survey resulted in the recruitment of respondents from pro-choice networks, likely oversampling abortion providers. This limitation also extends to our qualitative results, as respondents were similarly recruited. As a result, perspectives on CO shared here are largely those held by abortion providers and leaves a gap in our knowledge on the perspectives of people opposed to or undefined on their abortion-related values. Questions that focused specifically on the uses and consequences of CO broadly, and not explicitly each individual respondent's use of CO, helped ensure that their observations were captured. We believe that the providers interviewed are integral parts of health care teams who are familiar with the opinions held by objecting professionals. Further research is needed to explore how health professionals—especially professionals who are objectors—may respond to CO regulations such as those we are suggesting. A health systems analysis is imperative to monitor how CO interventions affect abortion provision and access.

Conclusion

This article identifies various ways that CO is used in Argentina that fall outside the scope originally imagined by liberalism. These include fear of stigmatization, increased workload, lack of knowledge of the law, and fear of legal repercussions. CO was also reported to have various impacts on women and health care teams, including further stigmatization, delays in care, increased workload for providers, and conflict among health care teams. A lack of clear regulation contributes to the misuse of CO, including institutional CO and the use of CO by hospital leadership.

We believe that Argentina is in the midst of a historic moment for abortion access. The question is not *if* but *when* abortion laws will be expanded, due to both the immense social movement in favor of safe, legal abortion (known as “the green tide”) and the likelihood that legislation to expand abortion rights will be approved. We are optimistic regarding the usefulness of our proposal for informing the language and implementation of this legal reform.

Finally, we propose clear regulatory language that we believe is necessary to ensure access to abortion. This access is urgently needed to guarantee the right of every woman and pregnant person to health, self-determination, and access to modern medical technologies. We believe that this proposal can be adapted for use in diverse social and political contexts.

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PERSPECTIVE

COVID-19 Clinical Bias, Persons with Disabilities, and Human Rights

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Persons with disabilities have historically been discriminated against by society, including fulfilment of the right to equal access to health care.¹ The more egregious practices, historically as well as today, include outright denials of access to health care, involuntary sterilization, forced institutionalization, coerced treatment, and substituted decision-making.² Discrimination also occurs by more insidious practices. For instance, the public health construct of DALYS (disability adjusted life years) “neutrally” devalues the lives of persons with disabilities relative to the lives of those without disabilities.³ Along the same lines, commonly accepted norms and practices lessen the priority of persons with disabilities for essential procedures, such as organ transplants.⁴ Moreover, clinical bias disproportionately affects some disabled people, particularly those who occupy racialized, gendered, and sexually marginalized intersections.⁵ Finally, many otherwise laudable programs, such as United Nations HIV/AIDS programming, neglected for decades to include persons with disabilities.⁶ This essay considers types of clinical bias against patients with disabilities in the context of the COVID-19 pandemic, how such stigma impairs their equal access to health care, and how the application of international human rights norms would mitigate such impacts.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), the first international treaty to acknowledge the human rights of persons with disabilities, responds to this persistent social and programmatic exclusion.⁷ The CRPD is based on a deontological normative commitment to the ideal of the inherent value and worth of persons with disabilities—and all humans—as an end in itself and not a mere means to other ends.⁸ In addition to recognizing the inherent dignity, autonomy, and equal worth of persons with disabilities, the CRPD contains provisions explicitly relating to the equal provision of health care.⁹ Prominently, article 25 (health) recognizes that persons with disabilities “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability,” and requires states parties to provide persons with disabilities “with the same range, quality and standard of free or affordable health care and programmes as provided to other persons.”¹⁰ Article 25 further mandates that states parties “provide those health services needed by persons with disabilities specifically because of their disabilities” and require health care personnel “to provide care of the same quality to persons with disabilities as to others.”¹¹ Relatedly, article 10 (right to life) reaffirms the equal quality of life of persons

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with disabilities by proclaiming that “every human being has the inherent right to life” such that states parties “shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.”¹² Connecting and enabling the rights contained in the CRPD are article 12 (equal recognition before the law) and interpretive General Comment 1, which assert that all persons possess the capacity to make decisions on an equal basis, regardless of disability, and underscore in the health care context that clinical determinations of patients lacking capacity cannot be grounds for circumventing the need for their consent to treatment.¹³ And wisely, article 8 (awareness-raising) requires “immediate, effective and appropriate measures” to “raise awareness,” “foster respect,” and “combat stereotypes, prejudices and harmful practices relating to persons with disabilities.”¹⁴

The CRPD has been ratified nearly universally, with the result that it has influenced health care laws and policies at both the domestic level (for example, some 32 states are currently revising their mental health laws) and globally (the Sustainable Development Goals, unlike their predecessor Millennium Development Goals, include persons with disabilities).¹⁵ These are great accomplishments, but stigma and lack of knowledge and awareness persist among health care providers both because of millennia-old instantiated social constructs and due to a lack of medical and public health education regarding persons with disabilities.¹⁶ We explicitly note that the United States—from which we draw several errant examples—remains within the minority of United Nations member states *not* to have ratified the CRPD, thus begging the question whether it lags behind global standards absent having this explicit rights framework in place to inform practice.

The COVID-19 pandemic, which is overwhelming health care systems and posing a dramatic threat to public health worldwide, highlights the issue of explicit and implicit bias against persons with disabilities in accessing health care and being treated equally and with full dignity therein. Reports from around the globe show how

biases that have always been present have become magnified by COVID-19. For instance, Romanians with disabilities with full-blown COVID-19 in institutional care have been quarantined instead of hospitalized, something that is not being done to those without disabilities.¹⁷ Descriptions of Guatemala’s sole public psychiatric hospital note that it is a “dumping ground” for persons with disabilities and a COVID-19 breeding ground.¹⁸ In the United States, there are claims of persistent discrimination against individuals with disabilities trying to access COVID-19-related health services, such as ventilators.¹⁹ Globally, the COVID-19 Disability Rights Monitor Dashboard—an organization that monitors experiences of injustice by persons with disabilities—has received approximately 1,600 complaints from people in more than 120 countries.²⁰

Moreover, clinical triage and treatment criteria predicated on social constructions rather than evidence-based studies have been promulgated and may result in standards that further discriminate against patients with disabilities when apportioning ICU beds, ventilators, and other care. At the start of the COVID-19 pandemic in the United States, for example, the state of Alabama explicitly recommended that patients with intellectual and developmental disabilities be viewed as ineligible for ventilators.²¹ Other US states issued similar triage and treatment guidance deprioritizing various categories of persons with disabilities; some of these crisis standards of care guidelines, after complaints to the US Office of Civil Rights, were subsequently amended to better ensure equal access and treatment.²² Nevertheless, some utilitarian-inclined academics have viewed these triage and treatment prioritizations, which give lower priority to persons with various disabilities, with approbation in some significant medical practitioner journals that are widely read and influence public policy.²³

In our view, much discussion regarding how to make the best decisions about which patients with COVID-19 should get care—and when and how—tends to presuppose that patients are philosophical abstractions with known prognoses and treatment costs that are fungible objects in a thought experiment. For instance, when discussing these kinds of

clinical decisions, it is common to hear questions framed thus: “Should you decline care to someone with features like patient X [often described as having a disability] so you can then offer care to three people with features like patient Y [usually, in these scenarios, described as being non-disabled]?”

Yet, contrary to abstractly grounded recommendations, real-life clinical decision-making is steeped in the richness of everyday clinical contexts and social textures and environmental impacts that often cannot be captured by top-down abstract formulations and recommendations. These details make all the difference in knowing the appropriate and ethical course of clinical care. Nonetheless, clinical decisions, especially in rapid and emergency situations—even when made in best faith—can be influenced by bias toward persons with various disabilities, such as patients with spinal cord injury, stroke, intellectual and developmental disabilities, and many other conditions.²⁴

To illustrate, let us consider COVID-19 care for a patient with paraplegia who has lost motor function and control below the waist. Even if we believe that all people with the same diagnosis or level of COVID-19 pathophysiology should have equal access to care, there are certain biases that distort how we estimate likelihoods of treatment success and survival. Specifically, as explained below, when viewing patients such as this patient with paraplegia, and when facing the same medical facts, we are likely to be more pessimistic about prognosis, treatment success, and survival and more likely to underestimate patient resilience. This is due to a number of biases that exist among the general public that also manifest in clinical life. These biases have been described at length, and we contextualize them here.²⁵ We address four biases in particular: ineffectual bias, fragility bias, friendliness bias, and catastrophe bias.

With “ineffectual bias,” there is a systematic assumption that patients with disabilities are lower in agency and competence than non-disabled patients with the same presenting medical complaint. This leads to patients with disabilities being treated with more paternalism by their clinicians. For instance, a patient with paraplegia’s subjective experiences

and choices are more likely to be discounted, when in fact respect for article 12 of the CRPD would imply that the patient should be the lead decision maker.²⁶ Amidst COVID-19, this would manifest as clinicians being more likely to act on behalf of a patient with paraplegia and not taking into account the patient’s autonomous preferences concerning care, whether in declining desired treatment or advocating for treatment when undesired.

With “fragility bias,” patients with disabilities are perceived as suffering more and having more severe symptoms than non-disabled patients with the same presenting medical facts. Amidst COVID-19, this would lead to less intensive and more conservative treatments that clinicians believe patients with disabilities “can handle.” These patients’ resilience and endurance would be underestimated, and care would be withdrawn earlier. This would undermine the obligations inherent in article 25 of the CRPD, as equal treatment and equal access to the same standard of health means that patients with paraplegia should get the same treatment and chance at attaining the highest standard of health as everyone else within their operative health care systems.

With “friendliness bias,” patients with disabilities are attributed as possessing greater warmth, trustworthiness, and prosociality than patients without disabilities. In the context of COVID-19, this clinical saintliness bias would manifest in a greater presumption by clinicians that patients with disabilities would be willing to give up their lives to save others amidst scarce resources. This tendency would be in conflict with article 10 of the CRPD, which suggests that respect for persons with disability as having equal dignity means that one cannot presuppose just by virtue of their disability that they necessarily have a lower quality of life or self-regard themselves less due to disability and can therefore be deprioritized for limited health care resources. The patient with paraplegia—just like any non-disabled person—should therefore be presumed to be both worthy of and wanting to be cured and live despite COVID-19, unless evidence suggests otherwise.

With “catastrophe bias,” the clinician will tend

to project more catastrophe onto the patient with a disability than the patient actually experiences. With this bias, COVID-19 patients with disabilities, such as the patient with paraplegia we are discussing, would be perceived as having less quality of life and more mourning concerning their situation than if they were not disabled. This leads to more clinical pessimism, as well as a higher threshold for initiating treatment and a lower threshold for withdrawing it. Clinicians are likely to “give up” sooner than they would for non-disabled patients. There is less hope for a good prognosis and a resilient patient who can endure the struggle of hospitalization. The entirety of the CRPD, and especially article 10, gives us normative weight against this bias, as the equal value and inherent worth of all patients with disabilities means that we cannot presuppose more catastrophe for the patient with paraplegia than is warranted by the standards of clinical history taking and evidence that would apply to any patient regardless of disability status.

We offer this information to help clinicians step back to engage in critical reflection about the processes that enter their minds when making treatment decisions for their COVID-19 patients with disabilities, and to help clinicians, scholars, policy makers, patients, family members, and advocates ensure that none of the above biases are distorting perceptions of patient prognosis, how likely treatment is to be successful, how likely patients are to benefit from treatment, how likely patients are to survive after treatment, and how resilient patients may be throughout the treatment and recovery process. This information is especially relevant in high-stakes emergency and critical-care settings, where clinical decisions about intensity and goals of care are soaked in value judgments that are particularly prone to contamination by the kinds of biases we have described that affect persons with disabilities.

Hope is crucial for the therapeutic alliance and treatment success. Patients with disabilities have enough barriers to adequate care, ranging from lack of physical and sign-language accessibility and inadequate insurance coverage to “inadvertent” discrimination (for example, CT machines

that little people cannot reach) to outright stigma (declining in vitro fertilization to women with disabilities because they would be “inappropriate” parents). Clinical life is ever more precarious if the biases of clinicians dissolve some of the hope that would otherwise be present between patient and clinician. While it is true that clinicians need to know more about their legal obligations to persons with disabilities related to required accommodations, everyday moral decisions are also important and probably more immediate, especially during pandemics such as COVID-19.

A lesson that ought to be reinforced from the experiences of the COVID-19 pandemic is that, at its most humane, clinical medicine is and should be situated in life as it is lived, for better or worse. Patients should be acted on as non-interchangeable precious particulars with unique needs, not generic abstractions or aggregates with equal baseline social situations. Another lesson is one that patients with disabilities have always known: even with the same diagnosis and treatment plan, life is more precarious not because of inequality in pathophysiology but due to inequity in cultural, historical, and social psychological factors, as well as normative anti-human rights presuppositions that creep into philosophical formulations of what constitutes “ethical” health care. Disparities arise from how we see one another and the degree to which we see dignity in one another as fully and equally human and as bearers of human rights. Finally, a lesson that has been dramatically highlighted by the COVID-19 pandemic is that clinicians can be disability rights agents for change.²⁷ Clinicians committed to human rights should resist the scrupulous ethical myopia of utilitarian thinking in the clinic and should empower their patients with disabilities and their colleagues to see clinical life and the health care needs of those with disabilities not with a lens of bias and burdensomeness, but with a lens of dignity, equality, and disability-based human rights.

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PERSPECTIVE

EU Migration Pact Fails to Address Human Rights Concerns in Lesbos, Greece

VASILEIA DIGIDIKI AND JACQUELINE BHABHA

On September 23, 2020, the European Commission released its draft Pact on Asylum and Migration.¹ The timing was not coincidental. Just two weeks earlier, on September 8, 2020, Moria camp, Europe’s first migrant “hotspot” and its largest refugee camp, had burned to the ground. In the five years since its opening, on the small Greek island of Lesbos, barely four miles off the coast of Turkey, the camp had become a symbol of the failure of European Union (EU) migration policy. It showcased the trudge to Europe for over one million Syrian and other distress migrants, forced to endure life-threatening journeys to seek safety. It also shone a grim spotlight on dramatic failures in refugee protection and basic human rights enforcement in the humanitarian response taking place at the heart of the wealthy Global North.² These failures included the rejection of responsibility to accept a share of asylum seekers by a growing number of EU members; the adoption of draconian border exclusion policies, including inhumane push-backs out to sea; and an acceptance of degrading and inhumane camp conditions threatening the basic safety and health of inhabitants.³

Efforts to address Europe’s migration challenges are therefore welcome. But will the new Pact on Asylum and Migration improve the situation? Does the EU’s attempt to launch an effective approach to migration based on “flexible solidarity,” allowing different member states different roles, contain the elements of a successful strategy for rectifying the abuses just noted? Does the pact guarantee basic human rights to refugees and others entitled, under both international and European law, to protection? Or is this “last-gasp realpolitik effort by European leaders,” as it has been described, likely to exacerbate exclusion policies and further reduce protection for vulnerable migrants?⁴

Early signs suggest little cause for optimism from a migrants’ rights perspective.⁵ The draft Pact on Asylum and Migration starts by acknowledging the need for migration in Europe and a commitment to migrant protection, and it includes some positive proposals, such as expanded opportunities for unaccompanied children to join relatives in countries other than their first country of entry. But the overriding message communicated by the pact is a call for more effective migrant exclusion, return, and deterrence.

