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SPECIAL SECTION

PUBLIC AND MENTAL HEALTH, HUMAN RIGHTS,
AND ATROCITY PREVENTION

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Caitlin Mahoney, and Amy Meade

In collaboration with the Cardozo Law Institute in Holocaust and Human Rights

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EDITORIAL

Proven Concepts in New Contexts: Applying Public Health, Mental Health, and Human Rights Strategies to Atrocity Prevention

JOCELYN GETGEN KESTENBAUM, ARLAN FULLER, CAITLIN MAHONEY, AND
AMY MEADE

For the past two years, the editors of this special section have worked in close collaboration to consider the various ways in which human rights and rights-based approaches can promote public health and mental health policies and practices in the prevention of mass atrocity crimes. In June 2019, we convened academics and practitioners engaged in work at the intersections of these disciplines across various contexts and at various intervention points along the continuum of harms that can be defined as atrocity crimes. Represented among these scholars and practitioners were psychologists, sociologists, social psychologists, epidemiologists, public health practitioners, political scientists, legal scholars, human rights practitioners, anthropologists, historians, peace studies scholars, and philosophers. All participants recognized that multi-disciplinary tools and frames were critical to their work in their respective disciplines to identify effective strategies to disrupt causal pathways of identity-based violence, human rights abuses, and mass atrocity crimes.

One result of this work is this special section, where the authors of the collected papers dive deeply into the public health and mental health rights dilemmas that emerge from prevention efforts related to identity-based violence and mass atrocity crimes—including war crimes, crimes against humanity, and genocide.¹ The authors examine the ways in which we can adapt rights and health frameworks, methods, research, tools, and practice toward a more sophisticated and truly interdisciplinary understanding and application of atrocity prevention. In their totality, the papers demonstrate the state of these current fields and the intersecting themes within human rights, public health, mental health, and mass atrocity prevention and, importantly, future potential directions for next collaborative steps.

The protection and fulfillment of mental health rights is critically important within the larger principle of the right to health, yet it receives disparate attention within the biomedical model. As the editorial for *HHRJ*'s special section on mental health and human rights in 2020 stated, “there is no health without mental health, but there is no mental health without human rights.”² Discrimination, disempowerment, and social

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exclusion are driving factors in the deprivation of health rights and mass atrocity harms. Moreover, individuals with intellectual, cognitive, and psychosocial disabilities face additional exclusion and neglect within the biomedical approach to delivering health care services.

Similarly, as the human rights discourse encourages a shift in emphasis away from the biomedical approach of “treating” or “hospitalizing” the individual, a greater focus needs to be made on preventive approaches that promote the social determinants of mental health.³ Both the onset and extent of many mental health disorders are influenced by the psychosocial environment, and the risk for developing certain disorders is directly associated with social inequalities.⁴ Through understanding and addressing the interdependence and interrelatedness of rights, policy makers and health practitioners can take action to improve daily life across the life course. Relatedly, addressing the social, economic, and physical environments that can improve mental health and well-being can assist in the prevention of mass atrocity and the reconciliation of disputing parties. Given that all three fields paradigmatically emphasize and understand the dynamics of preventing harms, ample room exists to adapt these frameworks for prevention (for example, practitioners, tools, programs, and institutions) to the emerging and still largely nascent atrocity prevention field.

Global discussions on mental health and health governance will be vital to address the necessary policy framing and delivery of services to meet the crisis of mental health, as identified by Tedros Adhanom Ghebreyesus, director-general of the World Health Organization.⁵ Decades of neglect and underinvestment in addressing public health, and specifically mental health, has left significant vulnerabilities to trauma and adversity, which can perpetuate cycles of atrocity. The global COVID-19 pandemic has exposed these vulnerabilities and exacerbated the shortage of adequate mental health treatment that existed long before the pandemic. As inequities in the distribution of vaccines are laid bare, so will the access to adequate mental health

services for those left behind in the wake of an uneven, inadequate global pandemic response.

Fulfilling the rights to health and mental health also is compounded by atrocity and violent conflict. In the midst of identity-based violence and mass atrocity, the need for public and mental health care becomes greater, and the ability to implement services is even more complex. Yet efforts to create, disseminate, and implement public and mental health care are further compromised in these conditions. Resources are usually scarce, infrastructure is often decimated, and vulnerable target groups face discrimination and marginalization in accessing care. In complex conflict and atrocity settings, individuals and communities face traumatic harms that need immediate short-term and ongoing long-term care. These conditions make the realization of the right to health—and especially the right to mental health—all the more crucial.

One important aspect that this special section considers is that, when addressing health harms at the population level—including intentional violence and trauma—public health, mental health, and human rights tools and frameworks lend themselves naturally to assist in the prevention of war crimes, crimes against humanity, and genocide. The concurrence of these fields, and the potential for innovation and next practices at their intersections, however, remains understudied and undertheorized. With a few important exceptions, the public health field has focused largely on preventing physical disease, addressing interpersonal violence, and responding to humanitarian disasters or crises once they occur or in their immediate aftermath. Similarly, the field of mental health, which has focused largely on the promotion, protection, and restoration of the cognitive, behavioral, emotional, and social well-being of individuals and communities, offers important frames and tools in both the primary prevention of violence and trauma and the healing of individuals and communities in the wake of mass atrocity to promote coping and resilience, while working toward sustainable peace and the prevention of recurrence of mass violence.

Mass atrocity prevention may be viewed at dif-

ferent points along a cyclical, dynamic continuum: prevention in pre-conflict and pre-atrocity settings, including by addressing legacies of trauma; prevention in conflict and atrocity settings; and prevention postconflict, post-atrocity contexts addressing the aftermath of atrocity crimes to prevent backsliding into atrocity and to promote healing and long-term peace. Ideally, identifying human rights violations as risk factors and accelerants allows for primary prevention of large-scale violence when opportunities for prevention are higher in number and lower in cost and risk, but efforts to address rights violations mid- and postconflict also may be leveraged to prevent further harm to individuals and targeted populations. The risk factors that set societies on a path toward, and impede recovery from, atrocity crimes include issues related to governance, conflict and atrocity histories, economic conditions, and social fragmentation—factors that straddle layers of social and contextual analysis and are often drawn along identity lines. Thus, by necessity, the field of mass atrocity prevention is interdisciplinary, requiring civil society and government cooperation at local, national, and international levels for immediate and long-term success.

In pre-conflict, pre-atrocity settings, the authors of the articles that follow identify how longstanding deprivations of rights and unaddressed legacies of trauma can lead to community strife and the potential for future identity-based violence, as well as serve as sources of agency with violent armed groups that can address needs for survival. In conflict and atrocity contexts, the authors illustrate ways in which assessments of legal obligations of various actors can create opportunities for access to public health and mental health services by protecting individuals as well as health care systems themselves. In postconflict, post-atrocity settings, the authors demonstrate how the recognition of human rights protections can provide safety, security, and dignity to all members of a community and create opportunities for trust, reconciliation, and long-term, lasting peace in the wake of conflict and atrocity crimes.

Pre-conflict, pre-atrocity settings, including addressing legacies of trauma

In “Disrupting Legacies of Trauma: Interdisciplinary Interventions for Health and Human Rights,” Joan Simalchik applies Ignacio Martín Baró’s theory of psychosocial trauma to elucidate the public and mental health challenges of long-term post-atrocity, transitional states. In particular, the paper explores how organized violence, institutional lies, and social polarization create and maintain “circles of silence” that perpetuate health harms. The author concludes with a call for interdisciplinary and community-led efforts to construct “circles of support” that address the social context and the injury to social relations, and may allow individuals and communities to heal.

In “Safeguarding the Lives of Children Affected by Boko Haram: Application of the SAFE Model of Child Protection to a Rights-Based Situation Analysis,” Rosie O’Connor, Theresa S. Betancourt, and Ngozi V. Enelamah explore child protection as a human right within a human security framework. In particular, they probe the security of Nigerian children within the context of and in relation to four core domains: safety and freedom from harm; access to basic physiological needs and health care (including mental health); family and connection to others; and education and economic security. Their theoretical analysis frames the risk and resilience factors contributing to youth involvement in the Nigerian conflict, identifies the gendered dynamics of those factors, and highlights areas for state and humanitarian actors to appeal to these youth and their needs while reducing subsequent vulnerabilities.

Conflict and atrocity settings

In “The Right to Mental Health in Yemen: A Distressed and Ignored Foundation for Peace,” Waleed Alhariri, Amanda McNally, and Sarah Knuckey explain the lack of adequate mental health care in Yemen and analyze how this is contributing to the recurrence of violence in the country. Their article advocates for the creation of a system of mental

health care that is efficacious, sustainable, and accessible because, they argue, future peace in Yemen depends on the provision of such mental health services.

In “Monitoring Attacks on Health Care as a Basis to Facilitate Accountability for Human Rights Violations,” Benjamin Mason Meier, Hannah Rice, and Shashika Bandara examine attacks on health care systems in times of conflict as violations of international human rights and humanitarian law, as well as threats to public health. Examining systematic monitoring mechanisms developed by the World Health Organization to prevent, protect, and provide accountability for health worker harms, the article recommends refining the monitoring mechanism to strengthen accountability and public health protection through global health governance.

In the Viewpoint “Addressing the Boko Haram-Induced Mental Health Burden in Nigeria,” Adewale Olusola Adeboye describes the burdens that the Nigerian conflict has placed on public and mental health facilities and providers, individuals, and communities, as well as the deliberate efforts that have been taken to address victims’ needs in the absence of a coordinated government response. The paper concludes with a call to expedite the passage of a robust national public mental health policy toward the full realization of mental health rights.

Postconflict, post-atrocity settings

In “Quantifying the Ripple Effects of Civil War: How Armed Conflict is Associated with More Severe Violence in the Home,” Jocelyn Kelly, Elizabeth Colantuoni, Courtland Robinson, and Michele R. Decker demonstrate the linkages between armed conflict and gender-based violence using quantitative methods to make visible the hidden architectures of violence and atrocity crimes continuing long past mass violence and conflict. The purpose of their research is to recognize these fundamental human rights violations in order to prevent future harms, and especially to disrupt the pathways between political and interpersonal

violence in postconflict and post-atrocity contexts.

In “Teaching Truth in Transitional Justice: A Collaborative Approach to Supporting Colombian Educators,” Gabriel Velez focuses on the value of critical and thoughtful teaching to promote acknowledgment and accountability after human rights abuses, in an effort to foster the psychosocial healing of subsequent generations. The author details a research collaboration with Colombia’s truth commission to aid its pedagogical efforts to develop effective resources and support Colombian educators’ instruction about the truth of past atrocities.

Finally, in “Societal Healing in Rwanda: Toward a Multisystemic Framework for Mental Health, Social Cohesion, and Sustainable Livelihoods among Survivors and Perpetrators of the Genocide Against the Tutsi” Alexandros Lordos, Myria Ioannou, Eugène Rutembesa, Stefani Christoforou, Eleni Anastasiou, and Thröstur Björgvinsson discuss the strengths and limitations of the current mental health system and other initiatives—including sociotherapy, transdiagnostic mental health care, and collaborative livelihood projects—in a post-atrocity society recovering from human rights abuses, where mental health outcomes have been, and continue to be, significantly impacted by these acts of genocide. Building on existing innovations, and in partnership with affected communities, they propose a scalable approach for recovery and resilience that would target mental health, social cohesion, and sustainable livelihoods within an integrated multilevel framework to reduce the risk of post-genocidal conflict, future human rights abuses, and atrocity crimes. The paper offers a multisystemic focus on health, human rights, and healing, with a focus on the social determinants of mental health, as a response to adversities that cut across layers of social analysis and place the onus for healing on societal-level factors to aid individual and community coping.

It is our hope that this collection will make significant and lasting contributions to the emerging field of atrocity prevention in both scholarship and practice while bringing additional perspectives to public health, mental health, and human rights scholarship and practice. We recognize the value

in the multidisciplinary nature of this project and see it as an opportunity for more cross-pollination among the fields of public and mental health, human rights, and atrocity prevention. The existing literature has not explored the intersections of public health and mental health frameworks and assessment tools in atrocity prevention in any comprehensive way, including in the contexts of early warning and response and of rights-based frameworks. Such discussions will serve to influence and innovate research, policy, and practices in these fields toward developing, adapting, and testing frames and tools for human rights and atrocity prevention. This critical work must be supported, and networks strengthened, toward our ultimate shared goals of preventing identity-based violence and promoting human rights, dignity, and equality for all.

References

1. An additional product of this deliberative process is our development of an edited volume, *Public Health, Mental Health, and Mass Atrocity Prevention*, which focuses on understanding and examining the inextricable linkages among public health, mental health, and mass atrocity prevention theory and practice while encouraging collaboration and innovation within and across the multiple disciplines working in these fields. Specifically, the multidisciplinary volume (1) connects concepts of public health, mental health, and mass atrocity prevention by framing and reframing strategies, as well as synthesizing the concepts at the macro level that intersect the fields of public health, mental health, mass violence, and mass atrocity prevention; and (2) addresses various models and interventions, as well as documentation and data collection, to prevent identity-based harms and improve responses to health care workers and others, including police officers, who are on the frontlines of atrocity prevention practice.
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Disrupting Legacies of Trauma: Interdisciplinary Interventions for Health and Human Rights

JOAN SIMALCHIK

Abstract

The devastation caused by war and atrocity extends beyond the battlefield and creates conditions with severe public health consequences in affected societies. The infliction of socially organized mass violence and the suppression of reporting of harms has an impact on multiple levels: the individual, the familial, and the social. Ignacio Martín Baró, a Jesuit priest and social psychologist, explored the impact of psychosocial trauma while living and dying in the 1980–1992 Salvadoran civil war. His depiction of the multilevel impact of atrocity provides insight into the connection between health and human rights. This article discusses how his analysis of the constituent parts of psychosocial trauma continues to hold relevance for understanding the legacy of historical events and points to possibilities for mitigating health harm in various contemporary contexts.

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Introduction

No part of the world has been spared the experience of mass atrocity in the last century, and the early decades of the current one are continuing the trend. Following periods of intense mass violence, some regions have transitioned to democracy with varying degrees of success. Prolonged exposure to repression, organized violence, and war, however, have produced cultures of fear that present psychosocial obstacles to the establishment of good governance, healthy populations, and a human rights culture. How does the process of democratization frame power relations within a context of contested memory and meaning? How can the psychosocial consequences of mass atrocity be understood? How can they be mitigated?

If, as Sandra Bloom posits, “the twentieth century has become known as the Century of Megadeath,” there have also been attempts to codify and address its traumatic effects.¹ “A traumatic event is a shocking, frightening, or dangerous experience that can affect someone emotionally and physically.”² The duration of one’s reaction may be acute, chronic, or complex. Ignacio Martín Baró’s theory is significant in that it address both how individuals and the societies in which they live are harmed by traumatic events.

Speaking to the impact of violence beyond the battlefield, Devon Hinton and Alexander Hinton’s *Genocide and Mass Violence: Memory, Symptom, and Recovery* highlights “expressions and meaning of distress that are culturally specific.” The authors state clearly that “psychological and somatic manifestations will vary and so, diagnosis and understanding must also vary.” They then go on to explain that “trauma persists as a memory, forgetting and remembering affect the physical and social bodies and that through this process recovery can also begin.”³ Each of these threads supplements Martín Baró’s theory, and its general application applies to other relevant traumatic contexts.

Andreas Hamburger, Camellia Hancheva, and Vamik Volkan’s *Social Trauma: An Interdisciplinary Textbook* provides a “bridging concept” for a multifaceted approach to post collective vio-

lence interventions.⁴ The methodology is intended to collapse the distance between clinical, social, and cultural remedies. Additionally, Karin Carrington and Susan Griffin’s *Transforming Terror: Remembering the Soul of the World* takes a similar approach, arguing for an interdisciplinary understanding of trauma that incorporates spiritual and cultural perspectives.⁵

Lisa Butler, Filomena Critelli, and Janice Carello’s *Trauma and Human Rights: Integrating Approaches to Address Human Suffering* emphasizes the importance of context and recontextualization.⁶ Their text offers an important intersectional examination of how race, gender, sexuality, age, health, and immigration status impact the experience of trauma. The concept is essential when constructing appropriate interventions in the aftermath of atrocity and demonstrates how and why essentialism should be avoided.

Taking into account the differences in the experience of trauma, others speak to the distinction by concentrating on specific case studies. Inger Agger and Soren Jensen’s *Trauma and Healing under State Terrorism* analyzes the specific trauma treatment developed by politically engaged health professionals working under the Pinochet dictatorship in Chile.⁷ The treatments they devised and delivered clandestinely were relevant for those persecuted in their shared understanding of the root of the terror. Al Fuertes’s *Community-based Warviews, Resiliency and Healing: The Internally Displaced Persons in Mindanao and the Karen Refugees on the Thai Burmese Border* supplies nuanced contextual framings of community backgrounds and explains how, with support, communities are capable of defining their own experiences and shepherding their own healing.⁸ Erica James’s *Democratic Insecurities: Violence, Trauma, and Intervention in Haiti* cites the specific obstacles, including chronic instability, that prevented the provision of assistance to women survivors during and after the country’s 1991 coup d’état.⁹

This particular set of contemporary theories recognizes and underscores the interdisciplinary nature of trauma. Many highlight the roles that

anthropology, history, political science, medical and public health, law, art, and religion can play in a psychosocial framing of trauma and its possible amelioration. They point to the relationship between the social context of the traumatic event and the psychological impact on individuals and the wider community. Most importantly, they underscore the importance of social context by considering the experience, practice, and direction of the affected communities themselves.