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The pact fails to strengthen mechanisms for enforcing compliance with existing international and EU standards relating to migrants' human rights. Rather, it calls for an even more stringent procedure to assess asylum claims for certain groups already facing high asylum refusal rates, lower protection standards for migrant children unless they are unaccompanied or under 12 years, more efficiency in removing rejected asylum seekers, enhanced efforts to deter Europe-bound migration, and increased externalization of humanitarian responsibility for forced migrants trying to find safety and security. Human Rights Watch notes that the proposals for border control wrongly assume that most arriving migrants do not have protection needs and that decisions on asylum claims can be made speedily.⁶ If, as seems probable, the Pact on Asylum and Migration is not extensively revised to take greater account of the EU's human rights obligations, violations such as those perpetrated at Moria and elsewhere at EU borders and offshore are likely to continue and multiply. On the other hand, if European policy makers take advantage of the opportunity to review their policies and renew their stated commitments to inclusion, to humanitarian responsibility sharing on the international stage, and to advancing development principles in a collaborative manner, then the normative framework already in place can be operationalized to strengthen mutually beneficial partnerships among countries within the EU.

Existing European standards

Relevant European and international standards pertaining to the circumstances of migrants in Europe are numerous; they span basic human rights such as the right to life, the right to freedom from torture and inhuman or degrading treatment or punishment, the right to the highest attainable standard of physical and mental health, the right to education, and, in the case of children (persons under 18), the right to have their best interests taken into account as a primary consideration. They also include migration-specific protections.

Human rights organizations have drawn re-

peated attention to severe violations of European and international human rights relating to migrants' reception, asylum procedures protection, security, health, and sanitation.⁷ They have pointed out that exclusionary provisions in EU migration policy, the protracted asylum process, and the externalization of humanitarian responsibility to ill-equipped peripheral regions clearly breach binding obligations, including those set out in the European Convention on Human Rights, the Charter of Fundamental Rights of the European Union, the Refugee Convention and its Protocol, the Convention on the Rights of the Child, and the Sphere Handbook.⁸ Standards specific to child migrants are set out in numerous European documents, including the Qualifications Directive, the EU Agenda for the Rights of the Child, and the Action Plan on Unaccompanied Minors.⁹

Circumstances on the Greek island of Lesbos illustrate the many ways in which current EU migration policy contravenes these well-established obligations and generates human rights violations that directly impinge on the health and well-being of distress migrants. The limited, informal, and unstructured education activities offered in the camp, justified by the notion that Lesbos was a short-term transit point and not a destination country, deprived children of crucial education, at times for periods longer than two years. The lack of artificial light in the camp, along with the coexistence of thousands of people of different ages, genders, and nationalities, soon turned the camp into an unsafe space for women and children, exposing them to cases of physical, psychological and sexual abuse, violence, and exploitation.¹⁰

Failure around COVID-19: Growing migrant destitution and local xenophobia

Years before the COVID-19 pandemic shone a spotlight on the human rights and public health violations caused by current EU migration policy, Moria camp provided stark evidence. Though Moria's design capacity was for 3,000 migrants, demand always exceeded that capacity. At times the camp hosted more than 20,000 migrants.¹¹

Its inhumane conditions—extreme overcrowding and deficiencies in basic sanitary and social protections—violated human rights to personal security, health care, and primary education.¹² The provision of basic care for both adults and children was limited: only a few nongovernmental health care providers served the camp during the week, and only one organization operated on a volunteer basis during the nights and weekends. As a result of these service shortages, thousands of patients seeking care were turned away, while those who were treated often received treatment outdoors and with a complete lack of privacy. The only public hospital on the island, which serves the whole local population as well as migrants, struggled to provide both specialized and basic services to either population.¹³ Because of the limited types of medical service provided, thousands of vulnerable asylum-seeking people, including children, the elderly, and pregnant women—among them hundreds with chronic diseases—were deprived of critical care.¹⁴ Extremely limited soap, clean water, and sanitation facilities (70 people per toilet and 80 people per shower) created a fertile ground for outbreaks of communicable diseases, including respiratory diseases and chickenpox.

Under these conditions, the COVID-19 pandemic has posed a grave threat, amplifying existing concerns. Despite calls for relocation, more than 13,000 asylum seekers remained crammed inside Moria as the virus spread across Europe. To protect the local population (but not camp residents), the entire camp was placed in quarantine in late March 2020, a lockdown planned initially for 14 days but extended to 160 days. News of the first COVID-19 positive cases in Moria broke in early September, after the lockdown ended. However, newly diagnosed COVID-19-positive asylum seekers refused to quarantine themselves in a separate area within the camp, outraging the remaining camp inhabitants and fueling tensions and infighting.¹⁵ On September 8, Moria was set ablaze and 60% of the camp was destroyed. The next day, a second blaze destroyed the rest of it.

For six days before Moria's replacement camp opened its doors a few kilometers from the initial

location, 13,000 migrants were forced to live and sleep on the main road, creating cribs for their babies out of rags and hastily salvaging their possessions from the wreckage. Six days after Moria burned down, Moria 2.0, a new EU-funded camp, opened on the island. Thousands of migrants were moved in despite extremely rudimentary living conditions: just 37 sanitation facilities, inadequate drinking water, thousands of tents erected over gravel and dirt, and no water drainage facilities. Heavy rainfall in early October predictably led to flooding, the destruction of personal belongings, and the creation of new health hazards as children waded in waist-high dirty water. Sadly, though the camp was built well into the COVID-19 pandemic, its design failed to prevent the spread of COVID-19, with cases among the migrant population rising to almost 300 within three weeks.¹⁶ Soon thereafter, new cases were documented among the staff working in the camp, including members of the Greek police force, the European Border and Coast Guard Agency, and international organizations.

Two months after the new camp opened its doors, and despite coordinated efforts to transfer more than 2,500 migrants from Lesbos to mainland Greece, thousands of vulnerable migrants remain in perilous conditions, in tents unfit for the fast-approaching winter and located a mere 65 feet from the sea.¹⁷ EU migration policy has failed both in terms of the facilities afforded to those forced to flee and more broadly in terms of its regional strategies and interventions. By failing to provide minimum standards of reception at its borders, allowing asylum determination processes to become increasingly protracted, and failing to enforce meaningful relocation to other EU locations, EU migration policy continues to violate asylum seekers' basic human dignity, forcing occupants to line up for hours to use sanitation services, collect water, and get food. More broadly, by failing to institute humanitarian corridors for asylum seekers in the wake of the Syrian tragedy, by collaborating with neighboring states (including Turkey and Libya) to complicate refugees' routes to safety, by curtailing life-saving interventions in the Mediterranean and withdrawing humanitarian protection, and by compelling

asylum seekers to remain within the territory of their first point of arrival, EU migration policy has privileged migrant exclusion over human rights enforcement.

The failure of EU migration policy to integrate migration considerations into a broader economic, social, and rights framework also has consequences for local host communities.¹⁸ The failure to apply relocation responsibility across Europe fuels resentment and growing xenophobia among local hosts. Lesbos's local population of 97,000 fears an imminent public health crisis on an island that lacks the capacity to respond appropriately. Official COVID-19 testing continues to confirm that as a result of the overcrowded and unsanitary conditions in the camp, the virus is present among migrants, hundreds of whom continue to leave the camp daily and interact with the local population. More specifically, with food shortages reported within the new camp, thousands of migrants are compelled to venture beyond the camp to the city center and neighboring villages to buy supplies during the window of time they are allowed to leave the camp; according to anecdotal data, few wear protective face coverings.

After years of bearing a disproportionate share of the responsibility to house distress migrants, with the predictably negative impact on tourism, which is central to the local economy, island residents fear more of the same with the construction of the new camp. Only last year, Lesbos recorded 22,250 asylum applications, double the number that Austria and almost triple the number that Finland recorded during the same period.¹⁹ Island residents doubt Europe's claim that the new camp is a temporary emergency measure—Moria camp was, after all, another “temporary solution” that came to an end after five years only because it burned to the ground.

What does the future hold?

Greek authorities had hoped that the recent humanitarian disaster at Moria would result in better living conditions in Lesbos and that negotiations at the EU level for a permanent relocation mechanism

would improve Europe's protective obligations toward refugees and other humanitarian migrants.²⁰ The new Pact on Migration and Asylum, however, proposes the “faster use of border procedure followed by swift return procedure, to speed up decision-making and make asylum procedures more efficient.”²¹ It allows member states to issue asylum and return decisions without predefined safeguards, paving the way for procedural unfairness that increases the risk of prolonged detention and refoulement. Given the pact's current emphasis on the externalization of migration control and humanitarian responsibility to third countries, the pressure on countries at the EU's borders (such as Greece) is set to increase. By the end of 2020, Samos, one of the five Greek islands currently hosting significant numbers of migrants in overcrowded camps, will be the first Greek island with a closed migrant camp (where migrants are not allowed to leave and return freely).²² Lesbos seems set to follow Samos, despite the reaction of the local population.

The new plan to fortify Europe will force Greece to turn its islands into de facto prisons for migrants, asylum seekers, and refugees, a policy that evokes Australia's much-criticized recent precedent in the Pacific.²³ For many years, a country that represents just 2% of the EU's population has been compelled to respond to 13% of the EU's asylum applications, a trend that will apparently continue unabated.²⁴

Forcing a tiny population dependent on tourism and agriculture for its economic survival to bear the long-term responsibility for the health, well-being, and livelihood of a sizeable, vulnerable, and desperate migrant population is likely to destroy empathy and reduce the humanitarian generosity on which inclusive humanitarian protection depends. The basic spirit of hospitality and inclusive humanity, previously felt strongly among host communities in Greece and beyond, is evaporating.²⁵ For now, despite rising frustration and fear, Lesbos's local population remains peaceful, with many island residents still sympathetic to the deep suffering of the migrants they see. The question is, for how long?²⁶

Distress migrants are entitled to fundamen-

tal human rights protections in terms of security, health care, education, and shelter as they attempt to build new lives. These are the principles on which the EU was built and that remain enshrined in both international and European law. The COVID-19 pandemic provides an additional urgent reason to reduce the incentives for xenophobia, discrimination, and exclusion. The EU should use the opportunity of a new Pact on Migration and Asylum to generate robustly protective humanitarian structures that deliver on the principles it proclaims: nondiscrimination, security, and justice.²⁷ The results will enrich the Union as a whole, enabling youthful and energetic new populations to contribute to building a diverse and vibrant zone of peace and prosperity that benefits all inhabitants. The alternative is bleak: a future that is likely to exacerbate xenophobia, nativist privilege, and abandonment of the rule of law.

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BOOK REVIEW

Preparing the Next Generation to Advance Human Rights in Global Health

PAUL HUNT

Foundations of Global Health and Human Rights, edited by Lawrence O. Gostin and Benjamin Mason Meier, Oxford University Press, 2020.

Over the last 25 years, the *Health and Human Rights Journal* has brought together the field of human rights and global health. This field has affected public health practice and global health governance.¹ Out of advocacy in the early years of the AIDS response arose an academic discipline, and courses in health and human rights have since sprung up throughout the world. Yet our field has never before had a foundational text to introduce students and practitioners to its basic tenets. *Foundations of Global Health and Human Rights* seeks to provide this necessary academic foundation, offering an educational tool for the next generation of human rights advocates to advance global health.

Human rights education is crucial to health policy, research, and advocacy. With a shared understanding of human rights norms and principles, students and practitioners alike can be empowered to participate in and challenge the systems that seek to drive rights realization. Human rights has too long been the sole purview of lawyers. Health professionals and practitioners need to be engaged in this work, and new educational resources can support their interdisciplinary involvement. Human rights education that provides tools for health professionals to engage with human rights will help ensure that rights become more than just rhetorical promises.² This textbook offers an authoritative educational resource for teaching in the field, providing a basis for harmonizing instructional methods and accelerating health and human rights education.

Foundations of Global Health and Human Rights reviews the inextricable linkages between health and human rights and the policy applications of human rights in global health. This new textbook is the first scholarly text to be developed with an explicit educational purpose, bringing together 38 leaders in the field to develop a foundation for teaching. Edited by Lawrence Gostin and Benjamin Meier, whose previous book *Human Rights in Global Health: Rights-Based Governance for a Globalizing World* compared international organizations in global health governance, this new Oxford University Press volume shares their vision of the academic field of health and human rights and the promise of human rights in global health education. With a stirring foreword by World Health Organization Director-General Tedros, who implores young people to “secure the future of global health and human rights, learning from the past to build a hopeful future,” this textbook seeks to provide an essential foundation for that future.

PAUL HUNT is New Zealand's Chief Human Rights Commissioner and former United Nations Special Rapporteur on the right to the highest attainable standard of health.

Over the course of 20 chapters, *Foundations of Global Health and Human Rights* offers a magisterial examination of the field, systematically exploring the development, implementation, and application of human rights for global health. The opening section outlines the norms and principles of the field, the role of global health law, and the centrality of the right to health. From this overview of the development of human rights under international law as a basis for public health, the next section seeks to “bring human rights home”—detailing the implementation and accountability mechanisms necessary to make human rights real in people’s lives. The third section applies the development and implementation of human rights to contemporary health-related human rights challenges—from communicable and noncommunicable diseases to a focus on water, sanitation, hygiene, mental health, and sexual and reproductive health and rights. Looking into the future, the fourth section analyzes rising human rights challenges in a rapidly globalizing world, from international trade to climate change. In recognizing the challenges of the present moment, the book ends by examining the existential threat of populist nationalism to global health and human rights. Reflecting on these challenges, the afterword shifts to a more personal tone, addressing students directly and providing advice for maintaining resilience in these difficult times.

This textbook will find wide application in teaching across schools of law, public health, global studies, and public policy. As a textbook, the chapters are intended to be read sequentially, with each chapter building from the previous one while adding new understanding of the field. Given the number of contributors and topics, it is inspiring that the editors have crafted a volume that reads as a single coherent text rather than a series of distinct individual contributions. This rich combination of contributors can be attributed to the consistent structure across chapters, with each chapter reviewing the historical evolution, current state, and forward-looking areas of a distinct subfield. To facilitate the use of this book in the classroom, every chapter includes three detailed case studies that

highlight practical applications of human rights in global health. Prompting further engagement, each chapter is followed by questions for student consideration and classroom discussion. This textbook design succeeds in providing an educational foundation for the field, creating a resource for new courses, and supporting a range of multidisciplinary instructors in teaching students the necessary skills for advocacy, research, and practice in health and human rights.

With the field now facing existential challenges, this textbook is more necessary than ever before. The health and human rights movement could unite the world, but the current age of populist nationalism has challenged assumptions about the overarching importance of human rights in global health.³ Recognizing these governance challenges amidst a cataclysmic pandemic, *Foundations of Global Health and Human Rights* looks to the next generation to reinvigorate the commitment to universal rights in global health. We have come so far in developing, implementing, and advancing human rights in global health. Human rights education will be the key to a future for global health with justice.

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STUDENT ESSAY

The Disproportional Impact of COVID-19 on African Americans

MARITZA VASQUEZ REYES

Introduction

We all have been affected by the current COVID-19 pandemic. However, the impact of the pandemic and its consequences are felt differently depending on our status as individuals and as members of society. While some try to adapt to working online, homeschooling their children and ordering food via Instacart, others have no choice but to be exposed to the virus while keeping society functioning. Our different social identities and the social groups we belong to determine our inclusion within society and, by extension, our vulnerability to epidemics.

COVID-19 is killing people on a large scale. As of October 10, 2020, more than 7.7 million people across every state in the United States and its four territories had tested positive for COVID-19. According to the *New York Times* database, at least 213,876 people with the virus have died in the United States.¹ However, these alarming numbers give us only half of the picture; a closer look at data by different social identities (such as class, gender, age, race, and medical history) shows that minorities have been disproportionately affected by the pandemic. These minorities in the United States are not having their right to health fulfilled.

According to the World Health Organization’s report *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health*, “poor and unequal living conditions are the consequences of deeper structural conditions that together fashion the way societies are organized—poor social policies and programs, unfair economic arrangements, and bad politics.”² This toxic combination of factors as they play out during this time of crisis, and as early news on the effect of the COVID-19 pandemic pointed out, is disproportionately affecting African American communities in the United States. I recognize that the pandemic has had and is having devastating effects on other minorities as well, but space does not permit this essay to explore the impact on other minority groups.

Employing a human rights lens in this analysis helps us translate needs and social problems into rights, focusing our attention on the broader sociopolitical structural context as the cause of the social problems. Human rights highlight the inherent dignity and worth of all people, who are the primary

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rights-holders.³ Governments (and other social actors, such as corporations) are the duty-bearers, and as such have the obligation to respect, protect, and fulfill human rights.⁴ Human rights cannot be separated from the societal contexts in which they are recognized, claimed, enforced, and fulfilled. Specifically, social rights, which include the right to health, can become important tools for advancing people's citizenship and enhancing their ability to participate as active members of society.⁵ Such an understanding of social rights calls our attention to the concept of equality, which requires that we place a greater emphasis on "solidarity" and the "collective."⁶ Furthermore, in order to generate equality, solidarity, and social integration, the fulfillment of social rights is not optional.⁷ In order to fulfill social integration, social policies need to reflect a commitment to respect and protect the most vulnerable individuals and to create the conditions for the fulfillment of economic and social rights for all.

Disproportional impact of COVID-19 on African Americans

As noted by Samuel Dickman et al.:

*economic inequality in the US has been increasing for decades and is now among the highest in developed countries ... As economic inequality in the US has deepened, so too has inequality in health. Both overall and government health spending are higher in the US than in other countries, yet inadequate insurance coverage, high-cost sharing by patients, and geographical barriers restrict access to care for many.*⁸

For instance, according to the Kaiser Family Foundation, in 2018, 11.7% of African Americans in the United States had no health insurance, compared to 7.5% of whites.⁹

Prior to the Affordable Care Act—enacted into law in 2010—about 20% of African Americans were uninsured. This act helped lower the uninsured rate among nonelderly African Americans by more than one-third between 2013 and 2016, from 18.9% to 11.7%. However, even after the law's passage, African Americans have higher uninsured rates than whites (7.5%) and Asian Americans (6.3%).¹⁰ The

uninsured are far more likely than the insured to forgo needed medical visits, tests, treatments, and medications because of cost.

As the COVID-19 virus made its way throughout the United States, testing kits were distributed equally among labs across the 50 states, without consideration of population density or actual needs for testing in those states. An opportunity to stop the spread of the virus during its early stages was missed, with serious consequences for many Americans. Although there is a dearth of race-disaggregated data on the number of people tested, the data that are available highlight African Americans' overall lack of access to testing. For example, in Kansas, as of June 27, according to the COVID Racial Data Tracker, out of 94,780 tests, only 4,854 were from black Americans and 50,070 were from whites. However, blacks make up almost a third of the state's COVID-19 deaths (59 of 208). And while in Illinois the total numbers of confirmed cases among blacks and whites were almost even, the test numbers show a different picture: 220,968 whites were tested, compared to only 78,650 blacks.¹¹

Similarly, American Public Media reported on the COVID-19 mortality rate by race/ethnicity through July 21, 2020, including Washington, DC, and 45 states (see figure 1). These data, while showing an alarming death rate for all races, demonstrate how minorities are hit harder and how, among minority groups, the African American population in many states bears the brunt of the pandemic's health impact.

Approximately 97.9 out of every 100,000 African Americans have died from COVID-19, a mortality rate that is a third higher than that for Latinos (64.7 per 100,000), and more than double than that for whites (46.6 per 100,000) and Asians (40.4 per 100,000). The overrepresentation of African Americans among confirmed COVID-19 cases and number of deaths underscores the fact that the coronavirus pandemic, far from being an equalizer, is amplifying or even worsening existing social inequalities tied to race, class, and access to the health care system.

Considering how African Americans and other minorities are overrepresented among those

getting infected and dying from COVID-19, experts recommend that more testing be done in minority communities and that more medical services be provided.¹² Although the law requires insurers to cover testing for patients who go to their doctor's office or who visit urgent care or emergency rooms, patients are fearful of ending up with a bill if their visit does not result in a COVID test. Furthermore, minority patients who lack insurance or are underinsured are less likely to be tested for COVID-19, even when experiencing alarming symptoms. These inequitable outcomes suggest the importance of increasing the number of testing centers and contact tracing in communities where African Americans and other minorities reside; providing testing beyond symptomatic individuals; ensuring that high-risk communities receive more health care workers; strengthening social provision programs to address the immediate needs of this population (such as food security, housing, and access to medicines); and providing financial protection for currently uninsured workers.

Social determinants of health and the pandemic's impact on African Americans' health outcomes

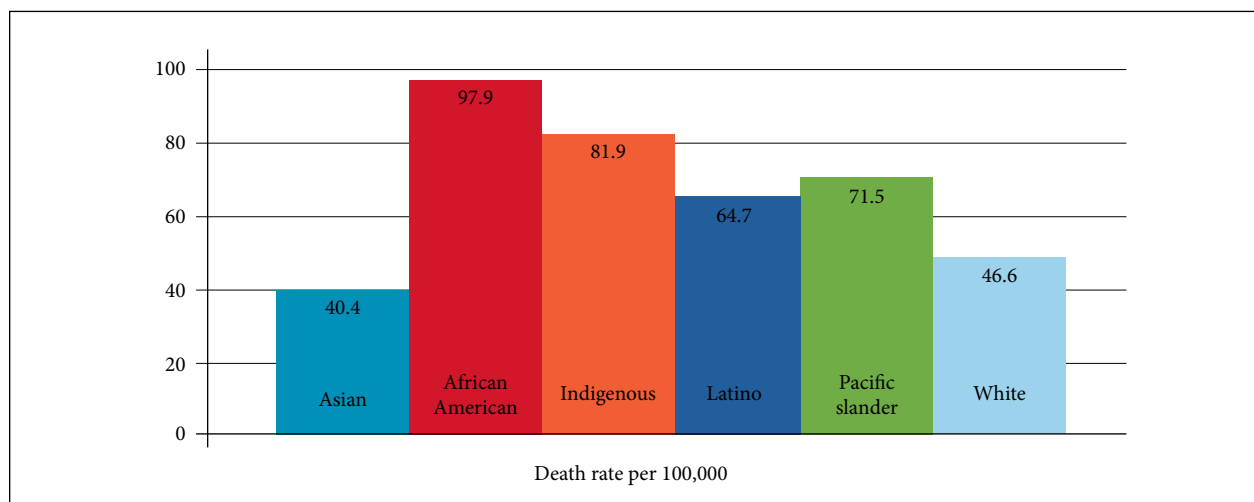
In international human rights law, the right to health

is a claim to a set of social arrangements—norms, institutions, laws, and enabling environment—that can best secure the enjoyment of this right. The International Covenant on Economic, Social and Cultural Rights sets out the core provision relating to the right to health under international law (article 12).¹³ The United Nations Committee on Economic, Social and Cultural Rights is the body responsible for interpreting the covenant.¹⁴ In 2000, the committee adopted a general comment on the right to health recognizing that the right to health is closely related to and dependent on the realization of other human rights.¹⁵ In addition, this general comment interprets the right to health as an inclusive right extending not only to timely and appropriate health care but also to the determinants of health.¹⁶ I will reflect on four determinants of health—racism and discrimination, poverty, residential segregation, and underlying medical conditions—that have a significant impact on the health outcomes of African Americans.

Racism and discrimination

In spite of growing interest in understanding the association between the social determinants of health and health outcomes, for a long time many academics, policy makers, elected officials, and others were reluctant to identify racism as one

FIGURE 1. COVID-19 deaths per 100,000 people by race/ethnicity, through September 10, 2020



Source: APM Research Lab, September 10, 2020. Available at <https://www.apmresearchlab.org/COVID/deaths-by-race>.

of the root causes of racial health inequities.¹⁷ To date, many of the studies conducted to investigate the effect of racism on health have focused mainly on interpersonal racial and ethnic discrimination, with comparatively less emphasis on investigating the health outcomes of structural racism.¹⁸ The latter involves interconnected institutions whose linkages are historically rooted and culturally reinforced.¹⁹ In the context of the COVID-19 pandemic, acts of discrimination are taking place in a variety of contexts (for example, social, political, and historical). In some ways, the pandemic has exposed existing racism and discrimination.

Poverty (low-wage jobs, insurance coverage, homelessness, and jails and prisons)

Data drawn from the 2018 Current Population Survey to assess the characteristics of low-income families by race and ethnicity shows that of the 7.5 million low-income families with children in the United States, 20.8% were black or African American (while their percentage of the population in 2018 was only 13.4%).²⁰ Low-income racial and ethnic minorities tend to live in densely populated areas and multigenerational households. These living conditions make it difficult for low-income families to take necessary precautions for their safety and the safety of their loved ones on a regular basis.²¹ This fact becomes even more crucial during a pandemic.

Low-wage jobs. The types of work where people in some racial and ethnic groups are overrepresented can also contribute to their risk of getting sick with COVID-19. Nearly 40% of African American workers, more than seven million, are low-wage workers and have jobs that deny them even a single paid sick day. Workers without paid sick leave might be more likely to continue to work even when they are sick.²² This can increase workers' exposure to other workers who may be infected with the COVID-19 virus.

Similarly, the Centers for Disease Control has noted that many African Americans who hold low-wage but essential jobs (such as food service, public transit, and health care) are required to continue to interact with the public, despite outbreaks in their

communities, which exposes them to higher risks of COVID-19 infection. According to the Centers for Disease Control, nearly a quarter of employed Hispanic and black or African American workers are employed in service industry jobs, compared to 16% of non-Hispanic whites. Blacks or African Americans make up 12% of all employed workers but account for 30% of licensed practical and licensed vocational nurses, who face significant exposure to the coronavirus.²³

In 2018, 45% of low-wage workers relied on an employer for health insurance. This situation forces low-wage workers to continue to go to work even when they are not feeling well. Some employers allow their workers to be absent only when they test positive for COVID-19. Given the way the virus spreads, by the time a person knows they are infected, they have likely already infected many others in close contact with them both at home and at work.²⁴

Homelessness. Staying home is not an option for the homeless. African Americans, despite making up just 13% of the US population, account for about 40% of the nation's homeless population, according to the Annual Homeless Assessment Report to Congress.²⁵ Given that people experiencing homelessness often live in close quarters, have compromised immune systems, and are aging, they are exceptionally vulnerable to communicable diseases—including the coronavirus that causes COVID-19.

Jails and prisons. Nearly 2.2 million people are in US jails and prisons, the highest rate in the world. According to the US Bureau of Justice, in 2018, the imprisonment rate among black men was 5.8 times that of white men, while the imprisonment rate among black women was 1.8 times the rate among white women.²⁶ This overrepresentation of African Americans in US jails and prisons is another indicator of the social and economic inequality affecting this population.

According to the Committee on Economic, Social and Cultural Rights' General Comment 14, "states are under the obligation to respect the right to health by, *inter alia*, refraining from denying or

limiting equal access for all persons—including prisoners or detainees, minorities, asylum seekers and illegal immigrants—to preventive, curative, and palliative health services.”²⁷ Moreover, “states have an obligation to ensure medical care for prisoners at least equivalent to that available to the general population.”²⁸ However, there has been a very limited response to preventing transmission of the virus within detention facilities, which cannot achieve the physical distancing needed to effectively prevent the spread of COVID-19.²⁹

Residential segregation

Segregation affects people’s access to healthy foods and green space. It can also increase excess exposure to pollution and environmental hazards, which in turn increases the risk for diabetes and heart and kidney diseases.³⁰ African Americans living in impoverished, segregated neighborhoods may live farther away from grocery stores, hospitals, and other medical facilities.³¹ These and other social and economic inequalities, more so than any genetic or biological predisposition, have also led to higher rates of African Americans contracting the coronavirus. To this effect, sociologist Robert Sampson states that the coronavirus is exposing class and race-based vulnerabilities. He refers to this factor as “toxic inequality,” especially the clustering of COVID-19 cases by community, and reminds us that African Americans, even if they are at the same level of income or poverty as white Americans or Latino Americans, are much more likely to live in neighborhoods that have concentrated poverty, polluted environments, lead exposure, higher rates of incarceration, and higher rates of violence.³²

Many of these factors lead to long-term health consequences. The pandemic is concentrating in urban areas with high population density, which are, for the most part, neighborhoods where marginalized and minority individuals live. In times of COVID-19, these concentrations place a high burden on the residents and on already stressed hospitals in these regions. Strategies most recommended to control the spread of COVID-19—social distancing and frequent hand washing—are not al-

ways practical for those who are incarcerated or for the millions who live in highly dense communities with precarious or insecure housing, poor sanitation, and limited access to clean water.

Underlying health conditions

African Americans have historically been disproportionately diagnosed with chronic diseases such as asthma, hypertension and diabetes—underlying conditions that may make COVID-19 more lethal. Perhaps there has never been a pandemic that has brought these disparities so vividly into focus.

Doctor Anthony Fauci, an immunologist who has been the director of the National Institute of Allergy and Infectious Diseases since 1984, has noted that “it is not that [African Americans] are getting infected more often. It’s that when they do get infected, their underlying medical conditions ... wind them up in the ICU and ultimately give them a higher death rate.”³³

One of the highest risk factors for COVID-19-related death among African Americans is hypertension. A recent study by Khansa Ahmad et al. analyzed the correlation between poverty and cardiovascular diseases, an indicator of why so many black lives are lost in the current health crisis. The authors note that the American health care system has not yet been able to address the higher propensity of lower socioeconomic classes to suffer from cardiovascular disease.³⁴ Besides having higher prevalence of chronic conditions compared to whites, African Americans experience higher death rates. These trends existed prior to COVID-19, but this pandemic has made them more visible and worrisome.

Addressing the impact of COVID-19 on African Americans: A human rights-based approach

The racially disparate death rate and socioeconomic impact of the COVID-19 pandemic and the discriminatory enforcement of pandemic-related restrictions stand in stark contrast to the United States’ commitment to eliminate all forms of racial discrimination. In 1965, the United States signed

the International Convention on the Elimination of All Forms of Racial Discrimination, which it ratified in 1994. Article 2 of the convention contains fundamental obligations of state parties, which are further elaborated in articles 5, 6, and 7.³⁵ Article 2 of the convention stipulates that “each State Party shall take effective measures to review governmental, national and local policies, and to amend, rescind or nullify any laws and regulations which have the effect of creating or perpetuating racial discrimination wherever it exists” and that “each State Party shall prohibit and bring to an end, by all appropriate means, including legislation as required by circumstances, racial discrimination by any persons, group or organization.”³⁶

Perhaps this crisis will not only greatly affect the health of our most vulnerable community members but also focus public attention on their rights and safety—or lack thereof. Disparate COVID-19 mortality rates among the African American population reflect longstanding inequalities rooted in systemic and pervasive problems in the United States (for example, racism and the inadequacy of the country’s health care system). As noted by Audrey Chapman, “the purpose of a human right is to frame public policies and private behaviors so as to protect and promote the human dignity and welfare of all members and groups within society, particularly those who are vulnerable and poor, and to effectively implement them.”³⁷ A deeper awareness of inequity and the role of social determinants demonstrates the importance of using right to health paradigms in response to the pandemic.