Martín Baró developed an earlier iteration of this concept under conditions of war and repression in El Salvador. His theory of psychosocial trauma and destruction provides insight into how systems of organized violence impact individuals, their families, their communities, and their health. He signifies three elements inherent to the creation and endurance of psychosocial trauma: (1) organized violence, (2) institutionalized lies, and (3) social polarization.¹⁰ All three serve as constituent elements that reinforce one another. When organized, systemic and institutional violence is practiced and then denied by the perpetrators, social schisms are created, and social polarization is intensified.¹¹ Under state terror, human rights crimes are inflicted but never acknowledged. During periods of democratic transitions, unless this problem is addressed, there remains a danger of leaving psychosocial trauma unabated.

Martín Baró describes how consequences of mass violence and atrocity create “circles of silence” that can persist past the violence itself.¹² Interrelated factors, personal, cultural, and social, can determine how persecuted individuals, their families and communities, and the wider society each constitute a closed circle that perpetuates denial. Circles of silence enclose the victims who have been rendered as the “other,” often without recourse to justice; the families who seek to protect; bystanders who fear repercussions; and the perpetrators who conceal the crimes. Each is entangled in interconnected webs that require propitiation.

This article discusses both the psychosocial consequences of “circles of silence” and the interventions that hold the possibility of creating

“circles of support” as potential antidotes to circles of silence. These circles of support may create opportunities to mediate traumatic effects on the intersecting levels of private and public pain. Disrupting traumatic legacies and breaking the silences require intercessions for and from individuals, families, communities, and the state, as well as an interdisciplinary understanding of health and human rights.¹³

Health, human rights, and the social consequence of global atrocity

In contemporary times, civilians have always been casualties of war or disregarded as “collateral damage.” During the 20th and 21st centuries, however, an increased erasure of boundaries between combatants and civilians became evident.¹⁴ “In the more than 100 civil wars between 1989 and 2010, nearly 50 percent of governments and 60 percent of rebel groups targeted civilians with severe forms of violence—massacring them, deliberately bombarding residential areas, burning homes and crops, or forcibly expelling people *en masse* from particular territories.”¹⁵ Historically, civilians have always been injured when in the line of fire, but in modern versions of conflict, civilians increasingly have been deliberately targeted or used as human shields to mask movements of armed forces.¹⁶

International responses to atrocities have ranged from outright condemnation to the creation of new policy initiatives for both prevention and harm reduction. In regions where access to health care is limited or nonexistent, the Universal Declaration of Human Rights’ article 25 guarantees the right to “medical care and necessary social services.”¹⁷ This right, however, has been proven inadequate in perception, development, and implementation. Senior scholar Leonard Rubenstein laments this lapse when conceptualizing care:

Yet even as the human rights community employed international humanitarian law in its work, it largely ignored the right to health in situations of political and armed conflict. This neglect extended beyond war, to situations of political volatility and

*violence, where international humanitarian law does not apply. In part, this neglect was a product of the general lack of attention to the power of the right to health to advance human well-being.*¹⁸

The post-World War II international rights machinery created unintended separations between the various rights agendas.¹⁹ While the right to health is affirmed as one of the 30 articles of the Universal Declaration of Human Rights, as Rubenstein maintains, “the right to health in situations of political and armed conflict” often remains unrecognized. If the right to health in these contexts is overlooked as a distinct right, then the role that public health can play is hindered.

Still, the concept of health, and that of its abrogation, is embedded in additional United Nations (UN) conventions that hold the potential to strengthen the nexus between health and human rights. In the aftermath of World War II and the recognition of the mass horror of the Holocaust, the UN Convention on the Prevention and Punishment of the Crime of Genocide was unanimously adopted in 1948 and included important language citing the infliction of serious mental harm. Although the final definition was limited by multistate negotiation of the term, the notion that the infliction of mental harm constituted an act of genocide remained.²⁰ In 1987, the UN Convention against Torture went further and included a provision for “full rehabilitation” for those so victimized.²¹ Yet the chasm between established international mechanisms and their implementation on the ground can be difficult to traverse.

One casualty of the disconnect between the right to health and human rights claims is the often inadequate response, even for the temporary provision of immediate care, to incidents of organized violence. During the 2019–2020 eruptions of mass public protests in Chile, for example, police fired anti-riot shotguns into crowds that resulted in thousands of eye lacerations, fractured bones, and other injuries with little medical help available to meet these emergencies.²² With public clinics and hospitals understaffed to meet crisis care on this scale, volunteer health professionals stepped in to provide cursory emergency medical attention

amid the protests. This provisional support was frequently disrupted when the Carabineros, the national police force, directly attacked the makeshift but vital relief stations. A dialectical understanding of how the right to health is inextricably linked to human rights extends beyond service provision to the notion of prevention of health harms. The right to receive adequate health care is superseded only by the right not to be victimized. When human rights claims are met with violent suppression, individual and public health is undermined. Seen as an intrinsic right and not only as a by-product resulting from war and atrocity, the right to health can fundamentally be valued and, subsequently, be effective.

Outside of open warfare, the consequences of socially organized violence multiply when considering the ways in which dictatorships employ repressive measures against civilian populations. Examples of these types of human rights violations and crimes include imprisonment, torture, rape, and other sexualized violence and forced disappearance. These tactics are either executed alone or in concert, but all are devised to deter resistance against regimes that hold power through violence. When Amnesty International first started to document the “epidemic” prevalence of the practice of torture, the organization noted how human rights crimes were utilized as a means “to deter third parties” from challenging repressive systems.²³ Decades later, the evidence continues to confirm this assertion. Ezat Mossallanejed, senior policy director for the Canadian Centre for Victims of Torture, writes, “Torture should not be approached in isolation. It is part and parcel of a strategy of political repression ... in order to paralyze the whole population ... it acts as a sinister shortcut to maintaining power that has not been derived from the cross-section of the populace.”²⁴ Regimes that likely would not be democratically elected employ a continuum of repressive acts that also include threats against family members and fear of losing employment and status in the community. All of these repressive measures create cultures of fear and long-standing effects on individuals and the communities in which they live.²⁵

Psychosocial trauma, circles of silence, and circles of support

One of the ways in which we talk about the long-standing health impacts of violence on individuals is through the lens of trauma. In his thinking about the context of El Salvador, Martín Baró parses psychological trauma and social trauma from the more complex phenomenon of psychosocial trauma. In the first case, harm exists within the individual as a consequence of “difficult” and “exceptional” experience. In the second, whole populations may share a common historical experience of harm, though, of course, the exact experience of individuals is shaped by their personal history and unique social location, especially their role in the conflict. Psychosocial trauma is more complex in that the origin of harm is social, “not something within the individual.” To Martín Baró, “psychosocial trauma [implies the] crystallization in individuals of the social relations of war that are experienced in a country.”²⁶ In particular, social relations are organized to cause alienation and harm and, over time, become less and less malleable, further stagnating the possibility of change and healing.

In the context of long-term and systemic oppression, Martín Baró cites three primary ways in which social relations become polarized and calcified. First, the experience, or even the threat, of violence seeds an embodied fear that can be documented in observable physical symptoms, such as trembling or stomach upset. At the level of individuals, this fear encourages an ardent denial of facts in the interest of self-preservation. One may deny having been victimized despite evidence to the contrary (for example, bullet holes in property or burned fields) out of fear of retribution. Added to this, “campaigns of polarization” keep a country in a state of heightened “psychological tension:”

[F]acts are ideologized, people are demonized, and the use of those very political spaces that have begun to open is criminalized—all of which leads to an apparent stagnation of social confrontation and to greater difficulty in trying to establish spaces for interaction of the various social groups with respect to objectives they share.²⁷

Finally, an “official story” [is created] which ignores crucial aspects of reality, distorts others, and even falsifies or invents still others.” The official story is propagated by intense propaganda, and further protected, as those that hazard to contradict the new “facts” are considered “subversive.” Though terrorism may be supplanted by military order, many of the actors remain the same, and the “militarization of order” demands that any public activity first receive institutional approval, thus preventing those that would challenge the status quo from interacting.

To Martín Baró, the primary psychosocial harm that individuals experience under such circumstances is this “alienation of social relations.” The individual experiences the stress that such social polarization lodges within the physical body (somatization), and those who are most at risk for polarization are likely to incur greater somatic harm. The climate of fear and silence shrinks one’s social world, limiting the potential to have one’s reality validated, which “corresponds to a sense of insecurity about what one thinks and to skepticism regarding the various social and political options.” The tension between what one has experienced and the lack of social validation may cause added stress, exemplified in the felt experience of very social emotions such as guilt and diminished self-worth. Finally, the militarization of social thought, feeling, and behavior is propagated by socialization such that it eventually becomes normalized:

People who are formed in this context (learn to) assume an inherent contempt for human life, adhere to the law of the strongest (or the most violent) as a social criterion, and accept corruption as a lifestyle, thus precipitating a vicious circle what tends to perpetuate the war objectively as well as subjectively.²⁸

Martín Baró believed that under such circumstances, the original and continued harm to individuals can only truly be mitigated by first addressing the social context and the injury to social relations that otherwise will prevent the potential for sustained and widespread healing. Barring an approach that focuses on the social origin of trauma, and its

perpetuation by a stagnated and normalized social order, any treatment of the individual (including the utility of psychotherapy) would remain “at best incomplete.”

If a solution is possible, Martín Baró suggests that it is

necessary to begin an intensive effort to depolarize, demilitarize, and deideologize the country, in order to heal social relations and allow people to work out their history in a better kind of interpersonal context. Stated in positive terms, it is necessary to work toward establishing a new framework for coexistence, a new “social contract” that would allow collective interaction without turning disagreement into mutual negation. There is an urgent need to work toward a process of greater social sincerity, in order to learn about realities before defining them, to accept facts before interpreting them. Finally, an effort must be made to educate by reason, not by force, so that coexistence can be based on mutually complementary efforts employed to resolve problems, not on violence used to impose one’s own alternative.²⁹

This vision is foundational to the creation of what I call “circles of support.” Fundamentally, an environment must be made safe for individuals to share their experiences and to have that experience validated in the present, and it should be reflected in the building of the social order going forward. This process includes how the past is dealt with in the present and how it will be remembered. The challenge for the historian is to do this work without further alienating and harming the individuals involved, beyond what pain is necessary to heal. Thus, liberatory frames that allow the oppressed to design their own emancipation from previously imposed silences seem essential.

History, memory, and circles of silence

Beyond emergency health responses during conflict, war, or repression, the insufficiency of care extends to other areas of health concerns.³⁰ After the cessation of hostilities, physical and psychosocial complications remain. People who are scarred by physical and psychological torture, imprisonment, deprivation, and terror have a right to be

recognized and treated.³¹ In conditions of precarious transitions away from conflict and atrocity, however, delicate political compromise can forestall the establishment of a human rights agenda for long-term health needs. The task of collapsing the difference between public and private pain remains incomplete and difficult to surmount. Erna Paris entitled her study of postconflict, post-atrocity countries *Long Shadows: Truth, Lies and History* as a trenchant pronouncement on transition states. After an examination of contexts as varied as the antebellum United States, post-World War II Europe, the former Yugoslavia, and post-apartheid South Africa, Paris concludes that the prevention of national amnesia of cataclysmic events requires justice and accountability to move societies out of cycles of violence.³² Impunity for perpetrators of atrocity can eclipse calls for justice and a righting of accounts. If there is institutional state failure to admit past wrongs and their impact, then there can be no consequent acknowledgment expressed for its victims.

In states of amnesia, little can be accomplished to discern the tasks needed to advance reconciliation under the image of a half-imagined history. Reconciliation, in this sense, would require all actors to shape a collectively understood past to prevent a conflicted future. Schisms can remain, wounds can fester, and propensity for division and conflict can remain alive. If it is said that Irish people have a memory as long as a rainy week, then Canada can also claim a stormy history. Contemporary Quebec automobile license plates read “Je me souviens” (“I remember”), in a direct gesture to an ostensibly unreconciled past. The mnemonic recounts the 1759 Battle for Quebec, when the British and French Empires fought for control of North America. Over two centuries later, the Canadian francophone province remembers the historic defeat of France and subsequent subjugation under British domination. This memory has strong resonance and contributes to contemporary secession debates. History’s shadows perpetuate unresolved loss and pain.

Individuals bear war wounds, but, in cases of mass atrocity crimes, the ultimate target of violence

is the body politic. Regimes that cannot hold power through democratic means resort to systems of repression to seize and maintain power.³³ Nonstate actors often employ terror to establish and hold a geographical power base, as exemplified by the Islamic State.

Beyond the individual level, cultures and societies are transformed by the infliction of deliberate destabilizing senses of safety and security. Constructed cultures of fear do not evaporate without explicit endeavors to deconstruct and replace them with transparency and rule of law.³⁴ Traditional civic supports and familiar communal routines are eroded in times of war and repression, when powers usurp social protections.³⁵ Under dictatorships and in failed or repressive states, for example, the conventional notion that police are protectors of the rule of law is nullified when police become officially sanctioned perpetrators of violence and atrocity.³⁶

The situation is exacerbated when censorship clouds reality and prevents the transparent transmission of fact-based information. Official denial of repression contributes to the diminishing of individual and collective psychosocial health. Under conditions of socially inflicted mass violence, human rights violations and atrocity crimes are integral to sustaining repressive power, but authorities most often deny their occurrence. Few regimes, or nonstate actors, admit to committing atrocity crimes. This denial contradicts the lived reality of the populace who know family or neighbors who have been disappeared and know that torture is inflicted. The disconnect between the official story and lived experience further undermines individual and public well-being.

People who recognize their own experience cannot find validation or understanding of their victimhood in the wider community. Individuals looking forward to finding recognition in the transitional state instead can find that their experiences remain theirs alone. The dialectical impact of damage done to individuals resonates in the impact of damage to the social fabric.

Institutional lies and social polarization

In *Writings of a Liberation Psychology*, Martín Baró posits that institutional violence has deleterious consequences by shrouding its impact in circles of silence. Mutually reinforced and overlapping threads of trauma weave complex webs that prolong the effects of atrocity.

Atrocity crimes and violence are predicated on dividing communities into categories, separating groups into “us” and “them.” Here, the other is created, produced, and then denigrated to the point of dehumanization. Ethnic, class, gender, sexuality, religious, and political differences are purposefully intensified and inflamed. Historic grievances are recast to serve a contemporary political agenda. In different situations, the “other” may be described as “subversives” (Argentina) or “infidels” (Iran) or through further dehumanizing rhetoric, such as “cockroaches” (Rwanda). The schisms created are not easy to dismantle in the aftermath of war and repression. The resultant injuries may be borne by individuals, but these harms continue to wreak havoc on individuals as well as the *res publica* when official silence persists.

A notorious example of how social polarization operates is illustrated by the wars in the former Yugoslavia. Prior to the late-20th-century wars in the region, and before his presidency, Slobodan Milošević took advantage of the 600th anniversary of the Battle of Kosovo, when Serbs were brought under Ottoman rule, to exacerbate ethnic rivalry between Serbs and Muslims.³⁷ In a build-up to the 1989 anniversary, Milošević began a deliberate campaign that violated the tenuous ethnic equality pact (originally organized by the 1919 Treaty of Versailles) by provoking division among the country’s Southern Slavs. The 1389 Battle of Kosovo was used by Milošević in a “Serbian victimization narrative.”³⁸ Historic grievances were recast to serve a contemporary nationalist agenda.³⁹

In the unstable contexts of transitioning from conditions of organized violence to some form of democratic governance, political compromises mitigate against official corroboration of past injus-

tices. In Spain, between 1936 and 1939, an estimated 500,000 lives were lost, with approximately 135,000 more assassinated during the Franco dictatorship.⁴⁰ General Francisco Franco's death in 1975 allowed for a new political reality to develop that was not possible in his lifetime. In 1977, an amnesty law was promulgated that entrenched the Civil War's schisms. According to the law, prisoners of Franco's fascist regime were freed, but the regime would not be held accountable.⁴¹ The arrangement left little room for post-fascist governments to address the past. After the amnesty law's promulgation, there were no prosecutions for executions, torture, or disappearances of civilians. Mass graves remained hidden and undisturbed. No truth commission was permitted. Only recently, decades after the cessation of hostilities, and only after persistent pressure from victims' families, has the Spanish government begun undertaking exhumations in the more than 2,000 mass graves still being located in Spain.⁴² Bodies of disappeared prisoners are being located on behalf of grandchildren and great grandchildren who are finally able to identify and give proper burials to their relatives.

In another example of a circumscribed transition to democratic rule, Chile's 1991 Rettig Report (officially the National Commission for Truth and Reconciliation Report), was mandated to investigate only those violations that resulted in death and disappearance. It took another 13 years for the Valech Report to document the tens of thousands of torture cases incurred during the Pinochet dictatorship, and the report required two more iterations to account for even more cases of torture.⁴³ South Africa's Truth and Reconciliation Commission had an amnesty provision embedded directly into its own operational protocol.⁴⁴ Typically, in transitional contexts, "truth" is circumscribed by circumstances, with the consequences being that reconciliation is measured out in small enough doses designed to be sufficient to placate the populace, or at least a part of the populace.⁴⁵

Thus, victims suffer first the trauma of original harms, and second the retraumatization of transitional compromises aimed more at struc-

tural stability than individual and community well-being.

During transitions out of mass violence, provisions for health care, notably psychological services for victims, have been only sporadically established and are often inadequately funded. Memorial and commemorative practices are usually undertaken, even if grudgingly so.⁴⁶ Varying in degree from country to country is the establishment of public memorials, museums, officially sanctioned ephemera, sites of remembrance, and testimonial archives.⁴⁷ Yet, the perfunctory manner in which many of these memorials and commemorations are instituted tends to undermine a comprehensive reconciliatory purpose and frequently creates new schisms in the emergent culture. When he served as the Ford Foundation's director of the Andes and Southern Cone, Alexander Wilde witnessed the "waning will for expressive politics" by Chile's transition government toward memorials to the country's victims of the Pinochet dictatorship. In 1994, when the memorial to the persons disappeared during the military regime was inaugurated in Santiago's general cemetery during summer vacation, a sub-cabinet official was the highest-ranking representative of the new democratic government in attendance.⁴⁸

In precarious political terrains, a reluctance to provoke perpetrators ultimately subverts the constitution of fundamental human rights regimes and the prevention of backsliding into mass violence and atrocity crimes. "The waning will" to memorialize renders social divisions intact and helps obscure past atrocity for the larger society.

Advancing circles of support

When the lived experience of individuals is at odds with the official record or narrative, it undermines the creation of healthy, forward-looking societies and serves as a barrier to progress. What had been known surreptitiously about past human rights crimes might be reluctantly exposed, but not always officially championed by states following war and atrocity. Ambiguity can shroud truth

through covers of equivocation. Sola Sierra, who served as president of Chile's Association of Relatives of the Disappeared in the years after the end of the military dictatorship, cogently expressed the transitional dilemma of speaking "half-truths, lies, [and] two-faced attitudes," admitting that "no society can establish solid moral pillars under those conditions."⁴⁹ Efforts, such as truth commissions, that set out the facts of past atrocities can begin to counter the legacy of institutional lies and help the past emerge into the national consciousness.

New realities continue to emerge that require a precise reading of the evolving political and social spheres after the cessation of hostilities and violence. Moving out from underneath the *onus probandi* (burden of proof) of past atrocity crimes is a complex negotiation between what is deemed politically and legally possible at any given time under existing jurisprudence, and what can ultimately lead to accommodation with impunity. For Martín Baró, context is key to understanding this process. A complicating problem affecting the notion of context is that circumstances surrounding atrocity crimes are dynamic, active and forceful—not static. They change, even if imperceptibly. New realities continue to appear, and the cessation of hostilities and violence does not automatically resolve the problem of contested memory.

Simultaneously, different sectors of society that ascribe separate and distinct meanings to lived experience perceive contradictorily the contours of any given context. Deeply held impressions may not correspond with the unstable landscape, and how these experiences are employed and deployed can pose barriers to newly constructed social and political projects.⁵⁰ Within a particular demarcated zone, societies continue to be divided, and these segments may be differently impacted. While society as a whole has been reshaped by atrocities, the past does not affect everyone uniformly or mechanistically.⁵¹ Individuals assume different perspectives, with some choosing to forget what they know or what they experienced, and others starting to learn about the past only after official denial and censorship is lifted. Changing power dynamics dislocate the institutional practices of memory as well

as the conditions that create and undo political and personal relationships.

Awareness of these contextual changes is critical to the forging of new pathways and to discerning how those pathways will be set. Determining possibilities for justice and accountability requires a clear understanding of new political and social terrain for successful remedies to be achieved. It also requires an understanding of human agency in its varied iterations.

Raul Hilberg's influential trilogy of perpetrators, victims, and bystanders is a taxonomic framework that defines distinct participants and their roles in atrocity crimes.⁵² But this formula can enmesh individuals in essentialist classifications when the changing landscape is not recognized as a nuanced space. The delineation of any transitional justice project provides possibilities for the agency of individuals to be engaged. Victims who organize for justice, provide testimonial evidence for human rights crimes, and create commemorative practices utilize their historic roles as active proponents of human rights. Marianne Hirsch explains how individuals considered vulnerable "can open up a space of interconnection as well as a platform for responsiveness and resistance."⁵³ Efforts, both individual and collective, to transform traumatic experiences hold the capacity to transform social relations as well and enlarge the social space to be more receptive to human rights possibilities.

New political terrain established during political transitions exposes more relational divisions that can impede reconciliation or even possibilities for reconciliation. Barriers to transformation include the denial of human rights crimes by perpetrators who seek to escape punishment for their culpability. But beyond the perpetrator classification exists a dimension of accountability for all sectors. Holocaust and historical memory studies scholar Michael Rothberg provokes us to look more deeply into the complicated responsibilities among and between victims and bystanders along with those of perpetrators. In *The Implicated Subject: Beyond Victims and Perpetrators*, Rothberg claims that entanglements of persons living in conditions of extreme violence blur lines between categories,

with no one left exempt from conscious or unconscious accountability. Complicity with atrocity is understood as a continuum among all actors in antithesis of Hilberg's three-pronged rubric. Rothberg's formulation demands consideration from all sectors so that trauma, individual and collective, can be allayed. "It both draws attention to responsibilities for violence and injustice greater than most of us want to embrace and shifts questions of accountability from a discourse of guilt to a less legally and emotionally charged terrain of historical and political responsibility."⁵⁴ In this understanding of historic grievances, the legacies of atrocity crimes implicate future generations to take action against denial of complicity and to accept responsibility. This can then preclude the diffusion of intergenerational trauma by expanding social engagement and creating accountability, if not reconciliation, beyond the present.

Rothberg posits that "[s]ocially constituted ignorance and denial are essential components of implication; as such they are also potential starting points for those who want to transform implication and reconfigure it as the basis for a differentiated long-distance solidarity."⁵⁵ Implicated subjects, and even their descendants, can transcend their confined roles by breaking through denial and acknowledging a more profound reading of social divisions. Rather than exchanging one role for another—perpetrator to victim, for instance—all individuals would be obligated to realize the complex multiplicity of culpability. Viewing histories with a nuanced perspective opens possibilities beyond a facile "black and white" reading. Failure to perceive, to admit, to act, for whatever reason, changes little and can keep in place cycles of violence.

Neglecting to dislodge the traumatic sequelae of atrocity condemns the past to remain as an open wound. Analyzing how context, power, and agency intersect can inform the forging of transitional possibilities toward healthy societies. Prioritizing analyses of context and power should not obscure the importance of human agency in the transition process. The ability of individuals and collectives to act is an essential element that can be at times

discounted by the political powers of the day.

For the forging of strong democratic relations, processes committed to genuine reconciliation are required. A rush to foreclose the brutal past by preemptively demarcating the present may inadvertently impede opportunities for the (re)inclusion of victimized individuals into a society from which they were forcefully ejected. Despite demonstrated resilience and agency, survivors are too frequently rendered inconsequential. Even more, they can be seen as unwelcome reminders of past horrors who threaten to end social denial.

For example, Helen Bamber was a young social worker in Bergen Belsen after the liberation of the Nazi concentration camps. She recalled how Holocaust survivors were first met with shock and sympathy, but as time wore on they were recast as displaced persons. Few countries were prepared to accept them. Survivors were unwanted by their original homelands and not able or willing to return to them. Well into the 1950s, Bamber recalled, "[Survivors] changed from being creatures for compassion to being irritating people—displaced persons who had nowhere to go."⁵⁶ They became embodied reminders of a genocidal past whose experience was not openly welcomed in postwar societies.

Similar treatment exists today for other survivors of genocide also deemed to be inconvenient for the politics of the present. A quarter of a century after the massacre of Srebrenica, where more than 8,000 Muslim Bosnians were murdered, thousands of survivors continue to live in refugee shelters set up as temporary facilities. Many more thousands are still internally displaced from their hometowns. Uprooted, unemployed, and depressed, families have seen their lives held in abeyance for generations.⁵⁷ Psychologists observe high levels of posttraumatic stress disorder not only in the original victims but also now in their children and grandchildren.⁵⁸ Avdo Hrustanovic, a second-generation survivor, grew up in these precarious conditions. He ruefully observed, "Every July, journalists go to Srebrenica for the anniversary of the genocide, but no one comes to Jezevac to see how the survivors of that genocide live now."⁵⁹ The living

have been expunged, not only from the past but also from the present. As embodied evidence of atrocity, they deserve the right to health, but their position on the margins of memory prevents its delivery.

In the state of official denial of atrocity pasts, there is often an innate desire to distance history and eclipse atrocity so that memory may be subsumed by the present. But remembrance of the past endures in new iterations of context. Trauma induced by repression can continue unabated unless the circles of silence can be transformed into “circles of support.”

One step to address institutional lies, organized violence, and social polarization is the pursuit of justice. Inherent in forging new social relations is the desire, by those victimized, for justice to be implemented and impunity to be ended for perpetrators.⁶⁰ If justice cannot altogether heal, acknowledgment of injustice restores notions of individual and collective security, especially for those whose rights have been violated. State interventions with criminal trials for human rights crimes establish official repudiation of past repression and can ease survivor suffering and allay intergenerational trauma. Given the multilayered dimension of psychosocial trauma, interventions on this scale, including human rights trials, can be seen as working on multiple levels beyond the institutional.

Psychiatrist and scholar Judith Stern’s *The Eichmann Trial and Its Influence on Psychiatry and Psychology* describes the crucial role that this trial played in recasting Holocaust survivors from silent victims to active witnesses in the promulgation of justice. Nazi officer Otto Adolf Eichmann was a major organizer of the Holocaust who was responsible for organizing the logistics of mass death. Following World War II, he fled to Argentina when, in 1960, Israeli agents captured him and brought him to Jerusalem. Indicted on 15 criminal charges, he was tried in a televised trial, convicted, and executed in 1962. The trial was much publicized and punctured the silence surrounding the Holocaust and those who survived it. Nearly 100 survivors provided first-person testimonies that formed much of the evidence against Eichmann. Prior to the trial, a “collusion of silence,” between health

providers, society at large, and Holocaust survivors existed for those not prepared to comprehend Holocaust experiences.⁶¹ The trial, however, offered the ability to provide a contextual understanding of the circumstances; there was a rationale for speaking, a meaning made of the atrocity, and an opportunity, at last, for society to witness survivor experiences.

“The Eichmann trial permitted the opening up of survivors’ experiences in public. Legal procedure enabled the witnesses to speak about what they had hidden until then. The judge’s presence gave legitimacy and power to the accusations, transforming the survivors from outlaws to partners in justice.”⁶² Stern details how intersecting levels of private and public pain were revealed as legal processes influenced health outcomes. Indeed, she outlines how more appropriate professional trauma informed therapy developed side by side with the social awakening to the lived realities of survivors. Similar processes of testimonial evidence were undertaken in Chile, Cambodia, and South Africa, among others.⁶³

The Eichmann trial punctured the circles of silence surrounding the Holocaust on multiple levels, both in Israel and internationally. On an individual level, survivors were given the opportunity to use their agency to testify about their traumatic experiences. Families and later descendants were able to amplify survivors’ voices. Society, in general and institutionally, was able to validate the experience and transform its traumatic impact by making meaning of the past. And as Stern documents, one important result was the mitigation of trauma, both individual and collective.

The outcomes of formal trials for perpetrators of human rights crimes are not uniform. Justice remedies that focus entirely on the legal aspect are insufficient as agents to meet the complex mental and public health needs of societies. While they may hold the propensity to precipitate a wider social response, courts alone are insufficient in this regard.

Alexander Hinton provides a salient example of how overreliance on legal remedies can limit comprehensive approaches to human rights development. In 2006, the Khmer Rouge Tribunal was convened to prosecute the senior members of Pol

Pot's genocidal regime in Cambodia (1975–1979). Hinton's *The Justice Façade: Trials of Transition in Cambodia* is a sharp critique of instances where legal mechanisms fail to address the private dimension of pain.⁶⁴ Hinton argues that the tribunal was merely a “justice façade” that left unreconciled the divide between the formal legal proceedings and the social and cultural context of the country. He particularly suggests that attention must be paid to the inclusion of the “survivors’ voice,” which should be intrinsic to any human rights intervention. He cites the work performed by civil society actors who were able to render the court proceedings into terms that fit the cultural and religious meaning of the community.

Contrasted with the Eichmann trial, where the legal mechanism provoked the need for specialized health and counseling for survivors, in Chile the treatment offered to persecuted persons created legal evidence for the indictment of General Pinochet on an international warrant.⁶⁵ During his 18-year rule, Chile became notorious for the infliction of torture, imprisonment, and disappearances. The Chilean testimonial model of treatment stressed the significance of survivors’ narration of the traumatic event as a historical record.⁶⁶ The testimony was intended to make meaning of the experience and become a useful device for human rights complaints to international bodies. The documents were archived by human rights organizations, and teams of health and legal professionals worked along with historians and archivists facilitating the agency of survivors.

Another instance of historical reclamation took place in Peru, where a nongovernmental organization, REDINFA, constructed a collective history of trauma following the country’s decade of violence in the 1980s. Organized from the grassroots, its mission was to produce a more detailed accompaniment to the 2001 National Truth and Reconciliation Commission:

The central feature of the program was the development of community historical memory, an exercise that we thought would acknowledge the value of individual and collective experiences. This led us to carefully collect their testimonies, mitigate

*their pain, and support their emotional recovery, while at the same time opening the path toward dignity, a symbolic form of compensation. In this way, the development of historical memory went beyond the mere historical reconstruction of what was experienced and became a space for expression, acknowledgement of individual and collective capacities, resources and learning, for the joint and consensual construction of a different future for the participants.*⁶⁷

Beyond “the symbolic form of compensation,” the testimonies brought individual experience into a collective framing of how traumatic experiences could be understood and mitigated for individuals and the wider society.

The replacement of circles of silence with intentionally constructed circles of support has effectively addressed psychosocial traumas in more recent times. For example, psychologist and scholar M. Brinton Lykes is a founder of the Ignacio Martín Baró Fund, which supports community-based projects in global contexts. The fund has supported psychosocial community workshops, including those with Mayan women in Guatemala and with children survivors of war in the Philippines.⁶⁸ Based in the United States, the fund has a dual purpose: to assist the process of healthy community development after atrocity and to “infuse historical and academic knowledge with voices and action ‘on the ground.’”⁶⁹

Repercussions of mass atrocity are global and extend past the borderlands of the affected geographical area. The creation of refugees is one example of how this operates. The Rohingya people who fled repressive onslaughts in Myanmar in 2016 have since been living in insecure refugee camps in Bangladesh. Both countries deny responsibility for them, and poor conditions have been exacerbated by COVID-19. Due to the pandemic, UNICEF has been forced to close schools for 460,000 Rohingya refugee children and, with a reduction of available camp workers, other services have also been reduced.⁷⁰ The right to health, in this context, is stymied by the opacity of responsibility (and thus agency) in such cases.

In another part of the world, refugees fleeing the Syrian conflict are being forcibly pushed out

of countries. While Turkey encourages would-be asylum seekers to enter Greece, Greece is expelling them into the Mediterranean Sea.⁷¹ Other European countries in proximity to escape routes are closing their borders. The United Nations High Commissioner for Refugees has commended Italy for being the exception in keeping its ports open through the pandemic and urges others to do the same.⁷² The United States under the Trump administration reduced the numbers of refugees it was willing to accept to an all-time low.⁷³ When nations retreat from obligations embedded in international human rights conventions, severe public health consequences arise. Refugee fatigue is compounded by fear of illness, which creates even more obstacles to finding safe havens. When viewed in this light, people who have been victimized can be reduced to a sum of their victimization without any connection to the systemic oppression that created the conditions for flight.

Conclusion

Writing the commentary “Wresting with the Angels of History” in *Genocide and Mass Violence: Memory, Symptom, and Recovery*, Laurence Kirmayer identifies how whole populations face global atrocities. He posits:

*[T]he remainders of violence can be seen at the levels of body, self, and society. The responses at each level have their own dynamics, involving physiological, psychological, and social processes that range from the intimate sphere of family systems to the wider arenas of neighborhood, community, nation, and the international networks of global society. These systems are deeply interconnected and we need interdisciplinary perspectives to trace the effects up and down these levels.*⁷⁴

Over the past century, understandings of the nature of trauma and its impact have continued to develop. Ignacio Martín Baró’s theory of psychosocial trauma and destruction, with its emphasis on the relationship between context, individual, and social well-being, is foundational to contemporary theory. He explains how trauma can be understood as having multiple impacts on individuals, families,

and society and how, without intervention, circles of silence will continue to prevent recovery at each level. Pertinent for present and future work is the dynamic quality contained in his writing. He offers no rigid formula to follow but instead provides a theoretical model that requires a critical inquiry for each instance. An analysis of historical and existent cultural conditions and power relations will influence the creation of appropriate trauma care for the individual, familial, and social spheres.