The Committee on Economic, Social and Cultural Rights has proposed some guidelines regarding states’ obligation to fulfill economic and social rights: availability, accessibility, acceptability, and quality. These four interrelated elements are essential to the right to health. They serve as a framework to evaluate states’ performance in relation to their obligation to fulfill these rights. In the context of this pandemic, it is worthwhile to raise the following questions: What can governments and nonstate actors do to avoid further marginalizing or stigmatizing this and other vulnerable populations? How can health justice and human

rights-based approaches ground an effective response to the pandemic now and build a better world afterward? What can be done to ensure that responses to COVID-19 are respectful of the rights of African Americans? These questions demand targeted responses not just in treatment but also in prevention. The following are just some initial reflections:

First, we need to keep in mind that treating people with respect and human dignity is a fundamental obligation, and the first step in a health crisis. This includes the recognition of the inherent dignity of people, the right to self-determination, and equality for all individuals. A commitment to cure and prevent COVID-19 infections must be accompanied by a renewed commitment to restore justice and equity.

Second, we need to strike a balance between mitigation strategies and the protection of civil liberties, without destroying the economy and material supports of society, especially as they relate to minorities and vulnerable populations. As stated in the Siracusa Principles, “[state restrictions] are only justified when they support a legitimate aim and are: provided for by law, strictly necessary, proportionate, of limited duration, and subject to review against abusive applications.”³⁸ Therefore, decisions about individual and collective isolation and quarantine must follow standards of fair and equal treatment and avoid stigma and discrimination against individuals or groups. Vulnerable populations require direct consideration with regard to the development of policies that can also protect and secure their inalienable rights.

Third, long-term solutions require properly identifying and addressing the underlying obstacles to the fulfillment of the right to health, particularly as they affect the most vulnerable. For example, we need to design policies aimed at providing universal health coverage, paid family leave, and sick leave. We need to reduce food insecurity, provide housing, and ensure that our actions protect the climate. Moreover, we need to strengthen mental health and substance abuse services, since this pandemic is affecting people’s mental health and exacerbating ongoing issues with mental health

and chemical dependency. As noted earlier, violations of the human rights principles of equality and nondiscrimination were already present in US society prior to the pandemic. However, the pandemic has caused “an unprecedented combination of adversities which presents a serious threat to the mental health of entire populations, and especially to groups in vulnerable situations.”³⁹ As Dainius Pūras has noted, “the best way to promote good mental health is to invest in protective environments in all settings.”⁴⁰ These actions should take place as we engage in thoughtful conversations that allow us to assess the situation, to plan and implement necessary interventions, and to evaluate their effectiveness.

Finally, it is important that we collect meaningful, systematic, and disaggregated data by race, age, gender, and class. Such data are useful not only for promoting public trust but for understanding the full impact of this pandemic and how different systems of inequality intersect, affecting the lived experiences of minority groups and beyond. It is also important that such data be made widely available, so as to enhance public awareness of the problem and inform interventions and public policies.

Conclusion

In 1966, Dr. Martin Luther King Jr. said, “Of all forms of inequality, injustice in health is the most shocking and inhuman.”⁴¹ More than 54 years later, African Americans still suffer from injustices that are at the basis of income and health disparities. We know from previous experiences that epidemics place increased demands on scarce resources and enormous stress on social and economic systems.

A deeper understanding of the social determinants of health in the context of the current crisis, and of the role that these factors play in mediating the impact of the COVID-19 pandemic on African Americans’ health outcomes, increases our awareness of the indivisibility of all human rights and the collective dimension of the right to health. We need a more explicit equity agenda that encompass-

es both formal and substantive equality.⁴² Besides nondiscrimination and equality, participation and accountability are equally crucial.

Unfortunately, as suggested by the limited available data, African American communities and other minorities in the United States are bearing the brunt of the current pandemic. The COVID-19 crisis has served to unmask higher vulnerabilities and exposure among people of color. A thorough reflection on how to close this gap needs to start immediately. Given that the COVID-19 pandemic is more than just a health crisis—it is disrupting and affecting every aspect of life (including family life, education, finances, and agricultural production)—it requires a multisectoral approach. We need to build stronger partnerships among the health care sector and other social and economic sectors. Working collaboratively to address the many interconnected issues that have emerged or become visible during this pandemic—particularly as they affect marginalized and vulnerable populations—offers a more effective strategy.

Moreover, as Delan Devakumar et al. have noted:

the strength of a healthcare system is inseparable from broader social systems that surround it. Health protection relies not only on a well-functioning health system with universal coverage, which the US could highly benefit from, but also on social inclusion, justice, and solidarity. In the absence of these factors, inequalities are magnified and scapegoating persists, with discrimination remaining long after.⁴³

This current public health crisis demonstrates that we are all interconnected and that our well-being is contingent on that of others. A renewed and healthy society is possible only if governments and public authorities commit to reducing vulnerability and the impact of ill-health by taking steps to respect, protect, and fulfill the right to health.⁴⁴ It requires that government and nongovernment actors establish policies and programs that promote the right to health in practice.⁴⁵ It calls for a shared commitment to justice and equality for all.

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VIEWPOINT

Paradigm Under Threat: Health and Human Rights Today

JONATHAN COHEN

Health is both a window and a door: a window into the challenges facing societies, and a door of opportunity for change.

When I look out the window, I see the health and human rights paradigm getting squeezed on both sides: squeezed from the right by populists who trounce on the very individual freedoms, democratic norms, and guarantees of equality that are essential for human health and well-being; and squeezed from the left by critics who question the legitimacy and impact of the human rights paradigm, particularly in relation to economic inequality and globalization.

When I look through the door, I see immense opportunity to improve public health outcomes by working for a better, more rights-respecting world—and vice versa. This opportunity lies neither in doubling down on the human rights paradigm nor in rejecting it. Rather, it lies in augmenting human rights with new approaches and understandings that capture the nature and urgency of the moment.

We face today a toxic mix of xenophobia, misogyny, climate denial, deregulation, right-wing evangelicalism, and state-sponsored violence that is not only darkening today's political landscape, but is also exacting a devastating toll on public health. Yet critics question whether human rights work is political enough for a moment like this. By appealing to evidence, facts, and universal norms, does human rights exempt itself from political struggle and underestimate the reality of power in shaping decisions? Can human rights defenders really afford to appeal to non-partisan norms enshrined in international law, and to avoid any domestic political project?

As someone who came of age in the health and human rights movement at the turn of this millennium, I see both sides of this argument. On the one hand, I often wonder what might have been had the human rights movement fully embraced the challenges of globalization in the early 2000s. The Battle for Seattle, the globalization of ACT UP and the Durban AIDS Conference, the World Conference on Racism, the Millennium Development Goals—all of these seemed to portend a new battleground for human rights that might help to offset the effects of globalization, racism, climate change, and economic exclusion. But after the attacks of September 11, 2001, the human rights movement seemed to retrench—and perhaps necessarily—into combating torture, war crimes, and other violations of first-generation rights.

On the other hand, when I look at the human rights movement in the last 20 years, I see tremendous innovation. I see global human rights organizations thinking, acting, and hiring locally. I see the development of new norms on everything from extreme poverty to the human rights obligations of non-state actors to the role of international financial institutions. I see the deployment of new tools from budget advocacy to forensic investigations of corruption to narrative change.

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Ultimately, I am left thinking that the critique of the human rights framework is sometimes as vulnerable to the same charges of elitism, globalism, and illegitimacy as the movement it takes aim at.

Let me illustrate this with a story. CB are the initials of a member of an HIV support group in Zingo Village in the Lake Chilwa area of Malawi. He began taking anti-retroviral treatment (ART) in 2004 and, until recently, collected his medicines from nearby dispensaries that were accessible only by boat. In the last year, however, the government has stopped regularly supplying these dispensaries with HIV medicines due to climate-induced dryness in the lake. CB now needs to collect his ART from a health center that is only accessible by road, at a cost of 6,000 Malawian kwacha (about US\$8) per return trip. He reports that he misses his dose on some days when he is unable to afford transportation for travel.

Three health and human rights organizations in Southern Africa came together in 2019 to document many cases like CB's.¹ Although they made many useful recommendations, they concluded that the link between environmental degradation and HIV risk was not something they could address through legal action. Whose fault is it after all that the lake is drying up? Is the cost of a motorcycle included in the constitutional guarantee of right to health? In a context where rural people live long distances from health care all over the world, what exactly is the source and remedy for CB's vulnerability?

Some may see defeat in this story. I see opportunity.

Equity and justice

The first opportunity I see is in bringing a stronger equity and justice lens to our work on health and rights. If human rights theory is rooted in the inherent dignity and freedom of all people, justice is rooted in the historical oppression, dispossession, and exploitation of people that is built into and effected through political and legal structures—and public health must be understood as a facet of the multigenerational effects of this oppression.² Such

injustices may include the impact of environmental degradation on lake-dwelling people in Malawi. They are large-scale social processes, not reducible to individual human rights violations, that differentially shape human health and well-being over time.

Thus, if human rights practice is focused on the identification and analysis of specific violations or infringements for which redress is then sought, then practices of justice are directed to radical or transformative change of the structures and systems of economic and social life. Such practices may include community organizing to rehabilitate coastal areas affected by drought, or to bring affected communities into closer contact with health providers. These are collective practices of local residents, not traditional human rights campaigns aimed at a single policy, population, or service intervention.

The theories and practices of justice are closely related to the concept of equity. In moral philosophy, equity is sometimes considered the practical application of distributive justice: the idea that benefits and burdens should be fairly distributed across members of a free and equal society, and that no one should be denied opportunity for belonging to a disadvantaged group.³ In public health, equity demands that we look at the factors that prevent certain populations from having the same opportunities for health and well-being as other populations. Some define justice as the actions and activism necessary to achieve health equity: so an equitable society is one in which justice has been served—and conversely, justice is served when health disparities are not associated with social advantage or disadvantage.

Intersectionality

A second, related framework I want to explore is intersectionality.

Intersectionality has taken on many meanings since the legal scholar Kimberle Crenshaw coined it in 1989.⁴ What began as a Black feminist critique of anti-discrimination discourse has become a rallying cry for building alliances across identities,

issues, and movements.

In public health, intersectionality is powerful in its mandate to reorient us from specific population cohorts to larger, often invisible forces of marginalization and oppression. For example, the HIV field still often targets “key affected populations” such as LGBT communities, sex workers, people who use drugs, prisoners, and migrants. Intersectionality urges us instead to lift our gaze to the social forces that oppress these groups—and indeed all of us—in the first place. This allows us to easily see how multiple forces can oppress a single individual at the same time.

For example, rather than targeting people who use drugs as a discrete category, intersectionality invites us to confront the universal impact of the “war on drugs”—its ideologies, power arrangements, and structures of law and policy—and the ways in which it affects different people differently. Rather than targeting transgender people as a category, intersectionality invites us to examine the universal impact of the gender binary—another system of power that is designed to hold certain institutional arrangements in place, and that is repeatedly invoked to stall social change.

This move towards intersectionality might also help us with the Malawi case I mentioned. After all, is CB a victim of identity-based discrimination? He is Black, but in most legal systems this is not sufficient for a claim of racial discrimination in health care. Perhaps, on the basis of his HIV status, one could argue for a legal remedy. Perhaps if CB were a woman, one could construct a legal case on the bases of gender equality. But it seems far more apt to understand CB as a victim of intersecting forms of oppression—of rural neglect, global inequality, HIV stigma, and the profound injustice of bearing the burden of climate emissions for which he bears no responsibility.

Systems transformation

The third and final paradigm I want to discuss is systems transformation.

The idea of “systems transformation” starts from the premise that individual countries and the

planet are in deep crisis. Systems thinkers argue that economic inequality, racial injustice, and climate change are all symptoms of a larger sickness, of deep patterns in our economic and political order and underlying institutional arrangements that work in concert to produce these results. Such patterns are “systemic” and thus require “changing the system” and thinking boldly about a new vision of the kind of world we want.⁵

Arguably the most prominent example of systems-change thinking in the United States today is the Green New Deal.⁶ The Green New Deal seeks to mobilize every aspect of American society at a scale not seen since World War 2 to achieve net-zero greenhouse gas emissions and create economic prosperity for all. Similarly, the European Green Party, for example, envisions a Europe that not only champions the greening of the economy, but that also pursues social and generational justice, inclusive democracy, citizen empowerment, diversity, the rule of law, international peace, and the Sustainable Development Goals.⁷ In Canada, the LEAP Manifesto envisions a country that is not only powered entirely by renewable energy, but where the jobs and opportunities of the energy transition are designed to systematically eliminate racial and gender inequality, and where caring for one another and caring for the planet are the economy’s fastest growing sectors.⁸

The case of CB in Malawi is amenable to systems thinking. At a simple level, this case shows how environmental degradation can directly interfere with access to health care, especially for people who are highly marginalized and vulnerable in the first place. More fundamentally, this case shows how climate change and denial of health care are both products of global economic system that unfairly distributes burdens across populations, countries, and regions. A bold alternative to this system must include both an end to greenhouse gas emissions, as well as universal health care for all.

In conclusion, each of these frameworks—justice and equity, intersectionality, and systems transformation—moves us beyond the rights of specific individuals or groups, envisioning a society in which power—and the advantages that accrue

from it—is fundamentally redistributed. Each of them locates health within a larger political project that seeks to reverse the multi-generational effects of oppression. Each of them seeks a society that is governed not only by the rule of law, but by ideals of fundamental fairness.

Perhaps, in the end, this is precisely what the human rights paradigm was always meant to do.

The Universal Declaration of Human Rights declares simply that the inherent dignity and the equal and inalienable rights of all members of the human family are the foundation of freedom, justice and peace in the world. Much criticism of the modern human rights movement can be traced to a subsequent cleavage between civil and political rights—as enshrined in the US Constitution—and economic and social rights, as enshrined in some Constitutions, most notably South Africa's. The Green New Deal is explicit in reviving President Roosevelt's idea of a "second Bill of Rights" that recognizes everything from jobs to education to health care.

If such a vision is adopted, perhaps the legacy will be not only a new political era, but also a new human rights era.

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VIEWPOINT

Address Exacerbated Health Disparities and Risks to LGBTQ+ Individuals during COVID-19

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As of August 12, 2020, there are over 20 million confirmed cases of novel coronavirus disease (COVID-19) worldwide with over 744,000 deaths.¹ Due to existing disparities in health outcomes, the consequences of this pandemic for LGBTQ+ individuals could be magnified in scope and severity.² Gay, bisexual, and other men who have sex with men (MSM), particularly those who inhabit multiple minority identities (that is, racial/ethnic minorities, immigrants), are already at greater risk for suicide, HIV, and unemployment, and commonly face systematic, institutional discrimination in the form of criminalization and other human rights violations.³ Vulnerable subgroups, such as unstably housed or informally employed LGBTQ+ individuals, may struggle to practice social distancing and prescribed sanitation measures. The recommendations presented here are data-driven and informed by a cross-sectional survey implemented by the free gay social networking app, *Hornet*, from April 16 to May 4, 2020. *Hornet* has over 25 million global users, and over 4,000 users from more than 150 countries completed this survey.⁴ The most responses were from Brazil, France, Russia, Turkey, Indonesia, and Mexico; the largest number of MSM responses were from Brazil, France, Mexico, Taiwan, and Russia.

Stigma, discrimination, and human rights

Global evidence demonstrates that governments are using COVID-19-related restrictions as an excuse to perpetuate stigma, acts of discrimination, and violence against LGBTQ+ persons.⁵ The South Korean government used cellular phone GPS, transportation history, and credit card transactions to “contact trace,” seemingly targeting the LGBTQ+ community.⁶ After COVID-19-related restrictions were relaxed, and supposedly gay nightclubs reopened, this community was blamed and harassed for an increase in new cases.⁷ Similar incidents were reported in Belize, Uganda, and the Philippines. These acts of discrimination and violence, all too often perpetrated by governments, religious leaders, and healthcare institutions, are clear human rights violations. They thwart the Yogyakarta Principles, as well as the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and others. Furthermore, fear of discrimination and abuse can itself significantly deter accessing healthcare. In the cross-sectional survey, 24% of the 2732 MSM respondents reported being worried they would face discrimi-

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nation or violence based on their sexual orientation and/or gender identity if they accessed government resources or healthcare.