Establishing foundations to build healthy societies following atrocity can be accomplished with greater international cooperation and recognition of the power of interdisciplinary engagement. Legal, health, humanitarian, philosophical, social, artistic, and political fields all hold the possibility to contribute to rupturing Martín Baró’s circles of silence and to construct circles of support as antidotes. Rothberg’s implicated subjects provide yet another type of opportunity to provide relief. The entanglements of those existing within and outside of global atrocity charge us to recognize how we all bear accountability for the creation of atrocity and, equally, for its amelioration and prevention.

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Safeguarding the Lives of Children Affected by Boko Haram: Application of the SAFE Model of Child Protection to a Rights-Based Situation Analysis

ROSIE O'CONNOR, THERESA S. BETANCOURT, AND NGOZI V. ENELAMAH

Abstract

The Boko Haram insurgency in northeast Nigeria is responsible for the highest number of lives lost in Africa in the past decade. The country has witnessed significant violations of the United Nations Convention on the Rights of the Child, which Nigeria has signed and ratified. For instance, Nigeria had the second-highest number of children recruited to armed groups and the third-highest number of abductions in 2018. Current humanitarian efforts primarily target camps for internally displaced persons, while state strategies focus mainly on addressing security through combatant-targeted interventions. However, there is a need for more rights-based, integrated, and multifaceted approaches to tackle the interrelated threats to the security of children and their families affected by the conflict. This paper uses the SAFE model of child protection—which examines the interrelatedness of safety, access, family, and education and economic security—to analyze the challenges of children and youth affected by the conflict. We highlight the need for a gendered approach; strategies that address poverty and cultural and governance barriers; and interdisciplinary, context-specific, and autonomous child protection systems. The paper calls for urgent and increased attention to the core rights and human security needs of these children to avoid a replay of negative outcomes of conflict, where the costs and consequences propagate a cycle of violence and disadvantage.

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Introduction

Compared with other nations, Nigeria has the world's fifth-highest death toll due to armed conflict, primarily from the activities of the Boko Haram insurgency, with casualties exceeding those of past major incidents in Africa (namely Rwanda and the Democratic Republic of Congo).¹ Over 2.4 million people have been displaced in Nigeria's affected regions.² Externalities from the conflict include food insecurity, disease outbreaks, forced migration, loss of business, and loss of infrastructure. In particular, the ongoing situation with Boko Haram in northeast Nigeria, which inflicts harm on civilians and renders women and children especially vulnerable, calls for a human security strategy to ensure safety and promote well-being while the active conflict awaits resolution. Humanitarian efforts focus primarily on internally displaced persons, and state-led interventions address security concerns through combatant-targeted strategies, to the neglect of the human rights of the broader civilian population.³ There is a need for more rights-based, comprehensive strategies targeting interrelated threats to the security of affected children in particular.

Over the last decade, the number of children living in conflict zones worldwide has increased by 74%, to over one billion.⁴ In 2018, Nigeria had the second-highest number of children (1,947; 1,596 boys and 351 girls) recruited for roles in the conflict.⁵ Nigeria also recorded the third-highest number of abductions in 2018.⁶ By 2017, Boko Haram had recruited approximately 8,000 children.⁷ Multiple instances of grave violations against children have been reported, including death, maiming, rape, other sexual violence, detention, and attacks on schools and hospitals.⁸ Further, while many children are harmed by Boko Haram, others have been detained by the country's security forces due to their parents' association with Boko Haram.⁹

Not surprisingly, nonstate actors often do not comply with the minimum standards stipulated for the protection of children in humanitarian settings. Further, there is a low level of coordinated response in general to ensure the protection of these children.¹⁰ Nigeria, as with many conflict-affected

countries, suffers from a disjointed and weak child protection structure and a dearth of evidence-based interventions, begging for systems that are responsive to the human rights threats facing children in the country.

The SAFE model of child protection is a human rights- and human security-based framework that examines the interrelatedness of safety, access, family, and education and economic security to understand individuals through a holistic, resilience-focused, person-in-environment lens. This paper uses the SAFE framework to analyze the risk and resilience factors contributing to youth involvement in the Nigerian conflict, as well as the gendered dynamics of those factors. Our analysis highlights how young people are particularly vulnerable to rights violations by various actors within the conflict. As applied, the model also identifies areas for state and humanitarian actors to brainstorm harm reduction approaches or approaches that appeal to these youth and their needs while reducing subsequent vulnerability. The analysis that follows suggests an urgent call to attend to the core rights and human security needs of these children in order to avoid perpetuating disadvantage and propagating cycles of violence. We conclude the paper with some suggestions for gender-specific community-based interventions and more macro-level countrywide infrastructure implementation.

Human security and child protection

The past few decades have seen a shift in the conceptualization and implementation of security and child protection toward a more holistic, person-centered approach that recognizes the interrelated nature of child rights and the individual, relational, communal, and structural societal systems required to actualize them. With the evolution of international conflict, significant vulnerabilities have been identified in the traditional approach to ensuring the security and protection of children. The field requires adaptation to meet the emerging understanding of contributing factors to peace, security, and child well-being.

Historically, the traditional framework of security in the face of external threats relied on states for the protection of their population. However, given that over 90% of current conflicts worldwide are internal as opposed to between states, this framework has become less relevant.¹¹ In addition, the assumption that the state can bear the responsibility of protecting its population is flawed when states suffer instability, may be the perpetrators of violence themselves, or may be ignorant or contemptuous of international humanitarian law. Even in the most stable of states, attempts to address the needs and rights of vulnerable populations are often disjointed and isolated.¹²

To accommodate these gaps, in the 1990s the United Nations Development Programme developed a *human* security framework, which shifted to a more people-centered focus and defined two main aspects of security: “safety from chronic threats” and “protection from sudden and hurtful disruptions in the patterns of daily life.”¹³ The human security perspective creates space for this evolving context of conflict, as well as for a more nuanced analysis of how the dynamics of conflict impact specific populations. In addition, the human security approach emphasizes proactive strategies, including conflict prevention and peace building, as opposed to relying mainly on humanitarian response.¹⁴

Within the child protection framework, there is lingering evidence of the more traditional approach to security and some progress toward integrating a more human-security lens. The Alliance for Child Protection in Humanitarian Action enumerates the minimum standards for child protection in conflict, describing child protection as the “prevention of and response to abuse, neglect, exploitation and violence against children.”¹⁵ Child protection efforts face challenges in the best of settings, and those challenges are further compounded in conflict.¹⁶ Too often, child protection program implementation is top-down in approach and overlooks community strengths and potential.¹⁷ Child protection responses can quickly assume colonial undertones and may propagate label-driven approaches targeted at vulnerable children such

as orphans, survivors of sex trafficking, or child soldiers.¹⁸ Such approaches miss opportunities to invest in long-term systems strengthening and solutions grounded in the autonomy and agency of those most impacted. Furthermore, they often develop siloed interventions that overlook the larger current and historical contributing factors. In humanitarian settings, limited resources and high levels of complex insecurity only compound these challenges.

To address gaps in the human security-based approach to child protection, the UNICEF Child Protection Strategic Plan initiated a shift from a prevention and response framework to a “survive and thrive” framework.¹⁹ Grounded in the right of self-determination and the right to participation codified in the International Covenant on Civil and Political Rights and the Convention on the Rights of the Child (CRC), respectively, this framework focuses on those who are most impacted and has the potential to tap into local problem solving.²⁰ The “survive and thrive” approach also more fully integrates an ecosystems model, where the individual is understood as being influenced and impacted by their ecological system on three primary levels: micro (for example, family and interpersonal relationships), mezzo (for example, group relationships such as school or religious communities), and macro (for example, attitudes and beliefs implicitly held in the wider culture and structural or governmental systems). This holistic view of the intersections between human security and child protection is required for sustainable structural change that can support conflict-affected young people.

While the integrated and ecologically informed approaches to human security and child protection have significant support at a theoretical level, it is still challenging to implement these practices in conflict settings. The SAFE model serves as a concrete tool to help integrate a holistic, strengths-focused, ecosystems lens of human security into a child protection analysis.

SAFE model

The SAFE model of child protection draws from

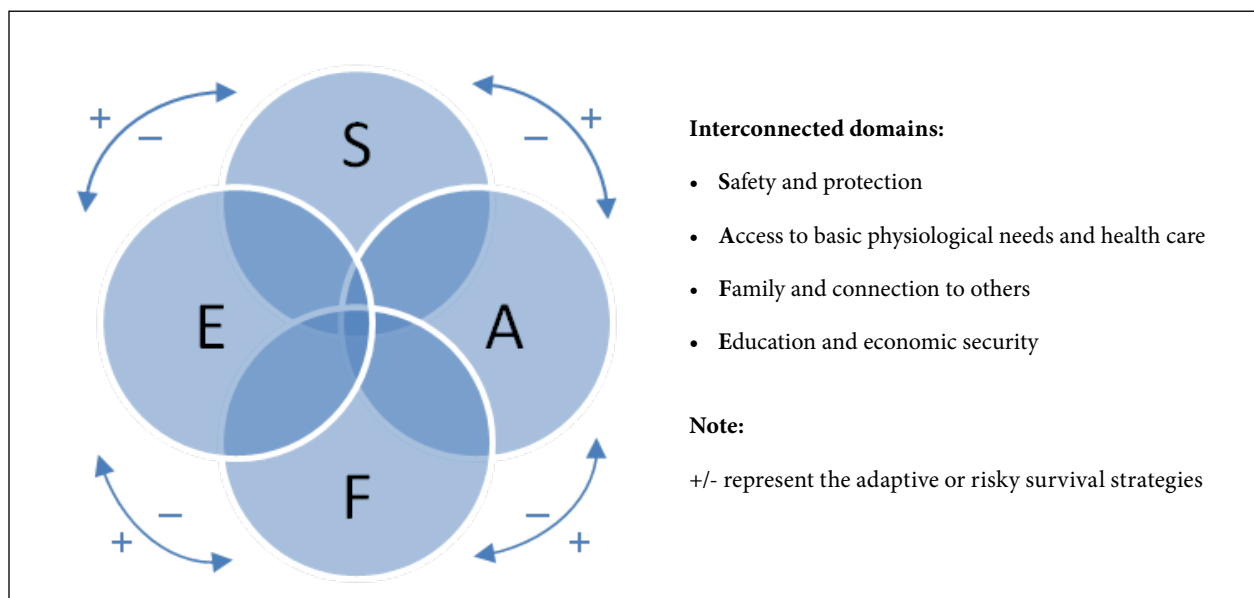
both human security and human rights frameworks to foster a more person- and rights-centered analysis for children affected by conflict.²¹ The CRC recognizes “the need to extend particular care to the child.”²² Guided by the principles of nondiscrimination, the best interests of the child, survival and development, and participation and inclusion, the CRC enumerates 52 articles protecting the social, political, cultural, and economic rights of children.²³ Signatories have a responsibility to protect children’s rights, including the right to life, survival, and development (art. 6), the right to an adequate standard of living (art. 27), the right to health care (art. 24), the protection of the family unit (art. 9), and the right to education (art. 28).²⁴ The person-centered and interdisciplinary SAFE model integrates these rights into its four core domains. The model recognizes the interdependency of human security, human rights, public health, and mental health in its focus on the individual and community experience within conflict situations.²⁵ The framework acknowledges survival strategies that youth and families employ in response to security threats and helps contextualize the way the ecosystem supports or detracts from stability in these domains. Such analysis can help advance a strengths-based approach, wherein risky survival

strategies are identified as opportunities for more adaptive and positive manifestations of agency to promote more resilient outcomes for individuals and families.²⁶

The SAFE model argues that children’s security should be considered in the context of and in relation to other core dimensions of rights and well-being by examining the interplay between four core domains of children’s lives: safety and freedom from harm; access to basic physiological needs and health care (including mental health); family and connection to others; and education and economic security (Figure 1).²⁷ In line with the CRC, the SAFE model examines the evolving capacities of the child, underscoring the importance of the family when the child is young and transitioning toward an emphasis on the child’s capacities as they mature. The SAFE model highlights the interdependency of the system, as strength in any one domain can buffer insecurity in others. The model also posits that insecurity in any core dimension necessitates the adoption of survival strategies that may take adaptive and more dangerous forms and have cascading effects on other dimensions of children’s lives.

The holistic nature of the model helps contextualize the individual in their environment and validate the survival strategies that children and

FIGURE 1. SAFE model



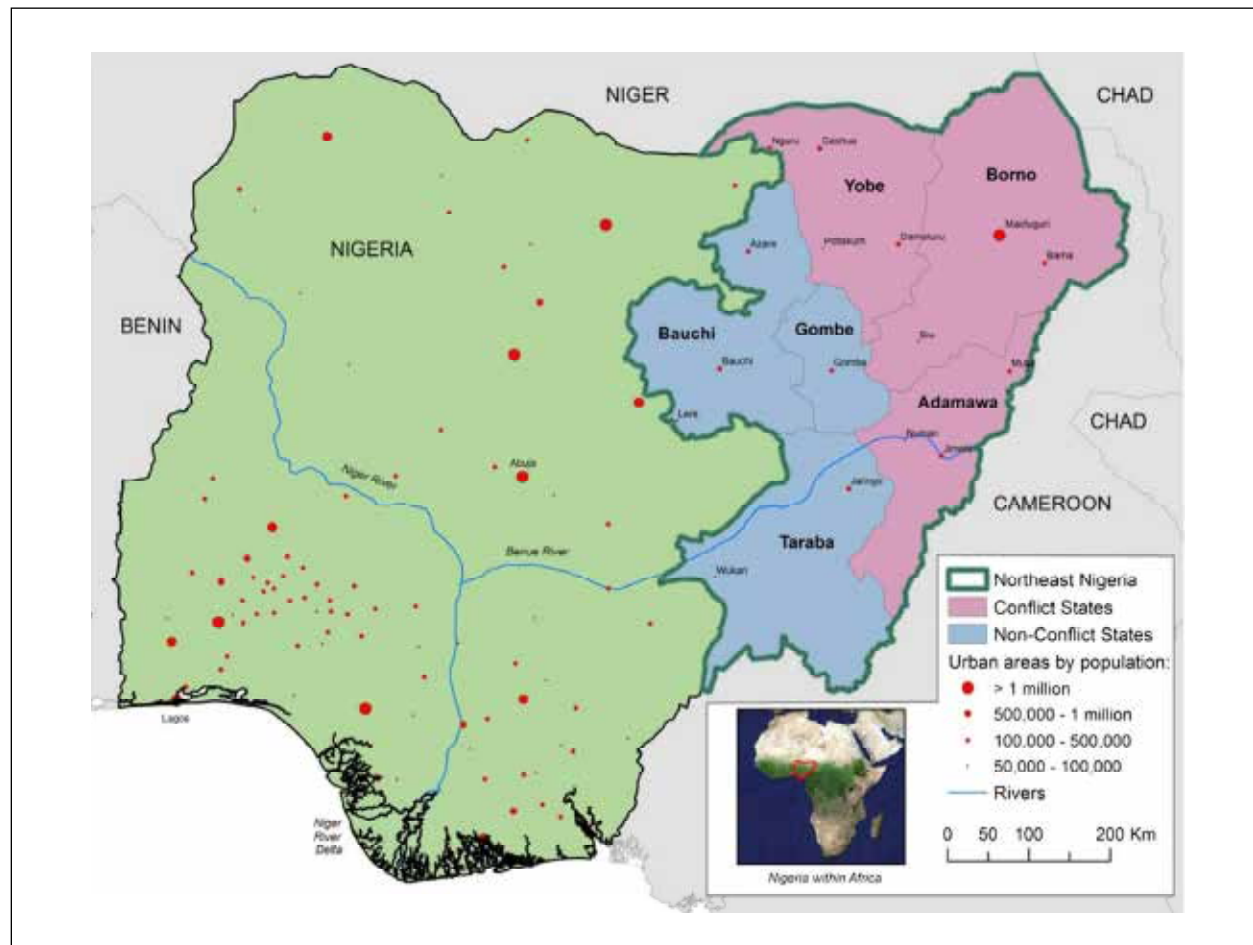
families adopt to meet their needs. Unlike a purely medical model of aid to families, the SAFE model appeals to psychosocial well-being by highlighting the importance of relationships, attachment, and connection to a larger community. The SAFE framework helps affected individuals and humanitarian workers conceptualize individuals facing adversity in the context of their dynamic, multifaceted environment. It focuses on the capacities and resources within the ecosystem to highlight solutions to challenges and to serve as a platform for more sustainable, community-centered responses. In recognizing agency within constrained choices, SAFE refocuses analysis away from “problem” individuals and instead looks at how systems can better protect rights and meet needs as afforded by international human rights law.