HIV prevention and care

Throughout the COVID-19 crisis, non-COVID-19-related healthcare has been deprioritized, restricted, or even completely unavailable. Access to HIV prevention and care, often already limited for LGBTQ+ persons, may be hindered further. This increases the likelihood of disease progression for persons living with HIV (PLWH) and HIV transmission to sexual and/or needle-sharing partners. In the survey, MSM reported feeling they had considerably less access to HIV testing, pre-exposure prophylaxis (PrEP), and post-exposure prophylaxis (PEP) since the start of the pandemic.⁴ Those with additional minority identities reported significantly less access to condoms and medications than their non-minority counterparts.

Nearly 25% of respondents could not access their HIV providers, and 20% could not refill their HIV medications. Only 17% of respondents indicated they could reach their HIV providers via telemedicine. COVID-19 is clearly exacerbating disparities in healthcare access, especially for those without access to technology. Telemedicine is not a panacea that overcomes healthcare access restrictions for all. Moreover, if global funding for the HIV response is reallocated to COVID-19 initiatives, the effects could be catastrophic to the remarkable progress made towards addressing HIV thus far.⁸ WHO and UNAIDS warn that a resurgence of the epidemic is likely.⁹ Ignoring this threat will have potentially deadly consequences for MSM and the global HIV response.

Mental health

Current circumstances pose new threats amid the ongoing mental health pandemic. Disease outbreaks such as COVID-19, the mitigation strategies to slow them, and the subsequent employment losses can cause stress that manifests in

various ways—anxiety and worry, exacerbation of existing mental health conditions, changes in eating or sleeping, substance use for coping, and more.¹⁰ For the LGBTQ+ community, and particularly for MSM, this current crisis may be a painful—and re-traumatizing—reminder of the devastating effects of the early HIV epidemic. This is a population already disproportionately affected by negative mental health outcomes; according to the American Psychological Association, LGBTQ+ youth have higher rates of suicidal thoughts and attempts than their heterosexual, cisgender peers.¹¹ Thirty-one per cent of MSM cross-sectional survey respondents reported experiencing moderate to severe psychological distress. Thirty-five per cent screened positive for depression, and 34% screened positive for anxiety; this was positively correlated with loss of employment. Additionally, access to mental health services, like access to HIV services, is already limited for members of the LGBTQ+ community and may be further hindered. This pandemic, and governments' social distancing measures, also restricts individuals' access to sex. Sixty-one per cent of survey respondents indicated they were currently not having sex because of COVID-19, and 49% were somewhat or extremely dissatisfied with their sex lives. While an important aspect of health in and of itself, sexual intimacy may also affect mental health, as sex can boost self-esteem and mood, act as stress relief, help with sleep, and ease anxiety and depression, rates of which may be elevated in a pandemic.¹²

Recommendations

Stigma, discrimination, and human rights

- Public statements condemning stigma and discrimination toward the LGBTQ+ community during this pandemic are necessary; public officials should make, or continue to make, these statements.
- Public institutions, including hospitals and social services, should indicate to LGBTQ+ individuals, including migrants and other non-citizens, that they are welcome. They must acknowledge

their role with regard to structural oppression and cultivate safe environments in which members of this community feel comfortable seeking services.

- States must protect, respect, and fulfill the rights of all their LGBTQ+ inhabitants. Such rights include, but are certainly not limited to, the right to privacy, bodily integrity, and health.
- Police brutality, particularly toward LGBTQ+ individuals with additional minority identities, is a social determinant of health that must be addressed. Additionally, law enforcement cannot be permitted to harass members of this community under the pretext of epidemic control.
- The creation of COVID-19 policies and protocols, like those for contact tracing, must involve LGBTQ+ persons. Lessons from the international HIV response should be used.
- Jailing individuals for not socially/physically distancing is antithetical to efforts to limit COVID-19 exposure, as socially distancing and sanitation resources in incarceration are limited, violating individuals' right to health.¹³

HIV prevention and care

- Maintain or increase global HIV response funding to mitigate the detrimental consequences COVID-19 will have on PLWH or those at risk of acquisition.
- Support and prioritize localized, innovative methods of HIV healthcare delivery during this pandemic; develop protocols to sustain HIV prevention and treatment in future crises and include PLWH in this planning.
- Issue guidance about reducing harm and exposure in pandemic conditions to PLWH, HIV and TB co-infection, and unsuppressed viral loads.
- Reconsider protocols that limit prescription medications (for example, prescriptions are often limited to three-month supplies for PrEP medications and/or only after an HIV test) and work with insurance companies to support on these issues during emergencies.

Mental health

- Include mental health in all pandemic-related policies; remote resources must be created and made widely available.
- The unique mental health challenges of LGBTQ+ persons, including associations of COVID-19 with the early HIV epidemic, must be considered in COVID-19 mental health resources and policies. This population should be included in formulating any guidance, and their experience with the ongoing HIV epidemic, and the potential compounded stress of both epidemics, should be recognized and respected.
- Sex must be recognized as an important aspect of mental health, and sexual health should be considered in pandemic-related policies. Policies should be sex positive, destigmatize sex generally, and concentrate on celebration rather than risk mitigation. Lessons learned from the HIV epidemic, like the ineffectiveness and stigmatization of fear-based public health campaigns, should be utilized.¹⁴

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Human Subjects Research

The secondary data analysis protocol for the cross-sectional survey cited in this paper was reviewed by the Johns Hopkins School of Public Health Institutional Review Board, which determined that the protocol qualified for Exempt status under Category 4.

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VIEWPOINT

Good Health Indicators are Not Enough: Lessons from COVID-19 in Peru

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Peru received international acclaim for being one of the first countries to implement a comprehensive package of measures to control the spread of the COVID-19 pandemic. The government imposed a general lockdown, combined with social protection measures—mainly cash transfers and the distribution of food parcels. This was an attempt to mitigate the impact of the lockdown, in a country where 70% of the population works in the informal sector.¹ Yet despite this, the transmission rate remained high, and as of early June Peru’s COVID-19 mortality rates were amongst the highest worldwide.² The pandemic has shed a stark light on Peru’s failure to guarantee the right to health and the limits of the tools used to assess the health system’s performance.

Over the past two decades Peru has been praised for introducing a series of reforms aimed at achieving Universal Health Coverage (UHC), primarily through the expansion of health insurance across low-income groups. Nevertheless, reforms have failed to overcome the historical fragmentation of the system, where access to services is determined by income, gender, and geographical location. Peru has focused on key health indicators, such as neonatal mortality, reduction of under-5 mortality and the prevalence of stunting, and the adoption of management systems such as contracts that prioritise health indicators included in national poverty reduction policies.³ However, the excessive focus on numerical targets rather than putting human rights at the centre of healthcare, has led to a system that overlooks significant vulnerabilities that have now been exposed, and even intensified, by COVID-19. Human rights-based imperatives, such as equality, acceptability, availability, accessibility, adaptability, and quality (known as the ‘AAAAQ’ criteria) are critical to the analysis of these vulnerabilities.

First, there are clear limitations regarding accessibility and adaptability that undermine state capacity to adequately respond to COVID-19. Despite steps towards UHC, the public system remains characterised by unequal distribution of resources and coverage between different sub-sectors of the system. The public health insurance plan (*Seguro Integral de Salud - SIS*) is targeted towards low-income users and it provides the lowest level of service coverage and has the least financial resourcing within the entire system.⁴ The deeply embedded fragmentation of the system has severely constrained the government’s response and quality of healthcare. The Ministry of Health (MoH) lacks a central information point so there is

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no real time information available about the level and status of equipment across the country, nor data on available beds or ventilators. Furthermore, the national prioritisation of certain health conditions and diseases, linked to global goals and national targets, has contributed to a health system that prioritises basic health packages that deliver on numerical targets. These packages provide essential care at primary health facilities, including preventive measures, such as antenatal checks, and cervical cancer and tuberculosis screening. However, a holistic approach to healthcare is missing, as is timely access to treatment, which results in poor health outcomes.⁵ This focus has come at the expense of capacity to test and treat for any other health conditions, including novel ones such as COVID-19.

Second, Peruvian hospitals are constrained by limited health workers and unusable essential equipment. In 2017 the Office of the Comptroller General of the Republic, the central regulator, reviewed 251 secondary and tertiary level hospitals across the country. This revealed a precarious system in which 43% of the facilities lacked sufficient health workers to function effectively. Basic pathology, such as immunological, haematological, biochemical and other tests were not being performed by 42% of hospital laboratories, and the same percentage lacked the minimum equipment necessary for sample processing, delaying patient diagnoses. These failings had not been corrected prior to the pandemic. In April 2020, 36 mechanical ventilators and oxygen plants (25% of the public sector EsSalud's stock) were found in disrepair, contributing to the loss of many lives.⁶ Urgent questions must be asked as to why and how these and other essential equipment were not functioning.

Third, the COVID-19 pandemic has brought attention to deep inequalities within the system, including gender and ethnic inequalities. Despite increased health coverage, out of pocket expenditure remains high and was increasing even before the pandemic.⁷ Given the limited supplies of oxygen within public hospitals, relatives of COVID-19 patients have been forced to buy oxygen on the

open market, paying high prices, and exacerbating the economic impact of the pandemic.

The inequalities exposed by COVID-19 draw attention to the Amazonian indigenous communities where basic sanitation conditions are limited and 60.8% lack access to a water pipeline or well.⁸ At the time the first COVID-19 case was reported in Lima, Amazonian regions of Loreto and Ucayali were facing a dengue outbreak that had put health services under great stress. Yet the Ministry of Health did not issue specific regional guidelines. Nor did it assess the capacity of the health system to respond to the double burden of two outbreaks, and it did not reinforce information systems, including epidemiology surveillance, making it impossible to perform a rigorous analysis of the health needs of people in these regions. Indigenous organisations produced some information showing the speed of the infection at the community level. For example, by May 22 there were 40 confirmed COVID-19 cases among indigenous communities in Ucayali. The number increased to 773 by June 16.⁹ Loreto and Ucayali, have the highest rates of COVID-19 (32.49% and 33.95% respectively) in the country (national average is 16.95 per cent).¹⁰

In conclusion, the early measures adopted by the Peruvian government to respond to COVID-19 must be analysed in the context of the structural shortcomings of the health system, which have been exacerbated by the pandemic. The global health agenda which prioritises progress on selected indicators, linked to global development goals, has come at the cost of a holistic, rights-based approach to healthcare in Peru. This analysis must contribute to an urgent review of the ideology that drives health indicators and is a renewed call to introduce human rights principles when designing and assessing health systems.¹¹

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VIEWPOINT

Revisiting Restrictions of Rights after COVID-19

LEONARD RUBENSTEIN AND MATTHEW DECAMP

The Siracusa Principles have had a good run over the past 35 years.¹ The public health provisions of the principles, which contain criteria for limiting civil and political rights to advance various public purposes, have offered governments standards for acceptable restrictions on rights to reduce the spread of infectious disease. They require that restrictions be based on a legitimate aim, law, and necessity; evidence-based; the least-restrictive choice; non-discriminatory; and arrived at through a participatory and transparent process. In particular, restrictions must not disproportionately harm marginalized or vulnerable populations or discriminate against them. The standards have proven durable as a human rights approach to controlling outbreaks and sensible from a public health standpoint.

Despite differing traditions and approaches, moreover, there has been convergence between Siracusa and approaches to restrictions on rights emerging from the field of bioethics.² Standards of necessity, relevance, proportionality, equitable applications and least restrictive approach, along with procedural fairness, have dominated ethics approaches to restrictions on rights in pandemics.³ Both approaches require application of the principle of reciprocity, that is, imposing an obligation to ensure that people whose liberty is restricted are not also deprived of rights to food, water, housing, and health, among others.⁴

As with many requirements of human rights and bioethics, these standards are often honored in the breach, from unwarranted detention of people with multi-resistant tuberculosis to fencing in an entire community in Liberia during the 2015 Ebola outbreak.⁵ During the COVID-19 pandemic, misuse of emergency public health powers is also evident, such as lockdowns in prisons as a social distancing measure and restrictions on access to abortion in the United States. For the most part, though, the closures and restrictions on travel and work established by public health authorities have respected, and must continue to respect, Siracusa and bioethical concepts. Calls for the UN Committee on Economic, Social and Cultural Rights to issue a General Comment to provide concrete recommendations for operationalizing the Siracusa Principles in law and policy should be uncontroversial.⁶

The principles were never designed, however, to address what has become a central feature of the public health response to the COVID-19 pandemic: the harm inflicted on the health of people who are exempted from restrictions on quarantines and lockdowns. In today's era of vast social and economic inequalities, people in low-paying service jobs are permitted to move around, but at the price of being deemed essential and therefore having to work in circumstances that result in far greater likelihood of exposure to the coronavirus. Their health and lives are subordinated to other community objectives, such as public transport, trash collection, food distribution and retailing, and care for the elderly.

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The perverse aspect of these policies is that marginalized people are not singled out for special restrictions on freedom of movement and other liberties but are rather excluded from public health protections. This exception amounts to a blatant denial of the right to health—sometimes spectacularly so, for example, in meatpacking plants in the United States, where the risks of transmission to a mostly immigrant workforce are enormous yet the industry has been singled out for mandatory continuance when hundreds of others are shut down.⁷

Moreover, unlike other essential workers (for example, health care workers), these service workers face significant additional hardships. Many lack sufficient or adequate personal protective equipment. Few have the option to stay at home, even if they have compromised immune systems or other heightened medical risks. If they decline to work, they may lose their jobs or be delayed in receiving (if not altogether denied) unemployment compensation.

Siracusa never anticipated these concerns. It was conceptualized from the standpoint of individuals whose freedom is restricted, and its concerns with discrimination focused on communities that were subjected to quarantines, detention, and lockdown when others were not. It did not consider circumstances where exceptions to restrictions risk health, not freedom of movement. Ethical analyses, too, failed to anticipate fully this concern, considering essential workers' continuing to work as supererogatory or voluntarily "beyond the call of duty," not a matter of human rights.⁸

The essential worker rules amount to limitations of the right to health under Article 4 of the Covenant on Economic, Social and Cultural Rights.⁹ The Committee on Economic, Social and Cultural Rights General Comment on the right to the highest attainable standard of health discusses limitations of rights and Article 4 but, like Siracusa, didn't foresee situations like those arising today.¹⁰

The drafters of the General Comment can be forgiven for not looking at limitations on the right to health in the context of pandemics, but it is time to fill that gap. There is a solution: when Siracusa criteria are met, *public health measures must be*

implemented to ensure that they protect the right to health, of all, not just those whose movement is restricted, including determinants such as safe working conditions. That requirement has three dimensions: first, no use of compulsion or economic penalty to require someone to take the risk of working when authorities have determined that, for the rest of the population, performing a job is dangerous to health; second, instituting effective measures for both ameliorating risk and promoting health of individuals who are considered essential; and third, ensuring that exceptions to social distancing and lockdown rules do not discriminate against particular groups, such as migrants, homeless people, and individuals with child- or elder-care responsibilities.

By emphasizing proportionality, remedies, and non-discrimination, these dimensions are consistent with Siracusa and fundamental bioethical principles even as they extend them to a new context. One could argue that the right to health and ethics requirements, properly construed, demand these approaches anyway. What is crucial is that these right to health considerations are built into decision-making by public health authorities when measures to prevent the spread of infectious disease are instituted in the first place.