Northeast Nigeria and the Boko Haram conflict

The conflict in northeast Nigeria has resulted in ongoing violence, displacement, death, and hardship for over a decade.²⁸ While most of northern Nigeria has experienced bombing attacks, three states in the northeast border area—Borno, Adamawa, and Yobe (collectively known as the BAY states)—have been the most impacted by the conflict (Figure 2).²⁹ Increased violent disruptions resulted in a declaration of a state of emergency in the BAY states in 2009.³⁰ While government forces work to contain the power and violence of Boko Haram, the group continues to regularly target civilians and humanitarian assets, including as recently as April 2021.³¹

Since the militarization of Boko Haram

FIGURE 2. Conflict-affected areas in Nigeria



Source: G. Dunn, “The impact of the Boko Haram insurgency in Northeast Nigeria on childhood wasting: A double-difference study,” *Conflict and Health* 13 (2018)

around 2009, over 35,000 individuals have been killed, with civilians making up nearly half of the death toll.³² Between 2009 and 2014, Boko Haram was associated with 42% of deaths from the violence in Nigeria.³³ Violence ramped up in 2011 with the bombing of the United Nations compound in Abuja, and peaked in 2014–2015, with over 20,000 Boko Haram-related deaths.³⁴ In addition, over 2.4 million people in the region have been displaced.³⁵

Applying the SAFE model to the impact of the Boko Haram conflict on children

A SAFE model analysis helps identify risk and resilience factors within the ecosystem to reinforce organic community interventions that strengthen the well-being of children and highlight opportunities for external intervention. The SAFE model assists in unpacking the choices of youth who engage with Boko Haram and in exploring harm reduction interventions. While affiliation with Boko Haram present risks to the youth, the association may also be a survival strategy to meet basic needs, including stability and protection amid the conflict.³⁶

This analysis demonstrates how the four basic dimensions of the SAFE model are undermined by

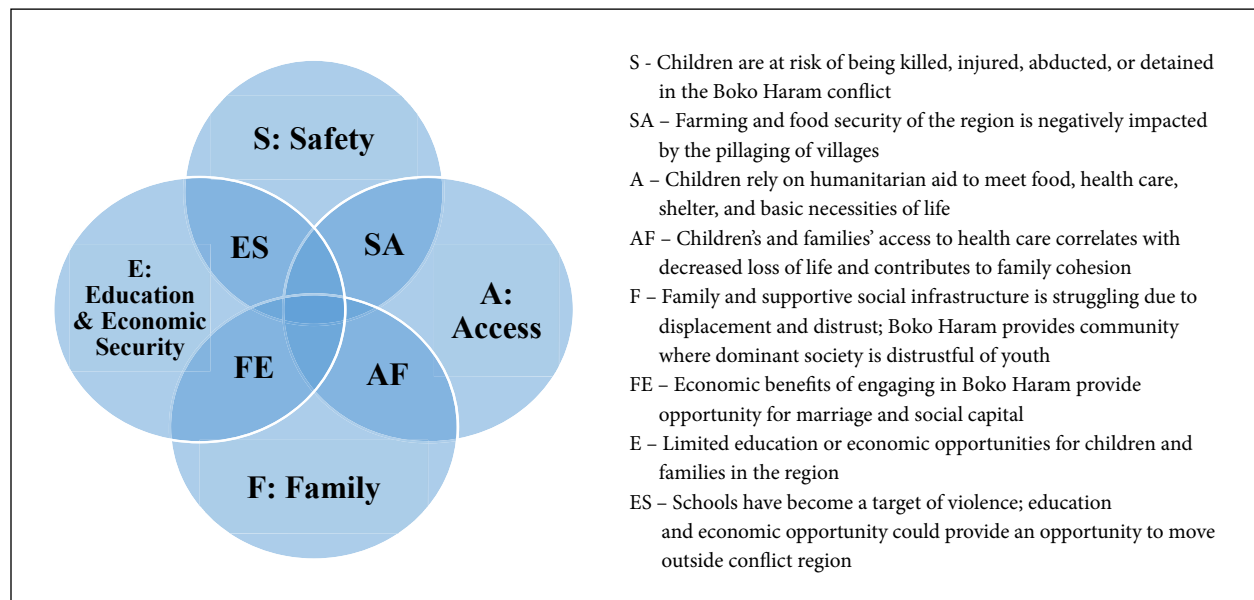
the conflict and may serve as push factors to joining Boko Haram. The examples and evidence that follow highlight the interdependence of the domains of the SAFE model, the cascading the interrelated sequelae of child outcomes in the face of conflict, and the gendered sources of risk and resilience (Figure 3). The analysis demonstrates a need for targeted systems-based approaches to strengthen prevention and protection initiatives.

Dimension 1: Safety, protection, and freedom from harm

Safety from violence-related injury and death.

Within northeast Nigeria, there have been widespread safety and protection concerns from the near-constant violence that affects the daily lives of individuals.³⁷ Resolution 1261 of the United Nations Security Council identifies six grave violations against children in conflict zones: killing and maiming, sexual violence, abduction and forced displacement, recruitment and use of children in armed conflict, targeting of schools and hospitals, and denial of humanitarian access.³⁸ Recent reports verified 5,741 grave violations against children in northeast Nigeria between January 2017 and December 2019.³⁹ The majority of these violations (3,170) were perpetrated by Boko Haram, with the

FIGURE 3. The SAFE model of threats to child protection in the Boko Haram conflict.



remainder attributed to state or state-backed forces.⁴⁰ Boko Haram has deliberately engaged in these grave violations through the intentional targeting of youth and consistent attacks on schools.⁴¹ In 2017 alone, Boko Haram used 146 children, mainly girls, as human bombs.⁴² In a context of pervasive violence, youth may join Boko Haram for the protection the group may offer.

Safety from abduction and recruitment. Due to the prevalence of child recruitment by Boko Haram, youth in northeast Nigeria are particularly vulnerable to the dual challenges of being targets for recruitment and stigmatized by their community for suspected affiliation with the armed group.⁴³ The CRC identifies the importance of family to children's well-being and development and the need to protect children from separation from their parents except in cases of abuse or neglect.⁴⁴ Armed groups' use and recruitment of children act as a twofold weapons, exacting violence on the youth themselves and on the community ethos by threatening family and community stability. Subsequently, unknown youth are viewed as suspicious by the community and state forces, reinforcing their isolation and vulnerability for recruitment.⁴⁵ While some youth make the strategic choice to join Boko Haram, many are kidnapped and forcibly conscripted. A kidnapped young woman refused a marriage to a member of Boko Haram and was flogged 100 times as a punishment.⁴⁶ She acquiesced to a later proposal to become a suicide bomber and was subsequently rewarded with regular food and better living conditions.⁴⁷ While this example highlights the complexities of agency and choice when engaging with Boko Haram, it also illustrates how the realms of safety and access are inseparable in these conflict situations. While engaging with the group does increase the risk of exposure to violence, it also can decrease the risk of imminent death. When youth engage and identify with Boko Haram, the group offers temporary security that the government has failed to assure. In addition, while this choice may place them in the line of further peril, the temporary security becomes a basis for connection.

Safety from the mental health consequences of witnessing or perpetrating violence. In armed conflict settings, experiencing, witnessing, or being forced to commit acts of violence has long-term debilitating effects on the mental and overall well-being and development of children.⁴⁸ International human rights and humanitarian law codify the protection of children from witnessing, experiencing, and being used as actors in violent conflict through numerous provisions, including article 19 of the CRC, which protects children from "all forms of physical or mental violence."⁴⁹ Applying concepts from social disorganization theory helps contextualize joining Boko Haram as a natural response to unmet social needs.⁵⁰ Often applied to gang involvement in the United States, the theory posits that where youth are excluded from conventional socialization opportunities, their natural response is to form peer groups with "antisocial" (not in alignment with the dominant social acceptance) tendencies.⁵¹ In this context, affected youth retain few conventional social opportunities due to disruptions to infrastructure and the latent suspicion of youth mentioned above. Furthermore, for adolescent youth, peers are the primary socialization force, so membership in Boko Haram proffers social opportunities, group identity, and belonging. Youth often report that gang membership fills some unmet needs, such as protection, money, and companionship.⁵² Membership in Boko Haram may also provide a buffer, albeit temporary, to the impact of violence through the socialization and normalization of its witness and perpetration. Furthermore, a common coping mechanism with severe childhood abuse and trauma is the perpetuation of violence and abuse onto others.⁵³ While membership may increase exposure to violence, the sense of belonging that membership affords may be incentive enough, particularly in a context of pervasive violence.

Dimension 2: Access to health care and basic physiological needs for youth in northeast Nigeria

Shelter and housing. Shelter is a basic right and need that is integral to children's feelings of safe-

ty and their capacity to thrive psychosocially.⁵⁴ In spite of over 10 years of humanitarian aid in northeast Nigeria, an estimated two million children still need shelter in the region.⁵⁵ The guerrilla tactics utilized in this conflict—which include the virtual destruction and occupation of captured villages—disproportionately impact civilians. In one three-day attack in 2015, satellite imagery showed that Boko Haram burned 57% of a village and its structures.⁵⁶ Using arson in this way, Boko Haram has destroyed shelters and cut off food, water, and power supplies, shifting the burden to humanitarian aid to fulfill these needs. In 2018, a weekly average of 4,500 individuals, primarily women and children, arrived at overcrowded and under-resourced camps.⁵⁷

For adolescent girls, the situation has gendered implications. While Boko Haram is sometimes dismissed as discriminatory against women, young women report various benefits to marriage within Boko Haram, including greater levels of safety, security, and independence than those found in normative culture.⁵⁸ For example, a young wife in Boko Haram relished “all the things he had gotten me for our house. A big family size bed, a chair, cupboard and utensils, clothes.”⁵⁹ Young and adolescent girls who have married combatants have also attested to enjoying increased financial stability and autonomy.⁶⁰ These extravagances may provide incentives to associate with the group, presenting a path for economic opportunity. In this way, Boko Haram capitalizes on the state’s failure to protect certain rights. Given that Boko Haram appears to offer some empowerment and agency to both sexes that is not as accessible in mainstream society, there is ripe opportunity for gendered harm reduction interventions.

Access to food and nourishment. Child protection is about ensuring the conditions necessary to promote healthy development, including access to food and water. Consistent access to such conditions enables the exploration of secondary psychosocial needs. In the conflict region, many youth struggle to meet their nutritional needs, and Boko Haram is capitalizing on this food insecurity to ingratiate

youth and build dependency. Although estimates of food insecurity have improved in the BAY states in recent years—from 3.7 million people in need in November 2017 to 2.7 million in August 2019—many are still dependent on humanitarian assistance for their food and cooking fuel needs.⁶¹ In October 2019, UNICEF treated over 10,000 severely malnourished children and over 35,000 moderately malnourished children in northeast Nigeria.⁶² The true extent of the problem is likely greater, as this count includes only those resilient enough to travel to outpatient programs. Due to security risks, health professionals face significant challenges accessing the fragile areas, where more than 823,000 individuals are estimated to experience extremely high levels of nutritional and health needs.⁶³ Boko Haram appeals to these survival needs to recruit children and youth. For example, while in initial recruitment, a child may have limited food; but once they adopt the group’s ideology, they begin receiving regular meals, as well as meat stew on Fridays.⁶⁴ Recognizing how Boko Haram exploits the nutritional needs of youth presents an opportunity for interventions focusing on safer ways to meet these needs.

Access to health care and vulnerability to disease. Densely populated areas such as camps for internally displaced persons are plagued by limited access to clean water, sanitation, and hygiene infrastructure. Overcrowding and other conditions lead to increased risk of waterborne diseases, as evidenced by the 2018 cholera outbreak in the BAY states.⁶⁵ A 2021 *Humanitarian Needs Overview* estimates that 5.8 million people need health care in the BAY states.⁶⁶ While the International Covenant on Economic, Social and Cultural Rights recognizes the rights of all people to attain necessary medical services and attention when sick, access to health care in the BAY states has decreased significantly due to insecurity and violence.⁶⁷ Boko Haram and other nonstate armed groups explicitly target health care infrastructure.⁶⁸ In March 2021, 35.4% of the health facilities in the BAY states were damaged, nonfunctional, or only partially functional.⁶⁹ There were 10 verified attacks on hospitals in 2018.⁷⁰ Despite the

substantial efforts of the Nigerian government and humanitarian assistance organizations, health and safety concerns abound. In March 2021, a group of female victims of sexual violence with immediate health needs were denied access to shelter and medical treatment at a registered camp for internally displaced persons due to capacity issues.⁷¹ While there is no evidence to suggest that membership in Boko Haram buffers the insecurity of access to health care, there also is no evidence to suggest that membership diminishes access to care or presents an increased risk of vulnerability to disease.

Dimension 3: Family and connection to others

Loss of connection. A significant factor in the well-being of children is the support of the proximal family unit. The right to family is enumerated throughout human rights law, including in the International Covenant on Civil and Political Rights, which recognizes “family as the natural and fundamental group.”⁷² The CRC further stipulates that children should not be removed from their parents except in cases of abuse.⁷³ Of the over 6,000 children in the Child Protection in Emergencies program within the BAY states, 92% were separated from their families as a result of the conflict.⁷⁴ Overall, there are over 32,000 unaccompanied and at-risk youth in the BAY region.⁷⁵ These numbers underscore the ethos of impermanence challenging children’s ability to foster secure attachments and meaningful community relationships.⁷⁶

Damage to the buffering ecology of proximal care. In ongoing conflict, the existence of positive family and community supports is an integral part young people’s management of impending threats. While many families may foster resiliency in the face of a conflict, a multitude of factors may contribute to a breakdown in familial support. With ongoing insecurity in the SAFE domains, there is a high likelihood that caregivers are experiencing additional stress. Children living with their parents are likely to be impacted by an increase in their parents’ conflict-related stress.⁷⁷ Parental stress may serve as a protective or risk factor, depending on how children experience that stress. An overpro-

TECTIVE parent, for example, may provide a buffer and less opportunity to engage with Boko Haram. However, by the same logic, an overprotective parent may also limit other pro-social peer relationships that could serve as protective factors.

Breakdown of community trust, connection, and efficacy. Reports indicate that communities in northeast Nigeria have defaulted to a state of distrust and fear. One civilian speaking with the Center for Civilians in Conflict stated:

*No one knows for sure who the enemy is. Boko Haram will attack the people, and leave. Then the military will come, and also arrest people. When the people try to cooperate with the military, Boko Haram will attack them again. Now the military thinks [some] civilians are Boko Haram. Civilians think some military are Boko Haram ... We really don't know who the enemy is now.*⁷⁸

In this state of distrust, youth are perceived as particularly suspect since Boko Haram uses young people for peer recruitment and as human bombs.⁷⁹ In 2018, state forces detained 418 youth due to their parents’ alleged association with Boko Haram, and the majority of these youth were in detention for over two years.⁸⁰ While Boko Haram is violating the right to freedom from exploitation, recruitment, and conscription afforded in the CRC, the local government is also violating the rights of these youth through policing and unlawful detention.⁸¹ Detaining youth can cause further harm to their socialization, development, and growth in ways that impact their ability to thrive later in life. The limited social opportunities available to youth in the region may elevate the appeal of Boko Haram, as the youth may be resigned to not being socially accepted elsewhere.⁸² The context of distrust, fear, and impermanence present challenges to young people’s ability to foster strong pro-social peer connections that are integral to identity development.

An alternative community in Boko Haram?

Engaging in Boko Haram can provide youth with a comparatively stable sense of community, since membership in armed groups can be perceived as

a protective buffer against the threat of violence.⁸³ As mentioned in earlier, social disorganization theory helps contextualize adolescents' choice to engage in illicit group activity as a natural response to the combination of systematic exclusion from more traditional community systems and the developmentally appropriate shift to peers as the defining factor for one's self-concept.⁸⁴ For boys in particular, Boko Haram may provide opportunities for the social capital, power, family, and community needed to fulfill the patriarchal expectations that are difficult to attain in the current civilian infrastructure.⁸⁵ Boko Haram is a semistructured organization that offers identity as a "soldier," as well as structured upward mobility with opportunities to become a "commander." Often, children are targeted for recruitment precisely for their malleability and impressionability.⁸⁶ Boys are quick to adopt this new social identity and to self-categorize as "soldier" because of their re-socialization within the group.⁸⁷ With these identity development shifts, armed groups often manipulate the trauma of past and current violence to reinforce the in-group/out-group dynamic and solidify the sense of belonging and group identity.⁸⁸ While these factors likely contribute to the sense of community offered by Boko Haram, the group also addresses more tangible Nigerian cultural, financial, and social expectations to ingratiate the youth.⁸⁹

Dimension 4: Education and economic security for youth in northeast Nigeria

Education risks. There are several challenges facing youth in northeast Nigeria in the realm of education and economic security. An estimated 52% of school-aged youth in the region have never attended school.⁹⁰ As of 2021, the majority of schools in the BAY states have had some closure, with many still closed or reappropriated for other humanitarian needs.⁹¹ Without a school environment, youth do not have the same opportunities to develop peer socialization skills or the education skills that support future stability.

Schools have been targeted during this conflict, in violation of international humanitarian law. In 2018 alone, the United Nations documented

15 attacks on schools and hospitals, noting at least four schools that have been used for military purposes.⁹² Because of these attacks, kidnapping, and the general threat of violence, many schools in the region are closed.

As of March 2021, 60% of schools in Borno state remained closed, and an estimated 1.3 million individuals, 97% of whom are children, were in need of education-in-emergencies support.⁹³ The translation of the name Boko Haram, "Western education is a sin," is a guiding ethos of the group and challenges the overall concept of formalized education—and subsequently children's right to education in the region.

Family, economy, and education. The community faces ongoing challenges in evaluating the relative risk and protective factors that are associated with education in the region. Nigeria as a whole is challenged with low levels of primary education, with 36% of females and 27% of males in Nigeria having no education.⁹⁴ However, the urban-rural divide is significant, and northeast Nigeria has the country's lowest levels of education, with 57% of women and 47% of men reporting no primary education.⁹⁵ Further, according to a recent evaluation of education in the region, parents cite cost as the single most important barrier to enrolling or maintaining their children's education.⁹⁶ The connection between poverty and education highlights the utility of the ecosystem lens of SAFE. By understanding the familial and community experience, the SAFE model contextualizes decisions around children's education. While the child protection sector identifies education as a primary goal, the community may have historically prioritized more basic survival needs. The SAFE model analysis highlights this as an opportunity for interventions directed at the community to address the economic and educational perspective of caregivers.

With little infrastructure, near constant physical insecurity, and limited industry, there are few viable paths toward economic security for youth in northeast Nigeria. These economic challenges impact the other realms of SAFE—namely, access to security and family connection. Because of the

conflict, families have abandoned or lost access to their farms and livelihood and are dependent on humanitarian aid.⁹⁷ As noted by a young girl from Borno, "If the government gives food, then we get food."⁹⁸ Education, trade, agriculture, and fishing industries are all precarious due to the violence, leaving little opportunity within the regional infrastructure for skilled or nonskilled employment for youth or caregivers.⁹⁹

Boko Haram as provider. In the current economic drought, many young men struggle to obtain the dowry required for marriage. Boko Haram helps facilitate marriages for its members.¹⁰⁰ Young girls in Boko Haram also report that marriage affords them more favorable treatment and community status than dominant Nigerian society does, including having servants, receiving their dowry personally, and receiving care from their husbands.¹⁰¹ As wives in Boko Haram, some young women have power and authority unparalleled to life outside the group. One 14-year-old girl who was kidnapped and married off to a commander reflected, "After I became a commander's wife, I had freedom ... All the Boko Haram men used to respect me ... I felt like a queen in a palace."¹⁰² Living with Boko Haram seems to provide a kind of economic stability through attacking and pillaging from others. In late 2019, the group conducted repeated attacks on villages, looting livestock, money, and other valuables.¹⁰³ It would appear that Boko Haram's community has clear roles, expectations, and possibilities for the future that provide an appeal beyond existing culture.

The benefits that Boko Haram provides are most saliently identified in testimony from deradicalization groups. A humanitarian worker speaking about the young women in deradicalization programs noted, "They felt that they were a chosen group. They had lived in relative luxury in the forest ... and really felt that there was nothing we could offer them."¹⁰⁴ Indeed, rehabilitation programs struggle with recidivism, as youth released back to their communities generally return to a space with little opportunity, no money, and no livelihoods. Reintegration is especially difficult after experienc-

ing the contrast of status and power within Boko Haram.¹⁰⁵ While rehabilitation programs attempt to include employment and training, insecurity in the region continues to seed the larger systemic challenges that require a more coordinated state effort, including a breakdown in infrastructure and industry.

Conclusion

While the rights enumerated in the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, and the CRC are aspirational, the SAFE model uses those rights to provide a framework to highlight where there are opportunities to affirm the well-being of and reduce the risk to children in complex conflict environments. While much of this analysis has focused on the individual and community level, the conclusions range from a targeted identification of specific areas for gendered interventions to broad recommendations for systemic change at the government level in Nigeria.

Gendered analysis

The gender-specific application of the SAFE model clarifies how Boko Haram targets and appeals to young women differently than young men. Counter to the narrative that Boko Haram brutally victimizes girls, some girls point to the fact that Boko Haram gives them more agency than dominant society, especially in realms of family, community, and economic independence. Identifying this benefit to women's and girls' membership in Boko Haram provides an opportunity for developing harm reduction approaches that address these specific factors. Next steps may include engaging and supporting communities to learn more about how Boko Haram meets the needs of young women and how these needs can be addressed within the community of origin. While this analysis highlights points in the system for reinforcement, the entire framework is based on interventions rooted in the community and individual needs. Thus, it would be important to allow discovery to unfold within the community around the needs and interventions.

Multiple community perspectives are necessary, particularly from young women formerly involved with Boko Haram, their family members, and community leaders. Some initial questions might include the following: What are community beliefs around the reason young women join Boko Haram? Are increased agency and economic independence in fact pull factors for women, or perhaps simply secondary benefits? Would more agency or economic independence in their home community have shifted the choices of women who joined? Where would the community be open to giving women more agency or economic opportunity? For women who do not join Boko Haram, what are their thoughts and rationales?

Similarly, the perception of community and family that Boko Haram offers young men—in contrast to the systematic exclusion and distrust that pervades in dominant culture—provides another gender-specific opportunity for intervention. Not only does Boko Haram appeal to the peer socialization of male adolescence, but the group has also instituted long-term, structured social capital and economic security in its familial framework, again highlighting the interdependency of these realms. Similar to above, the first step would require community conversations with different parties to understand the dynamic ecosystem and the beliefs, values, and interests of different parties. Possible questions to ask the impacted community in developing an intervention might include the following: What would need to happen to decrease the ethos of suspicion around young men in the region? Are there spaces for adolescent boys to engage in pro-social activities in the community without suspicion? How are more pro-socially oriented adolescent boys spending their time? How are individuals, families, and communities supporting one another and maintaining community in spite of displacement and disruption?

Using the SAFE model to apply a gender-specific analysis is likely to foster additional insights like the ones above onto the gendered child protection needs of youth in conflict regions.

Macro level

Poverty, culture, and governance. The SAFE analysis makes clear that Boko Haram capitalizes on poverty and instability and perpetuates an environment of insecurity to exploit, recruit, and retain members. There are some specific pieces of this analysis, such as ways that Boko Haram appeals to young women through empowerment, that represent shifts from dominant local cultural norms. However, many of the push factors that attract youth to Boko Haram are perpetuated by the group itself, including the constant threat of violence, housing and food insecurity, distrust of youth among the community, and lack of economic infrastructure. The Nigerian government must work to institute a more dynamic approach to address the micro, mezzo, and macro forces contributing to the exploitation and abuse of children.

Child protection systems. Similarly, there is a need for well-resourced child protection systems throughout Nigeria that encompass “formal and informal structures, functions and capacities that have been assembled to prevent and respond to violence, abuse, neglect and exploitation of children.”¹⁰⁶ Throughout the decade-long conflict, the affected community has relied heavily on international humanitarian aid, which, while valuable, is not sustainable in the long term. As this analysis highlights, the vulnerabilities that Boko Haram exploits in the ecosystems of youth are interrelated, rooted in cultural and historic challenges, and in need of an organized systems-level intervention to address. The government needs to develop national and local child protection systems that include culturally relevant interworking structures to address the SAFE realms of security, access to health care and physiological needs, family and connection, and education and economic security for all children.

Autonomy for interdisciplinary and context-specific protection systems. There is an urgent need for an overarching and unifying national child protection system. Recognizing that the ecology

of risks and protective factors facing youth varies throughout the country, this child protection system also demands that local branches have the freedom to address the specific local needs of the complex ecosystem. The local system would benefit from an interdisciplinary team of specialists, including community and religious leaders, health and mental health workers, law enforcement, legal scholars, logistical coordinators, and financial specialists. With government support and use of the SAFE model analysis, a team such as this could strategize a framework to deliver more holistic strengths-focused social service programs driven by evidence-based interventions and grounded in the ecology of the region and community. The youth-centered, community-grounded component is particularly important in a conflict setting that continues to systematically violate young people's rights. Using the SAFE model will prove a practical tool to center human security and children's rights in the dynamic landscape of the Boko Haram insurgency.

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The Right to Mental Health in Yemen: A Distressed and Ignored Foundation for Peace

WALEED ALHARIRI, AMANDA MCNALLY, AND SARAH KNUCKEY

Abstract

Mental health issues are all too common consequences of conflict and atrocity crimes, often causing upwards of one-quarter of the postconflict, post-atrocity population to suffer from physical and mental sequelae that linger long after weapons have been silenced. After more than six years of ongoing conflict, Yemen's already weak health care system is on the brink of collapse, and population resilience has been severely stressed by indiscriminate attacks, airstrikes, torture, food insecurity, unemployment, cholera, and now the COVID-19 pandemic. This paper examines Yemen's responsibilities regarding the right to mental health and details the few actions the government has taken to date toward fulfilling this right. It also presents the current status of mental health care in Yemen, discussing some of the barriers to accessing the available care, as well as alternative models of mental health support being used by the population. In light of the pandemic presently facing the world, the paper also discusses COVID-19's impact on Yemen, detailing its further degrading effects on the country's health care system and people's mental health. Finally, the paper highlights the importance of addressing mental health in furtherance of the peace process.

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Introduction

Yemen's fragile postrevolution transition was derailed by the Houthi movement's September 2014 takeover of the capital Sana'a and the subsequent military intervention by a Saudi- and Emirati-led coalition in March 2015. The ensuing war and its nearly 50 active frontlines has effectively fragmented the country; 80% of the population of 30.8 million lives in Houthi-controlled northern governorates, while government forces, the secessionist Southern Transitional Council, and militias split fluctuating control of the south.¹ Parties to the conflict have engaged in indiscriminate shelling, disproportionate airstrikes, obstruction of humanitarian relief, laying of landmines, recruitment of child soldiers, torture, arbitrary detention, and attacks on health care facilities.² This violence has directly killed or injured over 20,000 civilians, and combined with the resultant humanitarian catastrophe—regularly cited as the world's worst humanitarian crisis of our time—the war has killed an estimated 233,000 Yemenis.³ Four million Yemenis have been displaced, over 2.5 million have had cholera in the world's worst epidemic on record, at least 85,000 children have died of starvation, and 2.5 million children under the age of five are projected to suffer from acute malnutrition in 2021.⁴ The COVID-19 pandemic has only further exacerbated this dire situation.

For over six years, Yemenis have been continuously exposed to these stressors and harms, in addition to widespread economic insecurity, fractured social ties, poverty, the absence of basic services, and government neglect.⁵ The World Health Organization estimates that, 22% of the world's conflict-affected populations will suffer from a mental disorder, such as depression, anxiety, bipolar disorder, posttraumatic stress disorder, and schizophrenia.⁶ In Yemen, where the average 25-year-old has already lived through 14 armed conflicts, an estimated 19.5% of the population suffers from mental disorders, most prevalently anxiety, depression, trauma, and schizophrenia.⁷ Children have been particularly affected; studies have found that 55% of children are sad or depressed, 19% of children are always fearful, and 79% of school-aged

children in Sana'a report symptoms of posttraumatic stress disorder.⁸

The country's already weak health care system has been further deteriorated by the conflict and is unable to meet the demands of this potential mental health crisis. Only 51% of all health facilities are fully functional, health care workers' salaries have gone largely unpaid, and essential medications are in short supply.⁹ Mental health care is further burdened by a pervasive stigma that discourages specialized training by medical students and complicates people's willingness to access the few mental health resources that do exist.¹⁰ Many Yemenis turn to traditional healers, local sheikhs, and other community leaders for mental health support.

Before the most recent war, the Yemeni government largely ignored its legal responsibilities to respect, protect, and fulfill the right to mental health. The corruption, poverty, and disinterest that prevailed then have only been exacerbated and compounded by six years of war. Continued failure to realize the right to mental health for Yemenis, however, may have damaging effects for the ongoing peace process and future stability.

Mental health obligations of the government of Yemen and the international community under international law

The right to mental health has increasingly been recognized as an integral part of the right to health, which is enshrined in human rights instruments such as the International Covenant on Economic, Social and Cultural Rights (art. 12), the Convention on the Rights of the Child (art. 24), and the Convention on the Rights of Persons with Disabilities (art. 25)—all of which have been ratified by Yemen.¹¹ The International Covenant on Economic, Social and Cultural Rights contains the most explicit validation of the right to mental health in international human rights law by recognizing the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”¹²

As a party to these treaties, the Yemeni government is obligated to respect, protect, and fulfill

the right to mental health, including by refraining from interfering with the right and by ensuring that third parties (such as hospitals and residential treatment centers) do not violate this right. Through ratification, the government of Yemen has also committed to “adopt[ing] appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realization of the right to health.”¹³ Additionally, the International Covenant on Economic, Social and Cultural Rights outlines that mental health facilities, goods (including essential medicines), and services must be available, accessible, acceptable, of good quality, and provided without discrimination.¹⁴

Of course, the fulfillment of economic and social rights, including the right to mental health, can take time and resources to achieve. The covenant, therefore, calls for the progressive realization of these rights.¹⁵ Progressive realization, however, does not release Yemen of its obligations to respect, protect, and fulfill the right to mental health equally and without discrimination. Rather, “progressive realization means that States parties have a specific and continuing obligation to move as expeditiously and effectively as possible towards full realization.”¹⁶ Additionally, Yemen must meet non-negotiable minimum core obligations, including the obligations to ensure the right of access to health facilities, goods, and services on a nondiscriminatory basis; to ensure access to the underlying determinants of mental health (including minimum essential food, basic shelter, housing, and sanitation, and an adequate supply of safe, potable water); to adopt and implement a national mental health strategy; and to monitor the progress made toward realizing the right to mental health.¹⁷

There is also an obligation of international cooperation for the realization of the right to mental health recognized in articles 55 and 56 of the Charter of the United Nations, in international law principles, and within the International Covenant on Economic, Social and Cultural Rights.¹⁸ The Committee on Economic, Social and Cultural Rights has emphasized that it is “incumbent upon those States which are in a position to assist others” in the realization of the rights do so.¹⁹ This is reinforced by

the commitment to global partnership in working toward the Sustainable Development Goals.²⁰ Goal 3 is to “ensure healthy lives and promote well-being for all at all ages,” and includes target 3.4, which requests that countries “reduce by one third premature mortality from noncommunicable diseases through prevention and treatment and promote mental health and well-being” by 2030.²¹ Therefore, the international community should also take steps to assist in fulfilling the Yemeni people’s right to mental health.

Evolution of mental health care in Yemen

Yemen’s record in taking steps toward the progressive realization of the right to mental health in the country is brief. The first psychiatric sanatorium was established in Aden in 1966, when southern Yemen was still a British colony. The sanatorium’s rooms resembled jail cells, and the facility received its patients from nearby prisons. Prior to 1966, psychiatric patients were kept in prison among other prisoners without formal mental health services.²² In the 1970s, a clinic opened in Al Jumhurriyya Hospital in Sana’a, and later, a modern 208-bed psychiatric hospital was built in Aden, funded by the Kuwaiti government.²³

In an effort to create a national foundation for psychiatric practice, in the 1980s the World Health Organization helped establish psychiatric clinics in three hospitals (in the cities of Sana’a, Taiz, and Hudaydah), trained local doctors, and provided basic equipment, including electric shock therapy machines.²⁴ In the late 1980s and early 1990s, a national mental health program was established by ministerial resolution and administered within the primary care division of the Ministry of Public Health and Population that was established following the unification of the north and south of Yemen. This program sought to improve treatment in mental health hospitals and ensure that patients were cared for by qualified psychiatrists.²⁵

In the early 2000s, the International Committee of the Red Cross sponsored two national workshops on mental health, which resulted in the government’s drafting of a national mental health

strategy in 2004.²⁶ The draft strategy sought to promote mental health awareness among the Yemeni population and improve access to mental health care.²⁷ Following this draft, legislators proposed before Parliament a Mental Health Act based on the draft strategy.²⁸ According to the 2011–2015 National Mental Health Strategy, the proposed law addressed definitions and mechanisms to address mental health care.²⁹ However, the bill failed in part because it was vague in terms of its definitions and concepts.³⁰ But a larger factor was that officials did not see mental health as a political priority.

In 2007, the Ministry of Public Health and Population amended the 2004 proposed mental health legislation.³¹ The amended law was more comprehensive; it better defined mental health, included requirements for treatment, widened the range of patients' rights available, and set punishments for negligent treatment.³² The amended legislation, however, was not referred to Parliament.³³ As explained by Muteei Jubayr, an official in charge of drafting laws at the Ministry of Legal Affairs, there has been no further action "because it is neither a political nor a popular issue."³⁴ Jamed Juneid, deputy health minister, has further explained that "unfortunately, psychiatric disorders are not a priority ... [a]nd relevant health services including therapy sessions and medicines are limited."³⁵ Many officials from the Ministry of Public Health and Population and the Parliament's Committee on Health and Population have not even seen the draft legislation, and there has been no follow up from the Ministry of Public Health and Population.

In 2010, the Ministry of Public Health and Population and the Social Development Fund, a nongovernmental organization supporting development opportunities and building capacities at the national level, adopted the National Mental Health Strategy for 2011–2015.³⁶ The strategy included steps to promote mental health, improve the treatment of disorders, and address stigma and discrimination through community mobilization. The strategy sought to develop destigmatizing media campaigns using well-known public figures, identify nongovernmental organizations that could assist in providing mental health services, and be-

gin dialogues with religious and traditional healers on the reduction of harmful treatment practices.³⁷ In the period in which it was to be implemented, however, Yemen witnessed a popular uprising, and the subsequent unrest led to the abandonment of the strategy.