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VIEWPOINT

COVID-19 in Turkmenistan: No Data, No Health Rights

AYNABAT YAYLYMOVA

Turkmenistan, with a population of about 6 million, has, as of October 1, 2020, reported no SARS-CoV-2 infections, nor any COVID-19 related deaths.¹ There are no daily updates and barely any testing. However, there are reports of more deaths from acute respiratory illnesses than normal, and the autocratic government, known for endemic corruption, puts these down to dust and air pollution.²

Despite the government's refusal to acknowledge that COVID-19 is present in the country, reports of cases circulate among friends, in social media, and by civil society organizations, and efforts are being made to track COVID deaths.³ The pandemic and related insecurity arising from fear of disease and lack of any information are affecting the Turkmen people's physical and mental health. Despite known deaths in neighbouring countries, within its borders all the public hears is that "there are no confirmed cases of COVID-19 in the country."

To Turkmen, this denial of their right to information, to health care, and to transparency is normal. The public has not seen any public health data from the government in the last 29 years since it became an independent country in 1991. The Ministry of Health and the State Committee on Statistics, TurkmenStat, do not provide any statistics that concern human development in Turkmenistan.⁴ It has not reported any HIV infections since independence.⁵ Public health data is missing in the government's reports to the World Health Organization (WHO). Some UN country reports have acknowledged a significant difference between local and international data being reported.⁶

The Soviet healthcare system that was inherited at independence is now struggling to cope with a chronic shortage of healthcare workers, medicines, other health supplies and poor management.⁷ Ranked 101 out of 195 in the 2019 Global Health Security Index, Turkmenistan is poorly prepared to cope with a pandemic.⁸ People's rights to healthcare have been unfulfilled for so long, there is little confidence or trust in the population that the health system is able to help them.

Relying on civil society

In response to this pernicious and perilous, situation, alternative networks have emerged over the years to provide public health information. Since February 2020, Saglyk.org, a non-government organization founded in 2009, has been providing the public with science-based information on COVID-19, in the Turkmen language.⁹ The organization has also repeatedly sought to engage the Ministry of Health and WHO, and to provide science-based and ideology-free information, but Saglyk has received no replies to its requests.¹⁰

The government acknowledged the risk of COVID-19 early in the pandemic, and in March was closing

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borders and quarantining those entering Turkmenistan.¹¹ The country's small population and relative geographical isolation may have actually curbed the spread of the virus, but without access to data and scientific information letting people know how to protect themselves, the government squandered its opportunity, and failed to uphold its obligations, to keep the people safe.

In April, a WHO expert mission announced it would visit Turkmenistan but it took three months, according to the organization, to clear logistical issues. The 10-day mission took place in July and at its conclusion released a statement noting there were no confirmed cases, but advising the country to act as if COVID-19 is present in the country.¹² The WHO Head of Mission did not dispute the ministry's report of increased pneumonia cases in the country. The WHO statement was disappointing for the population that had been hopeful it might nudge the government to embrace reality and fulfill human rights. Saglyk.org released a statement to the public on the government and WHO's actions and expressing concern that the government and WHO were masking the public health emergency in Turkmenistan.¹³

Saglyk has also found that doctors received no information about the pandemic, nor medical treatment or prevention protocols, until mid-August. Despite ongoing reports of pneumonia, the lack of testing for COVID-19 removes any possibility of confirming the presence of the disease. On August 7, 2020, the head of WHO Europe, Hans Kluge, tweeted that he was alarmed by the increase of pneumonia cases in the country and proposed that COVID-19 tests from Turkmen patients be conducted in WHO reference labs outside Turkmenistan. He also said that the President of Turkmenistan agreed to the plan.¹⁴ Yet, this news was not covered by the state media and on August 31, Saglyk wrote to WHO Turkmenistan asking for any update on the agreed upon testing. WHO responded that they are once again having logistical difficulties gaining access to the country. Many people who likely are COVID-19 positive choose to suffer at home and avoid contact with the healthcare system due to its state of disrepair and corrupt practices.

The failure in communication and management of the pandemic has brought the public's trust to an all-time low. For the community, it is embarrassing that Turkmenistan has become a butt of jokes in international media.¹⁵ The Turkmen public watch governments of neighbouring countries providing COVID-19 data to their population but receive no similar data to help keep themselves safe from the virus.

The public and civil society are looking to WHO and other UN agencies to prevent deaths in Turkmenistan by not accepting or supporting Turkmen practices that defy reason, logic, science, and human rights, and continue to destroy trust.

Meanwhile it remains up to civil society in Turkmenistan to continue undertaking the state's duties to inform and educate the public, and to hold the government and WHO to account for acting in ways that are resulting in preventable loss of human life in Turkmenistan.

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VIEWPOINT

Ameliorating COVID-19's Disproportionate Impact on Black and Hispanic Communities: Proposed Policy Initiatives for the United States

AUDREY CHAPMAN

The COVID-19 epidemic has shone a bright light on structural racism in US society and on the inadequacies of a health care system that has significantly disadvantaged racial and ethnic minorities while giving preference to white Americans.¹ Research and disease surveillance have documented the disproportionate impact of the virus on the Black and Hispanic communities. Confirmed COVID-19 cases and deaths are disproportionately higher in communities in which these groups predominate. According to data from the US Center for Disease Control and Prevention (CDC), people of color are three times more likely to become infected with the coronavirus. The COVID Racial Data Tracker, an initiative that compiles data from state and local authorities, also indicates that Black people with the virus die at nearly 2.5 times the rate of white people, and Hispanic, American Indian, and Alaskan Native die at about 1.3 times the rate.² These trends are significant both in and of themselves and also because the United States is a party to the International Convention on the Elimination of All Forms of Discrimination which in Article 2 condemns racial discrimination and requires states to eliminate racial discrimination in all of its forms, including in the right to public health and medical care.³

These patterns reflect structural racism, which refers to the mutually reinforcing and inequitable systems of disadvantage that in turn reinforce discriminatory beliefs, values, and distribution of resources.⁴ Past and often continuing discriminatory policies towards racial and ethnic minorities in the United States have skewed the social determinants of health in neighborhoods that consist mainly of minorities in ways that have significantly disadvantaged them. Racial and ethnic communities living in segregated neighborhoods often lack accessible and good quality health care. They also suffer from considerably higher rates of poverty, poor quality and often crowded housing conditions, greater exposure to toxic pollutants in their air and water, and lack of available healthy food. In addition, they have fewer quality educational opportunities and less well paid employment. These social determinants in turn create conditions which leave people of color more susceptible to chronic diseases including asthma, diabetes, high blood pressure, heart disease, and obesity that make these populations more vulnerable to COVID-19.⁵

Eliminating the impact of decades of structural racism in US society and its health system, and transforming inequitable social determinants of health is nearly impossible in the short term but there are initiatives that could begin to ameliorate their effects during the pandemic. To begin with, it is important to have continued monitoring of the pandemic's impact on these communities. For example, there is little data available by zip code that would show how race and ethnicity interacts with places where structural racism is most embedded and affects disease rates.

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Racial and ethnic minorities have often had difficulty receiving testing and treatment for COVID-19. In large cities testing sites tend to be located in predominantly white areas. For example, when the radio network NPR investigated the location of public testing sites in Texas it found that in four out of six of the state's largest cities testing sites are disproportionately located in white neighborhoods despite the evidence that Black and Latino communities were harder hit. Testing disparities have also been reported in New York City and Chicago, and media reports suggest that the patterns identified in Texas are happening in other parts of the country. There are other barriers to COVID-19 testing for at-risk people, including cost, particularly in states which have not expanded Medicaid. Lack of transportation to testing sites is yet another issue.⁶ There is a need to reverse these trends in order to protect the most vulnerable populations by concentrating COVID-19 testing in areas in which ethnic and racial minorities live and, if needed, setting up testing sites in churches and other community centers. Additionally, the testing and follow-up treatment should be made available without cost, especially since so many in racial and ethnic communities lack insurance.

The failure to invest in adequate contact tracing has also disproportionately disadvantaged racial and ethnic minorities. It has meant that members of these communities who have been exposed in work or living situations have not been informed and as a result, they do not know to take measures to protect their communities and families. Moreover, where there has been contact tracing there has not been sufficient diversity among those conducting the efforts. So another helpful measure would be to institute adequate contact tracing in these communities and to train community-based partners who are more likely to win the trust of those who have been exposed to COVID-19.

Racial and ethnic minorities are overrepresented in jobs deemed essential to the functioning of the economy, and which cannot be performed from their homes. These jobs, such as agricultural workers, processors in meat packing plants, and home health workers, often require them to work

closely with others, and to be unable to maintain social distancing. Furthermore, they are often low paying jobs, without paid sick leave, resulting in sick people having little choice but to work.⁷ Black and Hispanic workers are often employed in jobs without occupational protections or benefits to ensure they receive minimum wages and access to sick leave. This is partly because these workers are not covered by the Fair Labor Standards Act of 1938 which exempted protections from domestic, agricultural, and service workers.⁸ Neither do these groups always have access to protective gear, something which should be mandatory for all in such situations. It has also been suggested that all workers considered essential should receive a guaranteed basic minimum income and paid sick leave at least until the end of the pandemic and that low-wage workers, who are predominantly racial and ethnic minorities, should receive savings accounts to help equalize their pay to that of white workers who have benefitted from employment law protections.⁹ I concur with these proposals.

It is important to have data to show that vaccines are safe and effective in the groups most effected by the pandemic. This requires their representation as participants in clinical trials, equal at least to their proportion of the population or even better represented commensurate with how much they are being effected by the disease. However, efforts so far to recruit minority populations into clinical trials for COVID-19 vaccines have been inadequate. Dr. Francis Collins, director of the National Institute of Health, described Moderna, one of the vaccine developers supported by the US government, as deserving a C for their efforts to recruit minorities.¹⁰ While minority populations account for some 32% of the US population, they have constituted far less of the population recruited into vaccine trials by US based vaccine sponsors. There are several reasons. Minority recruitment entails considerable extra effort and often increased costs. Also, a result of past neglect and abusive practices by medical practitioners many people of color are suspicious of medical research and the health care system. But vaccine sponsors could try to assuage these concerns by enlisting more Black

doctors as coordinators of the trials and minority church and community leaders to help recruit their members into clinical trials. They could also locate the trials at respected minority institutions. Two such institutions, Morehouse School of Medicine and Meharry Medical College, have been identified as clinical trial sites but other Black colleges and universities and schools with significant Hispanic representation need to be involved as well.¹¹

Moreover, it will be important to prioritize members of these communities to receive a vaccine once vaccines are available, and to provide the vaccine free. The draft guidelines of the panel sponsored by the National Academies of Science, Engineering, and Medicine propose a four phased approach reflecting the likely availability of vaccines. In the first phase all frontline health workers involved in direct patient care as well as others who risk exposure to bodily fluids and aerosols would be given the vaccine. In the second phase when more doses are available, individuals with co-morbidities and underlying conditions with increased risk are given priority. Within each phase vaccine access would also be prioritized for geographic areas identified as vulnerable through CDC's Social Vulnerability Index.¹² If these proposals are followed, many members of racial and ethnic communities will likely be among those offered the possibility of immunization in early stages of the vaccine rollout, but for the reasons mentioned in the preceding paragraph many of them may be reluctant to take it. Therefore efforts to win trust should start immediately, before any vaccine is available, using members of their communities to conduct educational initiatives that show the benefits and relative safety of the vaccines.

Compensating for centuries of discrimination and the effects of structural inequalities that favor whites at the expense of people of color in the United States will require a long-term effort. However, a commitment to racial equality and to human rights demands that meaningful measures be undertaken immediately. This viewpoint has sought to identify some of the initiatives that could begin to ameliorate the disproportionate impact of COVID-19 on Black and Hispanic communities.

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VIRTUAL ROUNDTABLE

A Virtual Roundtable with Special Rapporteurs on the Right to Health

CARMEL WILLIAMS AND JOSEPH J. AMON

Introduction

Since 2002 the United Nations, through the (now) Human Rights Council, has mandated experts to advance the right to the enjoyment of the highest attainable standard of physical and mental health. Dr Tlaleng Mofokeng, is the fourth, and most recent appointment to this post, and the first woman to hold it. Called Special Rapporteurs, these ‘independent experts’ promote and protect the right to health throughout the world. They identify general trends related to the right to health, highlight specific challenges and recommend solutions, and undertake country visits to examine the situation concerning the right to health in a specific country. Each Special Rapporteur maps out their own priorities for the mandate, and selects which countries to visit. Their visits are not limited to countries, but can include institutions, for example, Paul Hunt undertook missions to the World Trade Organisation, World Bank, International Monetary Fund and a global pharmaceutical company (GlaxoSmithKline). To mark the occasion of the new appointment, HHRJ invited the four experts to participate in a virtual roundtable discussion about the mandate. In the following conversation, we ask the former mandate holders to reflect on their achievements and challenges, and the new incumbent to expand on her priorities and hopes for the role. A full list of all the thematic and country mission reports of the first three Special Rapporteurs is available on HHRJ’s resource page.¹

Participants

Paul Hunt (August 2002-July 2008)
Anand Grover (August 2008-July 2014)
Dainius Puras (August 2014-July 2020)
Tlaleng Mofokeng (August 2020—present)

Roundtable

CW and JA: Thank you so much for participating in this virtual roundtable discussion. Let’s start with some general introductions. Paul and Anand, you are both trained as lawyers and Dainius, you are a physician. What were you doing just prior to being appointed as the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health?

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Paul: I worked as a human rights lawyer, and lived, in Africa (Gambia), Israel/Palestine, Geneva, United Kingdom, and Aotearoa New Zealand. To begin with I focussed on civil and political rights but, in the 1990s, began to specialise in economic, social and cultural rights. Most of my work was in non-governmental organisations, like Liberty (UK), but also the Africa Centre for Democracy and Human Rights Studies (Gambia). Just before my appointment as Special Rapporteur, I served on the UN Committee on Economic, Social and Cultural Rights (1999-2002) while also working as a Senior Lecturer in Law at the University of Waikato, in Aotearoa New Zealand (1992-2000). In 2000, I was appointed Professor in law at the Human Rights Centre, University of Essex, UK.

Anand: Along with Ms. Indira Jaising, in 1981 I founded the Lawyer's Collective, a non-governmental (NGO) in India which promotes human rights, especially on issues relating to women's rights, HIV, tobacco, LGBT rights, sex workers rights, drug users and access to medicines. As a Senior Advocate, I practiced in the Supreme Court of India, and directed the HIV/AIDS Unit of the Lawyer's Collective. I argued several landmark cases in the field of human rights law, including mass eviction cases, environmental cases, HIV, and LGBT rights, as well as work in opposition to patents for essential life-saving drugs.

Dainius: Before my appointment (and during it) I was a professor and the *Head of the Centre for Child Psychiatry and Social Paediatrics at Vilnius University* in Lithuania. I had been engaged for some 30 years as a human rights advocate focused on transforming public health policies and services, with special focus on the rights of children, persons with mental disabilities, and other groups in vulnerable situations. I also served as chair of the board of two NGOs in Lithuania: the Global Initiative on Psychiatry, and the Human Rights Monitoring Institute.

CW and JA: Tlaleng, since you may be new to

many HHRJ readers, let's talk more about your background.² You began your health and human rights activism early, setting up a youth friendly clinic at the University of Kwa-Zulu Natal in the Eastern Cape of South Africa, as a student at the Nelson Mandela School of Medicine. Did you study human rights formally or did you see this as simply an extension of medicine?

Tlaleng: Medicine is a science that deals with rights to health, and although I am not a lawyer, I did learn about human rights in family medicine and one of the principles of medicine is "being an advocate for patients and understanding underlying causes of illness" and those two principles inform my work as a physician who is also an activist.