The most progressive move toward recognizing mental health as a serious health issue was witnessed during the 2013–2014 National Dialogue Conference (NDC)—a transitional dialogue process facilitated by the United Nations (UN) and sponsored by the 2011 Gulf Cooperation Council Initiative for Yemen—and the 2015 constitution draft that resulted. The NDC outcomes proposed

*working to strengthen personal health and its importance to general health by creating the appropriate infrastructure for mental health services to be provided in hospitals in the major cities, the capitals of the governorates, and throughout the country. The necessary funding should be provided for mental health services, and the cadres working in this field should be trained.*³⁸

NDC outcomes further called for the prioritization of "mental health programs for children and youth, and a personal health program in schools."³⁹ The draft constitution took into account these recommendations and, in a major breakthrough, dedicated a constitutional article to Yemenis' right to physical, mental, and psychological integrity.⁴⁰ The draft constitution also emphasized the prevention of potential mental health impacts on children by prohibiting children's employment "in jobs that expose their physical, mental or psychological integrity to danger."⁴¹

Before the adoption of the NDC outcomes and the draft constitution, conflict broke out and the Houthi rebels took control over state institutions in a coup against the internationally recognized and regionally backed President Abdo Rabbu Mansour Hadi. The Houthi rebels took advantage of weak and corrupt leadership, as well as a transitional process based on a Gulf Cooperation Council agreement mired with flaws and the misguided interference of local power brokers and the international community.⁴² The agreement included an

unconditional immunity for former President Ali Saleh, his family, and his inner circle, which Saleh later used to maintain a political role as head of the General People's Congress ruling party. The majority of the party's officials and supporters, who were present in all state institutions, remained loyal to Saleh and helped him orchestrate an alliance of convenience with the Houthi rebels to overturn the transitional process in the hope that Saleh and his family would rule again.

Later in the conflict, the Houthi rebels clashed with Saleh, ultimately killing him and consolidating their power. At the time of this writing, the conflict continues unabated, and, as a result, governmental concern for mental health has fallen to the wayside.

By and large, mental health policy in Yemen is still being developed and requires "support in both human and material resources as well as the development of a database of resources, statistics and epidemiological information."³³ Notably, current laws in Yemen do not reference mental health.

Current mental health care services in Yemen

The lack of a mental health care policy at the national level has translated into few and poor-quality mental health services throughout the country. These services have become scarcer and poorer in quality during the conflict and accompanying humanitarian crisis, which have included systematic and widespread atrocity crimes perpetrated against the civilian population.⁴⁴ Mental health is not integrated into the primary health care system, and many Yemenis are unable to access mental health treatment when they first make contact with the health care system. A recent assessment, for example, found that only 10% of primary health facilities in Yemen had staff trained in the identification or treatment of mental health disorders.⁴⁵ Considering that 30.6% of the population lives more than 30 minutes from the nearest functioning primary health facility, it is likely that only a concerning low number of Yemenis receive mental health treatment from primary care facilities.⁴⁶

Shockingly few specialized resources exist for

the population of 30.8 million. There are only four psychiatric hospitals in Yemen—one located in each of the four most populous governorates of Sana'a, Aden, Hudaydah, and Taiz.⁴⁷ Yemen's Ministry of Public Health and Population recently reported that there are also 7 outpatient psychiatric clinics in public hospitals, 5 private psychiatric hospitals, 34 private mental health clinics, and 3 residential psychiatric treatment centers.⁴⁸ There are also mental health clinics in the central prisons of Sana'a and Taiz. The Family Counseling and Development Foundation has only recently established Yemen's first and only specialized mental health clinic for children.⁴⁹ These few available hospitals and clinics, moreover, are suffering from a shortage of qualified staff; there are only an estimated 130 trained therapists, and the number of psychiatrists in the entire country does not exceed 59.⁵⁰ These numbers indicate there has been little progress in building the cadre of mental health professionals in Yemen, as in 2010, there were an estimated 44 psychiatrists.⁵¹ Though the number of psychiatrists is on par with many conflict-affected countries in the region—in 2007, Iraq, Libya, Somalia, Sudan, and Syria also had fewer than 0.5 psychiatrists available per 100,000 persons—Yemeni mental health professionals have indicated that they believe the number to be inadequate for the needs of the Yemeni population.⁵²

The quality of care provided by the country's mental health services is at times suspect and deeply impacted by a shortage of staff and a lack of funding. A pervasive practice within the community, the shackling of persons with mental health disorders, even takes place in some mental health facilities.⁵³ In early 2021, a reporter visiting the Taiz mental health hospital found that many of the facility's patients were heavily sedated and shackled to "stop them from escaping."⁵⁴ Only two nurses were responsible for caring for the hospital's 143 inpatients, some of whom sat in urine-soaked clothing. The hospital receives enough funding to buy only a quarter of the medications needed to manage its patients; this reflects a common problem, as 75% of Yemen's health facilities report never having essential psychotropic medications available.⁵⁵

Improvements in the quantity and quality of available mental health services in Yemen will be difficult in the immediate future if the current funding crisis continues. The UN—a main donor of the Ministry of Public Health and Population—has raised less than half of the US\$3.85 billion necessary to fully fund the 2021 Humanitarian Response Plan for Yemen.⁵⁶ This, combined with the similarly large shortfall in 2020, has led to the shuttering of existing services. In 2020, the United Nations Population Fund had to withdraw funding from the Taiz mental health hospital and closed 80 of the 180 health care facilities it supports, including some providing psychosocial services.⁵⁷ The funding crisis has further diverted focus away from mental health care and toward emergency lifesaving treatment.⁵⁸ Yemen's Deputy Public Health Minister Ishraq al-Subaie has acknowledged that “efforts have been focused on rebuilding hospitals, treating the war-wounded and addressing reproductive healthcare ... Mental health has been completely neglected.”⁵⁹

Pandemic-related stressors

Public health emergencies, including health pandemics, are often more severe in conflict zones. Yemen in particular has been dealing with a number of outbreaks, with alarming numbers of individual cases associated with cholera and, more recently, COVID-19. In late 2016, health authorities announced a cholera outbreak, primarily resulting from old unmaintained sewage systems and heavy rains; the outbreak has led to over 2.5 million suspected cholera cases and nearly 4,000 deaths.⁶⁰ As it still struggled to contain the cholera epidemic, Yemen recorded its first positive COVID-19 test in April 2020.⁶¹ Reported positive cases subsequently increased exponentially, quickly overwhelming the health care system. As of May 20, 2021, there were 6,587 confirmed cases of COVID-19 and 1,299 deaths in Yemen, with many cases and deaths going unrecorded due to political interference and the lack of testing.⁶²

The response to these public health outbreaks

in Yemen has been left largely to international organizations such as the World Health Organization, Médecins Sans Frontières, and UNICEF.⁶³ With minimal resources and without the authority to enforce restrictions on gathering in public spaces, international organizations are severely hamstrung in their ability to deal with the pandemic. Local authorities have attempted to absolve themselves of responsibility and have neglected and undermined public health efforts by continuing military clashes which have created additional hardships for civilians and increased pressure on health facilities. At the onset of the COVID-19 pandemic, in the north of Yemen, authorities in Houthi-rebel-held areas suppressed information on COVID-19 cases and did not implement public health measures to prevent or contain the spread.⁶⁴ Meanwhile, the internationally recognized government in the south enacted restrictions without interventions intended to ease the economic hardship created by the pandemic.⁶⁵ Warring parties have continued fighting on a number of frontlines, which goes against the spirit of responsible leadership and the UN Secretary-General's plea for a global ceasefire in conflict areas. In particular, the Secretary-General has called on warring parties to declare a nationwide ceasefire in order to focus efforts on combating the spread of COVID-19.⁶⁶

The UN has additionally urged governments worldwide to take measures to protect the most vulnerable—including health care workers, young people, and those with preexisting mental health conditions—from the mental health impacts brought on by COVID-19.⁶⁷ COVID-19 has added new stressors to vulnerable populations worldwide; in Yemen, job loss and decreases in remittances have greatly magnified economic suffering.⁶⁸ Fear of becoming ill, worry about the lack of available health services, and increased social isolation have added to the stress of Yemen individuals, families, and communities.⁶⁹ With a severely weakened health care system now overburdened with COVID-19 and decreased international funding to Yemen, little has been done to address these added stressors.⁷⁰

Superstition and stigma further complicate mental health care access

In Yemen, mental health disorders have traditionally been associated with “myth, superstition, witchcraft and *jinn* (spirits),” and the topic of mental health is generally stigmatized and taboo.⁷¹ Many Yemenis might describe those seeking mental health support as “not normal,” “not stable,” “possessed by some kind of demon or *jinn*,” “crazy,” or “far from God.”⁷² Persons with mental health concerns are often considered dangerous, with accounts of crimes committed by persons with mental illness circulated on social media.⁷³ This stigma has contributed to a belief that mental health hospitals are only for people who are out of control and that persons with mental health needs should be kept apart from the rest of society.⁷⁴ Accordingly, many Yemenis turn to community-based or superstitious remedies (such as witchcraft) before seeking medical treatment.

Coping in the state’s absence

Turning to traditional healers, sheikhs, and other community and religious leaders for support for mental health conditions is one way by which Yemenis have sought to cope with the lack of services and information provided by the state.⁷⁵ Formal psychiatric treatment is often sought only for severe cases of schizophrenia or psychosis.⁷⁶ Instead, *wallies*, or traditional healers, are often the primary caretakers for people suffering from mental health conditions; these healers combine religion, hypnosis, suggestion, and native herbal medicine in the treatments they offer.⁷⁷

Social solidarity, or a sense of community interconnectedness, is an extremely important coping mechanism in Yemen. With deteriorating state institutions, private individuals help one another; namely, families, friends, and neighbors provide financial support, shelter, fuel, food, water, and companionship.⁷⁸ However, social networks are being eroded by the conflict.⁷⁹ Due to widespread displacement, many communities and families are now physically separated from one another. Many social gatherings have thus disappeared altogether,

with others made extremely difficult by the circumstances. In pre-conflict Yemen, men and women commonly gathered separately to socialize or chew *khat*—a stimulant plant chewed in groups—in the evening. Now, checkpoints, fighting, and darkness from lack of electricity lead people to stay in their own homes at night.⁸⁰

Yemen, the international community, and mental health

The government of Yemen cites the ongoing conflict as a major impediment to advancing human rights, including the right to mental health.⁸¹ Despite the challenges of the conflict, the responsibility to address issues related to the well-being of people in Yemen remains with the government, a fact emphasized by domestic and international civil society organizations and by UN member states at the Universal Periodic Review of Yemen in January 2019.

Ahead of the Universal Periodic Review, a group of representatives from the Sana’a Center for Strategic Studies, the Columbia Law School Human Rights Clinic, and the Brown School at Washington University held advocacy meetings with Human Rights Council member states, urging them to call on the government of Yemen to take measures to strengthen the right to mental health. Various UN member states—including Cyprus, Iceland, Malta, France, Switzerland, Brazil, and Slovenia—raised the issue of the right to mental health in their statements to the government of Yemen.⁸² Many other member states were interested in the group’s suggested recommendations for the government of Yemen, including the recommendations to ensure that mental health is an important factor in all its national planning; promote access to appropriate psychosocial support for persons living in Yemen; take steps to support more training for counselors, psychologists, teachers, and community leaders; immediately make all efforts to reduce the burden of the conflict on Yemenis, including by paying public sector salaries; reopen the Sana’a International Airport; lift unnecessary import restrictions; and reduce impediments to people’s movement.⁸³ The group also called on the Yemeni government

and all parties to the conflict (including the Houthis rebels and the Saudi-led coalition), along with the UN Special Envoy to Yemen and the international community, to ensure that mental health is taken into account during peace talks.⁸⁴ Three years later, these recommendations to the government of Yemen and various international actors remain regrettably relevant, as the crisis has only deepened and progress toward the realization of the rights to mental health has stagnated.

Emerging from war and atrocity: Addressing mental health in peacebuilding

Mental health is often overlooked during and immediately after conflict and mass atrocity; this neglect may have reverberating effects on future peace and stability. First, poor mental health can have direct effects on ceasefire and peace negotiations. For parties to the conflict and others who participate in peace processes, heightened threat perception, distrust, deteriorated intra-communal relationships, and other manifestations of poor mental health may impact the interest in, effectively engage in conflict resolution and peacebuilding.⁸⁵ Left unaddressed, prolonged exposure to violence and trauma may increase individuals' threat perception, leading to attempts to protect oneself with defensive violence and negative coping strategies such as an unwillingness to compromise.⁸⁶ Additionally, exposure to trauma may lead to a lack of confidence in reconciliation measures by intensifying feelings of anxiety, fear, and anger.⁸⁷ These constant feelings of anxiety and fear may transform into a general distrust—toward society at large, authorities, and even neighbors—which may undermine reconciliation efforts.⁸⁸ Conflict-induced poor mental health may also affect cognitive skills such as perspective taking and problem solving.⁸⁹ Depression and rumination can create a spiral of negative thinking that interferes with the ability to have perspective and find creative solutions.⁹⁰ Due to these manifestations, conflict- and atrocity-induced poor mental health has been associated with greater support for violence as a way to respond to conflict, and a

lower likelihood of envisioning nonviolent solutions, leading to reduced support for peace and reconciliation.⁹¹ Mental health and psychosocial interventions—including individual psychiatric services, the facilitation of community-based social support, and psycho-education—however, can temper these effects and even contribute to more constructive peacebuilding.⁹²

As part of a successful agreement to end armed conflict, Yemen will likely design and implement programs created to build peace while seeking justice for the human rights abuses that have occurred.⁹³ Truth-seeking mechanisms, criminal prosecutions, and reparations programs are three ways of advancing reconciliation and justice.⁹⁴ Considering the extent of mental health harms caused by conflict, it is important for these processes to find ways to meaningfully acknowledge and address these harms, improve the general well-being of the population, and prevent the effects of these harms from impeding participation in reconciliation.

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Monitoring Attacks on Health Care as a Basis to Facilitate Accountability for Human Rights Violations

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Abstract

Violence against health care systems is an assault on health and human rights. Despite the evolution of global standards to protect health workers and ensure the delivery of health care in times of conflict, attacks against health systems have continued throughout the world—violating humanitarian law, undermining human rights, and threatening public health. The persistence of such violence against health care, especially in humanitarian crises related to armed conflict, has prompted global institutions to develop systematic monitoring mechanisms in an effort to alleviate these harms, seeking to protect health workers from being harmed for their healing efforts. This article examines the development and implementation of the World Health Organization (WHO) Surveillance System of Attacks on Healthcare (SSA) as a systematic mechanism to collect and disseminate data concerning attacks on health care systems. Although the SSA provides a foundation for monitoring attacks in conflict zones, this research considers whether the SSA has collected the necessary data, categorized these data appropriately, and disseminated sufficient information to facilitate human rights accountability, analyzing the political, methodological, and institutional challenges faced by WHO. The article concludes that refinements to this monitoring mechanism are needed to strengthen the political prioritization, research methodology, and institutional implementation necessary to ensure accountability for violations of health and human rights.

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Introduction

As armed conflict threatens nations throughout the world, violence has continued unabated against health care facilities and health workers, endangering health and human rights. Increased disregard for international law within humanitarian crises has made health care systems more vulnerable to attacks. From the aerial bombing of hospitals in Syria to the targeted killing of health workers in Afghanistan, health care is under attack in conflict zones. Despite decades of international legal statements to grant protection to medical care, both on and off the battlefield, assaults against health care systems, health workers, and patients persist—violating humanitarian law, undermining human rights, and threatening public health. These continuing attacks on health care in complex humanitarian emergencies have impacted the global response to COVID-19, raising challenges to controlling the pandemic amid rising conflicts. The persistence of attacks against health care has prompted an urgency in global health governance to facilitate accountability for these harms against health workers. Where attacks on health care hinder the global push to achieve universal health coverage (UHC), an initiative seen as central to the realization of the right to health, these attacks undermine the human rights foundation of peace and justice in the world. Seeking to document the nature and the extent of attacks on health care, the World Health Organization (WHO) developed the Surveillance System of Attacks on Healthcare (SSA), as mandated by its member states in the World Health Assembly, to monitor attacks against health care in complex humanitarian emergencies, collecting and disseminating needed data as a basis to lessen the violence.

This article examines the development and implementation of WHO's SSA as a systematic mechanism to monitor attacks on health care in complex humanitarian emergencies, drawing from the international humanitarian law literature, thematic analysis of the SSA interface, and informant interviews with key stakeholders to analyze how the SSA can support efforts to facilitate accountability for violations of health and human rights.