In 2010 I was deciding which specialty I would train in, and I chose sexual and reproductive health because I felt that it would provide me with the most variety of courses and issues and give me an opportunity to be both an activist and a doctor. I continue to see myself as both, running a clinic and producing video blogs dedicated to providing comprehensive information to enable people to make informed decisions about their fertility. I am also a facilitator and educator of youth, LGBTIQ individuals, HIV positive people, discordant couples, sex workers on issues such as consent, understanding their own risks depending on the type of sex they are engaged in, how to use the male and female condom, and extensive pre-contraceptive advice to empower for informed choices regarding suitable methods. This is deeply rewarding, but it remains frustrating that sexual and reproductive health and rights services and related rights are seen as a burden to most health systems and governments. It is exhausting to constantly have to fight for rights to dignity and autonomy, such basic principles yet they are the political battleground where people seek to control women.

CW: Let's talk about the start of your mandates. Every candidate for the position of a UN Special Procedure writes a 'motivation letter'. How did you describe your motivation when you were a candidate?

Paul: At the start of a brand-new and highly controversial mandate, I explained that I wanted to put the right to health on the map. One, by promoting the right to health as a fundamental human right. Two, by clarifying what it means. Three, by showing how it could be operationalised, that is, made real in the everyday lives of everybody. Explicitly woven throughout these objectives were two interrelated themes: poverty and discrimination.

Anand: My letter reflected my previous work on HIV, and highlighted a few issues that I felt urgently needed to be taken forward, namely, de-criminalization of behaviours, including sexuality related, drug use, sex work, HIV transmission, and access to medicines. I wanted these to be taken up at the international level.

Tlaleng: Like Anand, I emphasized my past experience, including my lived experience of being a woman, from the global south, in Africa, together with my expertise in the field of human rights and health, in working with government, global aid agencies, civil society, human rights institutions; working through data, investigations and hearings; recommending policy or legislative changes.

CW: Paul, briefly, you just referred to the role as a controversial mandate in 2002. Could you expand on that a little, and reflect on whether it remains so now?

Paul: The International Bill of Human Rights—consisting of the Universal Declaration of Human Rights (1948), International Covenant on Civil and Political Rights (1966) and International Covenant on Economic, Social and Cultural Rights (1966)—is one of the most important documents of the twentieth century. It has a wide and rich vision of humanity and human rights. For sure, there are striking omissions, some of which have now been redressed, for example, by the UN Convention on the Rights of People with Disabilities and the UN Declaration on the Rights of Indigenous Peoples. Nonetheless, the International Bill of Human Rights

has an expansive view of humanity, that is, it does not confine itself to civil and political rights, it also encompasses workers', social and cultural rights. But, for decades, many (not all) in the human rights movement lost sight of that wide and rich vision of humanity. For many, the focus narrowed to civil and political rights. Economic, social and cultural rights—especially social rights—became marginal. The right to health is a social right.

In 1990s, the narrow focus on civil and political rights began to shift. The UN determined to give more attention to workers', social and cultural rights. Appointing a Special Rapporteur on the right to health in 2002 was part of an incipient trend in the UN to reclaim this wide and rich vision of humanity and human rights.

However, today, this reclamation of social rights is still contested. The right to health does not fit well with an individualistic liberal ideology that favours non-interventionist government. The ideological opponents of social rights devise all sorts of arguments to keep social rights marginal. They argue that social rights, like the right to health, are not 'real' rights. Or they are only 'aspirational' and give rise to no obligations. Or, because they are subject to progressive realisation, they are not measureable.

Although these arguments of social rights 'deniers' are bogus, they confirm we have yet to reclaim the wide and rich vision of humanity and human rights that is the hallmark of the iconic International Bill of Human Rights.

JA: Looking back now, how do you view the aspirations you had at the onset of your appointment? Do you believe you achieved your goals by the end of your second term?

Dainius: In my first annual report, in June 2015, I summarized the substantial work done by Paul and Anand in articulating the right to health and highlighting key health and human rights issues.³ Both had done a terrific job on setting the foundations of the mandate, formulating the elements of the right to health framework, and elaborating on the issues that are central to the

right to health. My decision was to expand on themes that were becoming increasingly important, but had not yet been thoroughly addressed by the mandate or by the global right to health and human rights community. In that 2015 report I emphasized the importance of strengthening health systems, and the need to place the well-being of individuals and communities at the centre of health policies, ensure access to information and participation, and to have accountability mechanisms in place. Other issues I raised included the importance of a gender perspective, the rights of children and adolescents to health, as well as people in vulnerable situations, including mental health and well-being, and persons with disabilities. I introduced my focus on a life-cycle approach to the right to health. Overall, looking back, I think that I achieved a large part of what I planned to achieve.

Paul: Like Dainius, I achieved much of what I planned—with the help of a thousand others. Certainly, I made more progress with objective one (promoting the right to health) and objective two (clarifying what it means) than objective three (operationalising it). To operationalise the right to health we need savvy health professionals who get the right to health. Cops listen to cops. Judges listen to judges. Teachers listen to teachers. And health professionals listen to health professionals—and I am not a health professional. Anand and I are human rights lawyer-activists and, as the first right to health ‘rappers’, as I affectionately call mandate-holders, Anand and I made numerous distinctive contributions. Dainius and Tlaleng are health professionals and, building on the foundational work of many others, they are well-placed to operationalise the right to health. Dainius did a fantastic job, especially in relation to the right to mental health, and I am sure Tlaleng will be equally successful. Her professionalism, passion, and experience are exceptional.

Anand: Thank you Paul. I’m happy to be considered a distinctive health ‘rapper’. Overall, I felt I was able to achieve what I had set out to do. At first, I felt a little constrained in not having dedicated staff to

assist me in the work. As I had to earn an income as a professional lawyer, I found it difficult to continue what I had done with the first report without a dedicated team. Thereafter I got a dedicated team which was of enormous help.

CW: Tlaleng, do you have any particular themes or countries that you are planning to focus on in the first 18 months?

Tlaleng: It is too early to know about countries in our current pandemic, but I will centre ‘vulnerability as a human right’ and urge member states to focus on restoration of dignity in all their efforts to realise the right of everyone to the highest attainable standard of physical and mental health.

As Dainius mentioned, it is important to build on the work of one’s predecessors rather than attempt to redesign the wheel. It is also important to be strategic in our engagement with member states—drawing on previous successes and learning as we build on and advance the next phase of work. While each Special Rapporteur has his or her own area of expertise, we also have to look broadly, and be specific in recommendations. I can see it’s a balancing act!

I think partnering with others can be really effective—both civil society NGO partners, national, and UN partners. For example, in 2017 I briefed the UNFPA Executive Director and UN Secretary General’s Envoy on Youth on sexual and reproductive health and rights in the [African] region. I have also briefed the Independent Expert on the enjoyment of human rights by persons with albinism, on her country visit to South Africa, and in 2020, I was invited to a two-day meeting with the newly appointed UNAIDS Executive Director, during her global consultative process to inform the strategy for UNAIDS.

Collaboration within UN entities in promoting respect for human rights is crucial. In my current role as Commissioner at the Commission on Gender Equality (CGE), a national human right institution in South Africa, I led the country delegation to the 77th session presenting South Africa’s progress in March 2020.

JA: Paul, you mention promoting the right to health as your first objective and where you made the most traction. Can you describe more how you addressed this and what barriers you faced?

Paul: I am grateful to the *Health and Human Rights Journal* for carrying an article called “Interpreting the International Right to Health in a Human Rights-Based Approach to Health” in which I set out the evolution of the international right to health in the last few decades.⁴ As the article explains, until 2000 there was little clarity about what the right to health meant. There was not even a common vocabulary for discussing the key features of the right to health. Frankly, we were all over the place. This deficit was addressed by the UN Committee on Economic, Social and Cultural Rights in 2000 when it adopted General Comment 14 on the right to health.⁵ I had the privilege to serve on the Committee between 1999-2002 and helped to draft General Comment 14. Of course, General Comment 14 has its shortcomings but at least it outlines the contours and content of the right to health. It provides a map. An imperfect map—but a map, nonetheless.

I tried to apply General Comment 14 to thematic issues (for example, sexual and reproductive health, neglected diseases, the work of the World Trade Organisation, access to medicines, health systems, and so on) and real-life country situations (for example, in Uganda, Peru, Romania, Mozambique, Sweden, and elsewhere).⁶

By applying General Comment 14, I had to clarify and refine what the right to health means. In 2010, Sheldon Leader and I wrote an article “Developing and Applying the Right to the Highest Attainable Standard of Health: The Role of the UN Special Rapporteur (2002-2008)” which explores how I tried to clarify and refine the right to health.⁷ For example, I used my reports to explore how indicators and benchmarks can be used to hold governments accountable for the progressive realisation of the right to health. It’s not very exciting, but without indicators and benchmarks it is impossible to ensure that governments keep their promises to progressively realise the right to health. This work led to a major *Lancet* study on health sys-

tems and the right to health in 194 countries.⁸

I think it is fair to say that, thanks to the work of many, we now have a common vocabulary for understanding and talking about the right to health. Personally, I think it is extremely important this vocabulary is neither lost nor blurred. Of course, it will evolve and deepen. But it must not become a ‘lost’ language. If the common vocabulary for talking about the right to health loses its currency this will make life much easier for our ideological opponents, that is, the right to health ‘deniers’.

CW: Anand and Dainius, what would you consider the most important issue of your tenure?

Anand: For me, it was firstly the decriminalization of behaviours, such as sexuality, issues concerning the LGBTIQ communities, sex work, drug use, sexual and reproductive health and the criminalization of those behaviours and how that adversely impacts on the right to health. Rather than addressing the issues in silos, I had taken them broadly under the rubric of criminalization. These are included in two reports to the Human Rights Council presented in 2010 and 2011.⁹ These reports had a good impact amongst civil society and in some states as they started recognizing that criminalization is the wrong strategy to address behaviours. They started seeing linkages of common issues for themselves and some states responded positively. The reports strengthened the move towards decriminalization. The Global Commission on Drug Policy is a good example.¹⁰ Of course this was strengthened by my work in India, on Section 377 Indian Penal Code, covering sex work and drug use.

The second issue of importance was access to medicines. Civil society, academia, and states in low and middle income countries got a fillip with the reports on access to medicines.¹¹ It was no longer a technical issue which people could not understand. They could relate the report to their experience, on high drug prices which impacted adversely on access and availability to health goods, services and facilities.

Dainius: My priority was the right to mental health. I was ready for this challenge, which I think I had

been preparing for through my whole professional life. It is not for me to assess how effective my reports and other activities on mental health and human rights have been. Other experts are doing this and, hopefully will continue doing so in the future. But I am convinced that it was the right decision and the right time to address the failure of status quo in global mental healthcare. Mental health is emerging as a new priority, globally. The global community seems to have agreed that mental health needs more investment and parity with physical health, but we also need to decide how we should and should not invest. The messages from my reports are very clear about this.¹²

Some experts think that the messages I formulated are too radical, while other experts think that that I have made too many compromises with regard to assessing the status quo. It will be very interesting to observe how global mental health develops over the next 10 years.

CW: Paul and Anand, did you experience similar criticism from ‘experts’?

Paul: Yes, I did. Some philosophers said the right to health was ‘incoherent’. Some political scientists said the right to health was blind to political economy. Some economists said the right to health did not permit trade-offs between competing rights and other interests. Each criticism has to be taken seriously. There is a response to each one. When hearing these criticisms I would ask myself: the right to health can dignify and empower individuals and communities, is the critic trying to torpedo the right to health or is s/he trying to strengthen it?

I tried to protect myself from criticism by building on human rights values, law, literature and analysis, and by listening carefully to the disadvantaged, including those living in poverty.

Anand: I did not have much criticism from “experts” in the way that Dainius has mentioned, but I did face criticism from States. I protected myself from the negative impact of criticism by taking great care in two respects. In reports, the contents must be supported by evidence and properly ref-

erenced. No statement should be made without it being backed by an authoritative document or a record that is maintained by the mandate holder. Thematic reports should use evidence-informed references that support the point of view being advanced. In reports on country missions where claims can be contested, I consider it important to check that facts and comments are backed by somebody “on the ground, whose statement is recorded.” Also, all protocols which have been laid for issuing appeals, considering urgent appeals, and so on, must be followed. Don’t take short cuts!

CW: Were there issues that you feel you overlooked—and when did you discover this?

Paul: As my mandate came to an end, I wish I had given more attention to palliative care.

Dainius: The mandate is very broad, so it’s not realistic to cover many important themes. Besides my main priority, which was the right to mental health, I managed to produce thematic reports on the right to health in early childhood, the right to health in adolescence, the right to health and Agenda 2030, corruption and the right to health, deprivation of liberty and the right to health, health workforce and medical education, roles of sport and healthy life style in realization of the right to health. During the final months of my mandate, the COVID-19 pandemic started. Although there was not enough time for me to explore this issue, I managed to prepare my final report on the right to health and COVID-19. This report will be presented by my successor Tlaleng to the UN General Assembly in October this year.

I have addressed some other important issues (drug use, healthy food, right to health of LGBTI persons, right to health and TB) in my open letters and other statements. But, I wanted to do more on two issues—universal health coverage and palliative care. I regret that I did not manage to have full reports on these extremely important issues.

Of course, this is all mainly about process and about contributing to the visibility of the theme, formulating the position of the mandate and

strengthening the rights discourse and topics. In terms of measuring outcomes or impact of the role, I think now, as I did from the start of my tenure, that one mandate and one mandate holder cannot expect to achieve measurable change in the global right to health field. Rather, we make our contributions to the collective effort to the process of realizing the right to health.

Anand: I overlooked the role of business enterprises and philanthropic organisations. I had it in my mind all the time but I could not put it in my agenda as there was just too much to do. In light of Paul and Dainius' comments about palliative care, I joined with the Special Rapporteur on torture to make a recommendation that controlled medicines for palliative care are added to the WHO Essential Medicines list, and also included that recommendation in one of my reports.¹³

JA: What key partnerships did you feel helped you in your work? Did you collaborate with other mandate holders? With NGOs? Academics? UN agencies? Foundations? Others? Can you give examples of how these partnerships advanced your work?

Paul: My work depended on an extensive network of allies to whom I am forever indebted. For example, among my more successful country visits were to Peru and Sweden. In Peru, I had extraordinary support from the UN country team, especially PAHO and UNDP, as well as civil society. In Sweden, the support of civil society was exemplary. The visits were successful because of this support in Peru and Sweden. I had great support from a few brave souls within WHO. I must say that for six years I received top-notch sustained support from the OHCHR and Essex University colleagues.

Anand: NGOs who were working on the issues I was focusing on, providing key partnerships along with foundations who supported the consultations and meetings. This gave rigour to the thematic reports and also helped to build a support base on the issue, for example, on the migration report that I presented to the Human Rights Council in 2013 I

had a consultation with groups working on migrant worker issues in the Asia Pacific region.¹⁴ Similarly the report on the impact of criminalization of sexual and reproductive health, I had a smaller consultation with key actors on the ground.¹⁵ The consultations, on the one hand provided valuable inputs for the reports, while on the other they also developed a constituency to support the report and disseminate it.

I was also able to collaborate with other mandate holders on a few initiatives by issuing joint statements.¹⁶ But as mandate holders work on their own, it is difficult to join forces and do joint work.

Dainius: I believe our main partners are the states, because this reflects the mechanism and composition of the UN and the special procedures. The fact that mandate holders are independent (also from the UN) and have a right to go public, including with “naming and shaming”, creates a meaningful tension between the mandate holders and Member States. I think that this tension is one of major driving forces in the field of human rights, including for the right to physical and mental health.

Of course, other stakeholders, especially civil society, are of great importance. International and national NGOs were my main partners in all activities, especially during consultations when working on both thematic reports, and country missions. I devoted half of every day to meetings with civil society during the country missions. Space for civil society and mutually respectful cooperation between state agencies and civil society—these are crucial elements of the successful realization of the right to health.

JA: Can you describe a moment when you felt exalted in pursuing your work?

Paul: I decided to frame maternal mortality as a human rights issue and, when I presented this to the General Assembly, it was greeted with applause. I am pretty sure the applause was from observing NGOs, not states! But, in any event, the General Assembly is a very tough gig (it's as responsive as a bowl of porridge) so I really appreciated the pos-

itive reaction. The issue of maternal mortality and human rights led to thematic and country reports, for example, my mission to India, as well as other publications, such as a book called *Maternal Mortality, Human Rights and Accountability*.¹⁷

Anand: On my Vietnamese mission an issue arose relating to detention of sex workers. I was persistent in voicing my opinion about there being no need to detain them. On the final day the local MP in charge advised me that they would look into it more closely as they felt my arguments were persuasive.¹⁸

Dainius: The moments when I felt we were making progress were mainly related to responses to my thematic reports. Several reports—such as three reports on right to mental health (2017, 2019, 2020), the report on the right to health in early childhood, and another on adolescence, as well as those on corruption and right to health and on the health workforce and medical education—sparked a broad range of responses. Resolutions of the UN Human Rights Council on mental health and human rights, especially the one from 2020, was an obvious positive outcome of concerted efforts of Human Rights Council, Member States, OHCHR and mandate holders.¹⁹

CW: What about feeling despondent?

Anand: When I had issued an urgent appeal to Sri Lanka on retaliation against the Liberation Tigers of Tamil Eelam (LTTE), the Sri Lankan representative told me that they would make a complaint against me on my urgent appeal as they alleged I had not followed protocol. I felt the ground under my feet open up. I was sinking. Then I calmed down and called my official assistant in the OHCHR and asked her to send me all the correspondence relating to the urgent appeal we had issued. Fortunately, it showed that we had followed all instructions and protocol. I was then very angry at the Sri Lankan representative who had made a false accusation against me. But I maintained my cool, and advised him that he was out of line as he had not checked facts properly.

Paul: Early in my first term, I spoke to a large meeting of health professionals and, as the event proceeded, my heart sank because it was clear from expressions and body language that the majority had no idea what I was talking about, and the minority that grasped what I was talking about didn't much care for it.

It was very sobering but taught me that I had to adjust my approach and language without selling out. Without compromising on the right to health, I learnt to 'translate' right to health terms and concepts into terms and concepts that health professionals could relate to.

After meetings and over a drink I would tease my new colleagues by calling them 'lawless fetishists'. 'Lawless' because they attached scant importance to binding human rights law, and 'fetishists' because they were obsessively preoccupied by a bizarre and narrow understanding of what constitutes evidence.

Dainius: There were moments when it was difficult to defend the position I had formulated. But this is normal for most independent experts. The most difficult time for me was not so much related to my own mandate, but during the year (June 2018 - June 2019) when I was Chair of the Coordination Committee of all the Special Procedures. I could see how fragile the entire global situation about the protection of human rights is, and how important it is to defend the best of what humankind has achieved—the human rights of everyone, without exceptions.

CW: The understanding of the meaning of the right to health has deepened enormously since the first UNSR was appointed in 2002. What do you believe are the greatest gains in the development of, and our understanding of, the right to health over the past 20 years? Are there areas within the right to health that you would like to see further developed, either in policy, law, or operationally?

Paul: As mentioned, we have advanced our understanding of the right to health. We've clarified and developed General Comment 14 on the right to health, although there is still plenty of room

for improvement. Now the key priority is to build on this and make the right to health practical and operational in the everyday lives of everybody. The United Nations in Geneva and New York have a role to play in advancing this practical work, but it cannot be done in the corridors of the United Nations. Real-life practical implementation will occur on the ground in communities, clinics, hospitals, work places, housing estates, schools, universities, and elsewhere. Today, that's our priority challenge.

Dainius: In my view, the right to health has been well established as an economic and social right, and especially with regard to accessible, available, acceptable and good quality healthcare services. However, this has led to some imbalances and to selective approaches by many stakeholders. Many governments consider investment in healthcare services to be the most important aspect of the right to health. When I was planning official country missions, there were government expectations that first of all I would be visiting healthcare facilities and would be investigating whether medicines, vaccines and medical devices were available. This is, of course, an important element of the right to health. However, such an approach is too narrow and it may lead to excessive medicalization, to neglect of the social determinants of health, and to undermining broader human rights-based approaches. This led to my decision to address on several occasions the indivisibility and interdependence of all human rights, including civil rights and freedoms. Space for civil society, democracy, rule of law—these are crucial requirements for the effective realization of the right to health.

During the six years I held the mandate, (2014-2020) there were obvious signs of attacks on universal human rights principles in many parts of the world. My approach was that the right to health cannot be exercised without considering this broader context. For example, discrimination on very different grounds, within and beyond healthcare services, is detrimental to physical and mental health.

Some people commented that my approach moved away from a conventional interpretation

of the right to health towards “human rights and health”. But I deliberately chose that position. I am convinced that undermining any human right can be detrimental to right to health. And this is not only about inequalities and poverty being harmful for physical and mental health—which is well understood already. I spent more than 30 years in the Soviet Union, and I know how the undermining of civil and political rights is detrimental on public health. As a result, throughout my tenure, I often reminded states and others that all forms of violence and discrimination, on any ground, as well as shrinking space for civil society, is as damaging to health as are poverty and inequality. In other words, if attempts to achieve equality are made by force, and people are deprived of meaningful participation in this process, as happens in totalitarian and authoritarian regimes (an example was the forced collectivization of rural population in the Soviet Union), this is detrimental to the health and well-being of societies and individuals.

Anand: The greatest strength of the right to health is that the ICESCR is universally ratified. However, I don't think this right is understood by states, judges, lawyers, and activists. The fact that the right to health is a progressively realizable right makes it very complex. General Comment 14 doesn't clearly explain the concepts in a simple manner.

Moreover, there is criticism of its application. I still remember a judge of the Supreme Court of India asking me about a matter involving right to health - what could be done in the matter? There is hardly any jurisprudence on the right to health in India. I think there has to be huge effort to popularize the meaning of the right to health in simple language and also to address its critics. Secondly the areas of “respect, protect, and fulfil” have to be clarified in a simpler manner. There is a need for better and more consistent alignment of obligations. For example, with the Guidance on Business and Human Rights, protection of human rights is framed as a recommendation rather than acknowledging it is indeed a legal obligation.²⁰

Tlaleng: We need to ensure existing good laws inform policy and at the end of the day, must lead

to tangible and inclusive services and access. Many laws are great on paper but the impact on health outcomes isn't as expected. Locating issues of access, innovation, biomedical development, and research within a rights framework ensures accountability and that we truly leave no one behind.

CW: We are having this discussion in a particularly challenging moment, with many countries in lockdown as a result of the COVID-19 pandemic. Our last roundtable discussion highlighted the restrictions of rights that many are facing and challenges to accessing health care, education, justice as well as protection from violence and freedom of expression. But more broadly, we're also seeing a number of other trends harmful to realizing the right to health stemming from populism, increasing environmental crisis from climate change, and state and corporate efforts to dismantle social and economic rights. Violence and deadly health disparities, racism and invasive digital surveillance technologies often seem intractable and immune to rights claims. How well equipped do you think the rights movement is to address these challenges?

Anand: I don't think the human rights movement is able to challenge the dominant paradigm. Apart from restrictions that are imposed, which by the way have not been thoroughly challenged in courts of law, the fundamental right to equality and non-discriminatory access to health goods, services and facilities is being undermined by private non-state actors with the full backing of states. Vaccines and drugs are going to be given to those who are able to pay. Profiteering is the name of the game on diagnostics, drugs, and vaccines which result from research which has been publicly funded. It is like the old wild west out there.

Dainius: I have highlighted these issues during my tenure, and COVID-19 is demonstrating the indivisibility of human rights. Crises, such as the current one, present good opportunities for positive change. During my final months as special rapporteur when the COVID-19 pandemic started,

I could see some encouraging moves towards the revitalization of universal human rights principles, international solidarity, and multilateralism. On the other hand, many threats to human rights were activated. The most painful paradox in response to the public health crisis was that many stakeholders were escalating the importance of right to health at the expense of other rights, and especially civil rights and freedoms. I worked with other mandate holders to demonstrate that at all times—before, during, and after the pandemic—there is a need to strengthen, and not to weaken, broad human rights-based approaches. COVID-19 is a different pandemic compared to AIDS epidemics, but the principles of addressing such crises remain the same. The best “vaccine” is a human rights-based approach, and we all need to work hard on this.

Tlaleng: COVID-19 is exposing existing challenges and again and again it shows that we do not learn from history or previous disasters or health epidemics/pandemics.

JA: A number of critics have faulted the human rights movement for failing to address structural causes of rights violations. In many ways, it seems that the critique is that human rights advocates and institutions (national, international and non-governmental) or the protections and tools for accountability that these actors use are not sophisticated enough to combat privatization, financialization, deregulation, and the undermining of state systems of social protection and redistribution, that have produced deepening inequality and political and social crises around the world. Do you agree with these critiques?

Tlaleng: The main concern for me is the tendency to want to depoliticise the issues or the lives of the people and communities. The human rights movement did not cause oppressive systems, however, we must address structural causes of rights violations and name these systems so that we can be intentional about efforts to end them. We need to deepen understanding and be careful to not co-opt justice

language, intersectionality, inclusivity/diversity without matching that with action for what those frameworks mean. For example, we still accept race as a risk factor for ill-health when in fact it is racism that does that with spatial planning, poor access to water and sanitation, industries destroying indigenous land for capitalistic gains, leaving communities with pollution and poor health outcomes.

Dainius: I believe the human rights community has been doing its best in these difficult times of prolonged attack from different sides on universal human rights principles. I think that the most serious threat is coming from the “virus” of populist nationalism. Representatives of this widely spread wave try to pretend that they are fighting inequalities, and at the same time they reduce space for civil society, attack sexual and reproductive rights, escalate the concept of “protection of traditional family values”—all this is detrimental to the realization of the right to health. We need to strengthen the critical mass of those forces that defend and promote the best features of modern humankind—universal human rights principles that are embedded in the UDHR and in the UN conventions.

Anand: I don’t think it is an issue of lack of sophistication. It is simply that business is not made amenable to human rights. The fact is, for example, why are Business and Human Rights guidelines only voluntary? This is the core issue. Business entities who today control huge resources are without any real rights obligations. Unless that changes I don’t think there will be substantial progress.

JA: Even other Special Rapporteurs, such as Philip Alston, have painted a pessimistic portrait of respect for economic and social rights; for example, in his 2016 report to the Human Rights Council he said that the acceptance by States of ESC rights remains marginal and that that marginality is also reflected in the work of “many of the most prominent civil society groups focusing on human rights”. Is there any hope for optimism? What are some examples of civil society groups doing great work? Where have

you seen States take steps forward in terms of ESC rights?

Tlaleng: I will speak for my experience and what gives me hope and ideas on groups doing good work. Examples include National Human Rights Institutions (for example, the Commission for Gender Equality, South African Human Rights Commission), Section27, CALS, Nalane for Reproductive Justice, Iranti, Soul City Institute.

Anand: I think the marginality is due to the lack of understanding of ESC rights and primarily the concepts of progressive realization and underlying determinants. Unless these are clearly and simply spelt out, we are not going to get anywhere. Civil society groups also face the same problems. Very few groups are doing general ESC at the domestic level using international legal jurisprudence. At the State level I see South Africa moving forward but I think it is an exception.

Unfortunately, Special Rapporteurs are professional people who have to earn their living while they undertake time consuming work of the Special Rapporteurs. The workload is very high. It leaves little time for the Special Rapporteurs to do pedagogic work to explain the content of the right to health. This should be addressed in terms, for example, having meetings when on missions to explain the content and meaning of the right to health, especially in the academic and the legal world.

CW: If you think back to when you started the role, is there one piece of advice you wished you had received? Is this advice you would give to Tlaleng? Is there other advice you would give her relevant to this specific moment?

Paul: The right to health is a social right. In many quarters, there is an ideological resistance to social rights, including the right to health. All of us must be aware of this ideological resistance otherwise it is impossible to make sense of the obstacles we encounter in our work.

Dainius: My advice to Tlaleng would be to use the analytical right to health framework that Paul developed in his tenure. I think it is important not to lose the direction and guidance of this framework. But otherwise, each rapporteur must choose their own thematic priorities. The field of this mandate is so broad that it is impossible to cover everything. So each mandate holder adds with their own background, like I did with my approach and with a focus on mental health.

Anand: It would not be proper for me to “advise” Tlaleng. But as you have asked I am going to make a few points. I think she would have an idea about the issues she wants to push, primarily in terms of thematic reports which will overflow into her country missions. She should pursue those issues without being pressured by any states or civil society. It is important to have consultations with civil society actors and affected persons. That gives strong support on the ground which then augurs well when taking on the states on these issues. In reports it is good practice to make sure everything is supported by evidence and properly referenced. Finally, it is important that a mandate holder has good rapport with the assistants in Geneva. This helps ensure they are supportive of the mandate holder if difficult issues arise.

JA: Are there any ways that you think the mechanisms of the mandate should change? Is one Special Rapporteur addressing all aspects of the right to health really feasible? Are country missions worthwhile, and do they contribute to change within that state? What would be a good balance of thematic reports and country mission reports? Could they link in further to other accountability mechanisms, in terms of assessing state responses to the recommendations?

Anand: I was happy with the system of thematic reports and country missions. However, I think country missions need to be organized better. I think that there should be more time in the HRC and the Committees to exchange in dialogue. On country missions, apart from the plenary discus-

sion, there should be more time for rapporteurs and the country to interact in an open fashion.

Dainius: The methods used by mandate holders, and the rules set by the UN, are not perfect. But they are really good for creative work and for the independence of the mandate. The main concern now, with the pandemic and measures to address it, is that the special procedures survive this difficult time. The fact that mandate holders cannot travel is a very serious challenge, especially with regard to official country missions. We will need to find creative solutions so mandate holders can still fulfil this important aspect of their role.

Paul: The right to health cannot flourish if it is confined to national and international human rights systems, that is, the human rights ‘mainland’. The right to health must also be situated beyond this ‘mainland’-it must be scattered across ministries of health, UN agencies, business, civil society, and elsewhere, in what I call the human rights ‘archipelago’. The immense right to health challenge is to entrench this human right in both the human rights ‘mainland’ and its ‘archipelago’.²¹

CW: Tlaleng, do you have questions for the former Special Rapporteurs?

Tlaleng: How did you handle pushback?

Paul: I hesitate to say this, but I think the human rights movement, including the right to health, is experiencing pushback because human rights have lost their way. We have to reassert key human rights values, such as dignity, respect, decency, fairness, equality, freedom, and community. We have to do all we can to ensure our societies place these values at the centre of everything they do. These values are embodied in the International Bill of Human Rights. Human rights include, civil, political, workers’, social and cultural rights, as well as the right to a healthy environment, and indigenous peoples’ rights. We have to reclaim the universalism of human rights: they extend to everyone. Responsibility for human rights applies to all those wielding public

power, including powerful corporations. We have to insist on accountability for human rights, not in the law courts, but where we live and work. We need to demand evidence: according to the evidence, which policies and projects deliver human rights for everyone? If the policies don't deliver—change policy. If the policies deliver—keep going. We have to listen to the disadvantaged, including those living in poverty. As the Universal Declaration of Human Rights says, individuals have responsibilities to their communities (article 29(1)). We have responsibilities to each other, for example, not to be racist, and to future generations not to mess up our magical environment.

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