Beginning in the normative frameworks that have arisen to prohibit harm to health workers, the first part of this article chronicles the evolution of international humanitarian law to establish protections for health workers and ensure the delivery of health care services in times of conflict. Where these international legal standards have failed to prevent attacks on health care, the second part details the development of the WHO SSA as a global health governance mechanism to monitor these threats to health care systems in complex humanitarian emergencies. It is necessary to understand the structure, process, and effectiveness of the WHO SSA as a data monitoring platform and the use of SSA data by external stakeholders to facilitate human rights accountability. The third part examines the implementation of the SSA, with interviews across the humanitarian landscape providing a basis to understand the data collection and dissemination necessary to monitor attacks against health care as a health and human rights challenge. With the SSA facing limitations as a resource for stakeholders to facilitate accountability for attacks on health care, the fourth part analyzes the political, methodological, and institutional challenges facing the SSA, offering recommendations for strengthening SSA data collection, reporting, and dissemination. The article concludes that the SSA provides a foundation for monitoring attacks on health care, but refinements will be necessary to strengthen the political prioritization, research methodology, and institutional implementation needed to ensure accountability for violations of health and human rights through global health governance.

Evolving policy efforts to prevent attacks against health care

Principles of *jus in bello*, or “law in war,” regulate the conduct of parties engaged in armed conflict, establishing the normative framework that forms the basis of “rules of engagement” to guide wartime decision-making.¹ *Jus in bello* maintains that before engaging in violence, soldiers must understand the critical distinction between combatants and noncombatants, considering the proportionality

between military action and civilian harm.² Although armed combatants actively contribute to the war—and in doing so, relinquish their rights not to be killed in the scope of combat—noncombatants do not, and as a result, the targeting of noncombatants has come to be seen as a war crime.

Illuminating the immorality of attacks on health care systems, health care workers providing care are considered under the *jus in bello* framework to be noncombatants, operating under a mandate of saving lives both on and off the battlefield. Given the recognition of medical operations as protected acts in wartime, requiring that those who contribute to or receive medical services be treated as noncombatants, health personnel hold a right to protection from arbitrary deprivation of life regardless of their proximity to the fighting.³ The targeting of health operations in armed conflict is thus unjustified, with health care provided non-combatant status and humanitarian protections.⁴ An attack on health care, whether intentional or borne of a failure to distinguish military and civilian objects, dismantles the critical distinction between those who are active combatants in a conflict and those who are not, exacerbates a cycle of violence that prevents the effective and safe delivery of health care services, and undermines health and human rights.

Violence against health care workers has come to be formally proscribed under international humanitarian law, with this longstanding global condemnation of attacks on medical volunteers and military medicine laying a legal foundation for modern efforts to protect health personnel in armed conflict. Beginning in the 19th century, international humanitarian law—shaped by the Geneva Conferences, two world wars, changes in technology, and advancements in ethical norms—has evolved to solidify a wide array of protections for health workers in times of conflict. These protections of health care systems under international humanitarian law, placing obligations on both state and nonstate combatants, have provided crucial support for human rights to promote public health.⁵ Manifested in a series of conventions and protocols, these protections reflect international agreements

to codify ethical norms under international law and defend medical operations in wartime contexts.

Beginnings in Geneva

The first initiative to protect health care in wartime began with Henry Dunant, a Swiss businessman, who sought to advocate for a neutral organization to care for wounded soldiers. After witnessing the battle of Solferino in Italy, during which he organized the local townspeople to care for wounded and suffering soldiers, Dunant founded the Committee of Five to protect both the wounded on the battlefield and those caring for them.⁶ Leading in 1864 to the inaugural Geneva Conference, 16 states developed the Convention for the Amelioration of the Condition of the Wounded in Armies in the Field. This initial Geneva Convention delineated 10 articles to outline the protections granted to wounded soldiers and medical personnel and presented three recommendations. The second of these recommendations declared that

*in time of war the belligerent nations should proclaim the neutrality of ambulances and military hospitals, and that neutrality should likewise be recognized, fully and absolutely, in respect of official medical personnel, voluntary medical personnel, inhabitants of the country who go to the relief of the wounded, and the wounded themselves.*⁷

This recommendation served as an impetus for the broader movement to protect medical personnel during wartime.

In the decades that followed the inaugural Geneva Conference and adoption of the initial Geneva Convention, states further refined international humanitarian law to protect health workers in conflict zones. The Geneva Convention provided specific protections for health care operations, seeking neutrality for all military medical personnel and hospitals, which would be designated by the emblem of a red cross. The groundwork laid in these years galvanized the establishment of the International Committee of the Red Cross (ICRC), an independent international organization that would operate to ensure “humanitarian protection and assistance for victims of armed conflict and

other situations of violence.⁸ The ICRC would seek a neutral role in armed conflicts—not only in providing essential medical services but also in promoting respect for international humanitarian law. The protections afforded to health workers under international humanitarian law would soon be broadened to include other voluntary aid societies and those providing care for prisoners of war.⁹ These protections for health personnel would become crucially important as devastating wars challenged the world order.

Postwar policy: World Wars I and II

World War I, the largest war the world had then known, produced 40 million casualties, 10 million of whom were civilians.¹⁰ At the end of the war, there was a crucial need for a global institution to support the maintenance of peace, with states at the 1919 Paris Peace Conference developing the League of Nations to institutionalize international governance. As a basis for “collective security,” the Covenant of the League of Nations reflected international concern for the cataclysmic suffering of war.¹¹ Following from the establishment of the League of Nations, the 1929 Geneva Convention sought to provide more robust protections to prisoners of war, including explicit commitments regarding the protections granted to medical operations. The 1929 convention maintained that all prisoners of war should be given all relevant medical care, with the implication that all health care personnel should be permitted to safely carry out their impartial medical work, recognizing specifically “the humanitarian work which the International Red Cross Committee may perform” in wartime.¹²

Yet a mere 10 years later, the world witnessed another world war, and by the end of World War II, 15 million had been killed in battle, 25 million had been wounded, and 45 million civilians had lost their lives.¹³ Recognizing that institutional efforts to prevent the atrocities of war were insufficient, states came together amidst the war to create in 1943 the United Nations Relief and Rehabilitation Administration to provide necessary wartime relief to vulnerable populations.¹⁴ These wartime efforts of the Relief and Rehabilitation Administration

would lead in 1945 to the postwar establishment of the United Nations (UN) as an institutional basis “to save succeeding generations from the scourge of war.”¹⁵

In furthering international efforts to promote justice in war after the injustices of World War II, the development of the 1949 Geneva Conventions established the principal postwar system of international humanitarian law. These four Geneva Conventions each addressed a different aspect of war: (1) wounded and sick soldiers on land; (2) wounded, sick, and shipwrecked military personnel at sea; (3) prisoners of war; and (4) civilians, including those in occupied territory.¹⁶ These new standards of international humanitarian law would help solidify prior efforts while enacting new rules to address weaknesses highlighted by the atrocities of the war.¹⁷ Across the conventions, the protection of health care systems and workers in the context of war was codified with greater detail than ever before. Granting comprehensive protection to military medical units, operations, and personnel in all circumstances, the 1949 Convention for the Amelioration of the Condition of the Wounded and Sick strengthened protections for health workers by categorizing them firmly as noncombatants. Extended by the Convention for the Amelioration of the Condition of the Wounded and Sick in Armed Forces in the Field, states declared that “fixed establishments and mobile medical units of the Medical Service may in no circumstances be attacked, but shall at all times be respected and protected by the Parties to the conflict.”¹⁸ With additional protections for the humanitarian activities of the ICRC and other impartial humanitarian aid societies, the postwar Geneva Conventions provided unprecedented safeguards to health workers and humanitarian organizations in times of war.¹⁹

Additional protocols

Yet the divisions of the Cold War continued to highlight the limitations of these institutional efforts to protect health care systems during armed conflicts. Recognizing the collateral harms of Cold War conflicts, Additional Protocols I and II were adopted in 1977 to supplement the 1949 Geneva

Conventions, enhancing civilian protections and applying humanitarian law to civil wars.²⁰ To ensure that medical units and personnel would be protected, the 1977 protocols included protections for all medical transports as a means to provide access to adequate care during conflicts.²¹ As military technology continued to advance in the late 20th century, so did the ability to attack targets more precisely, raising the possibility of reducing collateral damage to health systems. In response to these emerging strategies, Additional Protocol I focused on indiscriminate attacks, creating a need for more detailed protocols to require that warring parties distinguish between combatants and non-combatants, protecting health care facilities and workers. While these developments established legally binding prohibitions, none successfully facilitated accountability to prevent such violence, as states continued to lack the political will and institutional capability to enforce international law in armed conflict. Soldiers could be prosecuted under national and international law for war crimes and crimes against humanity; however, even with the establishment of the International Criminal Court, few have been tried or punished for violating these fundamental principles.²² Looking to the development of new principles under the responsibility to protect (R2P), wherein the international community is seen as having a responsibility to hold state parties accountable if they fail to protect their citizens from crimes against humanity, these R2P obligations have faced obstacles in protecting health systems.²³ Humanitarian advocates have repeatedly raised the *jus in bello* framework to condemn attacks on health care, demanding that soldiers take due care to ensure that any foreseeable harm to noncombatants be as minimal as possible, yet these moral imperatives did not lead to policy reforms to prevent attacks on health care.²⁴

As attacks on health care continued, repeatedly striking beyond the reach of international law, efforts to mitigate these attacks against health care systems began to take shape within global health institutions. Drawing attention to these attacks, an array of nongovernmental organizations (NGOs) demanded that WHO leverage its normative au-

thorities and research capabilities to address attacks on health care. WHO member states came to back these NGO demands, examining attacks against health care as part of the global health policy agenda and resolving that WHO should formulate a response.²⁵

WHO addresses the protection of health care in humanitarian emergencies

Established under a 2012 World Health Assembly resolution, the SSA seeks to institutionalize WHO monitoring in humanitarian crises related to armed conflict, using WHO's geographic reach and technical legitimacy to collect and disseminate data on attacks on health care. The World Health Assembly's efforts to prevent attacks against health care built on previous resolutions to protect health services in times of conflict—pushed forward by growing demands from WHO member states and NGO advocates. Civil society organizations came together in 2011 to request that the WHO Director-General convene experts to create a platform to monitor attacks against health care workers. This demand occurred alongside a World Health Assembly side event that sought to catalyze international debate about attacks on health care, discuss WHO's leadership role in preventing these attacks through data collection, and create partnerships across health ministries, NGOs, and other stakeholders.²⁶

Responding to member state requests and highly publicized violence against health care workers during the Arab Spring protests, WHO Director-General Margaret Chan raised WHO's responsibility for addressing attacks on health care in her opening address to the 2011 World Health Assembly:

*We are extremely distressed by reports of assaults on health personnel and facilities in some of these conflict situations. We urge all parties to ensure the protection of health workers and health facilities in conflict situations, to enable them to provide care for the sick and injured.*²⁷

In buttressing WHO efforts later that year, the ICRC's 2011 report *Health Care in Danger* examined

specific attacks against health care systems across 16 countries, seeking to determine the types of violence against health facilities, medical vehicles, and health personnel in countries experiencing armed conflict and other situations of widespread violence.²⁸ This ICRC study found that the prevalence of violence against health care operations was growing, with the rights of the wounded and sick violated by armed state and nonstate groups alike. While the ICRC report concluded that responding to these threats would require reforms of international humanitarian law, there remained no systematic data across countries to understand the nature of the threat and frame these proposed reforms.

With growing demands on WHO to collect data on these threats to health systems, WHO member states, international medical societies, and NGOs (led by the Safeguarding Health in Conflict Coalition (SHCC)) looked to the World Health Assembly to mandate that WHO assume a greater leadership role in monitoring attacks on health care during humanitarian emergencies. These proponents saw WHO as uniquely positioned at the forefront of global health governance, with the health cluster leadership, international political legitimacy, and cross-national data that would allow it to play a leading role in monitoring attacks against health care. Given the repercussions of these attacks on health care across the globe, the development of a global monitoring mechanism to collect and disseminate data on such attacks was seen as falling under WHO's constitutional mandate—to protect the integrity of health operations in conflict zones as a foundation to safeguard the human right to the highest attainable standard of health.

WHO member states began to develop a proposal for WHO to coordinate the systematic collection of data concerning attacks against health care. Introduced at the January 2012 meeting of the WHO Executive Board, Norway and the United States advocated for a World Health Assembly resolution to request that WHO “develop methods of systematic data collection and dissemination of attacks on health facilities and personnel in complex emergencies.”²⁹ From this initial proposal, state

delegates worked with SHCC to develop a draft resolution, recognizing previous UN Security Council declarations that found attacks on hospitals to be one of the six “grave violations” of the rights of children in armed conflict (calling for enhanced monitoring and reporting mechanisms on these attacks) and acknowledging complementary efforts to identify and monitor attacks on health care (including through the ICRC).³⁰ States sought to have WHO take a leadership role in systematically collecting and disseminating data to mitigate attacks on health care.

The World Health Assembly adopted Resolution 65.20 in May 2012, calling on the WHO Director-General to

*provide leadership at the global level in developing methods for systematic collection and dissemination of data on attacks on health facilities, health workers, health transports, and patients in complex humanitarian emergencies, in coordination with other relevant United Nations bodies, other relevant actors, and intergovernmental and nongovernmental organizations.*³¹

Recognizing the harm of attacks against health care systems, Resolution 65.20 drew on past World Health Assembly and UN General Assembly resolutions to call for “systematic data collection on attacks or lack of respect for patients and/or health workers, facilities and transports in complex humanitarian emergencies.”³²

In implementing this World Health Assembly resolution, WHO began in the following year to devise a mechanism that would allow it to collect, analyze, and publicize data to monitor attacks on health care; yet, despite continuing pressure from advocates, the implementation of this WHO mandate moved slowly. Internal resistance to this unprecedented data collection mandate, along with methodological challenges inherent in designing such a comprehensive system, made the task daunting for the WHO Secretariat.³³ As the WHO Secretariat proceeded slowly in designing a monitoring methodology, the WHO Health Cluster for Northern Syria (a group of partner organizations that collectively respond to humanitarian emergencies within the region) began collecting and

reporting its own data on attacks on health care facilities and providers by the Assad regime.³⁴ These regional data collection efforts increased pressure for WHO Secretariat action, and in 2016, WHO released its first report on attacks on health care.³⁵ While this initial WHO report was compiled from secondary data sources, it raised an imperative for WHO to collect its own data to monitor attacks on health care.³⁶

As WHO sought to develop its own methodology for monitoring attacks, it continued to engage with political initiatives to prevent attacks on health care. WHO supported the unanimous passage of UN Security Council Resolution 2286, which condemned violence against health care systems, demanded that all parties to armed conflict comply with human rights law and international humanitarian law, and called on the UN Secretary-General to engage in preventative measures, including through data collection and UN reporting.³⁷ Following the passage of this resolution, Geneva-based diplomatic missions formed a group known as Friends of 2286 to continue their advocacy to prevent attacks on health care, and WHO participated as an observer in their meetings, updating members on WHO's activities to monitor attacks.

WHO developed its methodology for data collection, analysis, and reporting through collaborative efforts between senior management, donors, academic consultants, relevant NGOs, country offices, and information technology support teams. To facilitate the development of the SSA methodology, WHO created a staff position within the emergency department to work with stakeholders and consultants in establishing its monitoring system. The establishment of WHO's monitoring mechanism would seek to build on the networks and expertise of other organizations—including Médecins Sans Frontières (MSF), ICRC, Physicians for Human Rights, and SHCC—that were already collecting select data on attacks against health care in armed conflict. Yet, as these organizations at the time either collected data from secondary sources or did not make their primary data public, WHO would seek to collect primary data concerning at-

tacks on health care across complex humanitarian emergencies and disseminate those data publicly. WHO monitoring was thus seen to be uniquely advantageous, providing comparative data across humanitarian emergencies and legitimacy among member states. Given the need for primary data collection, WHO worked closely with its country offices to ensure feasibility, technical capacity, and confidence in its reporting system. Following three location-based tests from March 2015 to March 2016 and an independent evaluation of its methodology, WHO established a data reporting and verification method that would meet the end goal of disseminating timely and reliable data.³⁸ In December 2017, five years after the passage of World Health Assembly Resolution 65.20, WHO officially launched the SSA, establishing a systematic mechanism to collect and disseminate data on attacks on health care.

The Surveillance System of Attacks on Healthcare

Monitoring attacks on health care as a threat to public health, the SSA collects and disseminates data on attacks on health care systems in order to comprehend the nature, scope, and magnitude of attacks. These attacks on health care would be defined by WHO as “any act of verbal or physical violence or obstruction or threat of violence that interferes with the availability, access and delivery of curative and/or preventive health services during emergencies.”³⁹ WHO's commitment to collecting and disseminating these data in emergency affected countries and fragile settings reflects an effort to provide accurate data from primary sources concerning attacks on health care, clarify the extent of the attacks and the consequences for health care delivery and public health, and, through these monitoring efforts, create an evidence base that can support global efforts to prevent these attacks.⁴⁰ As reflected in Figure 1, the SSA seeks to collect data on attacks on health care through WHO country representatives, country-level health clusters, local NGOs, and other sources, utilizing WHO's global

network of information gathering and institutional partnerships to provide a systematic understanding of where attacks on health care are occurring and how these attacks are affecting health systems.⁴¹ The use of these SSA data, identifying global and context-specific trends and patterns of violence, provide a foundation for a wide range of stakeholders to engage with violations of health and human rights. WHO disseminates SSA data publicly, allowing SSA data to be used as a basis for advocacy, risk reduction, and resilience measures so that health care is protected and health services are available in complex humanitarian emergencies.

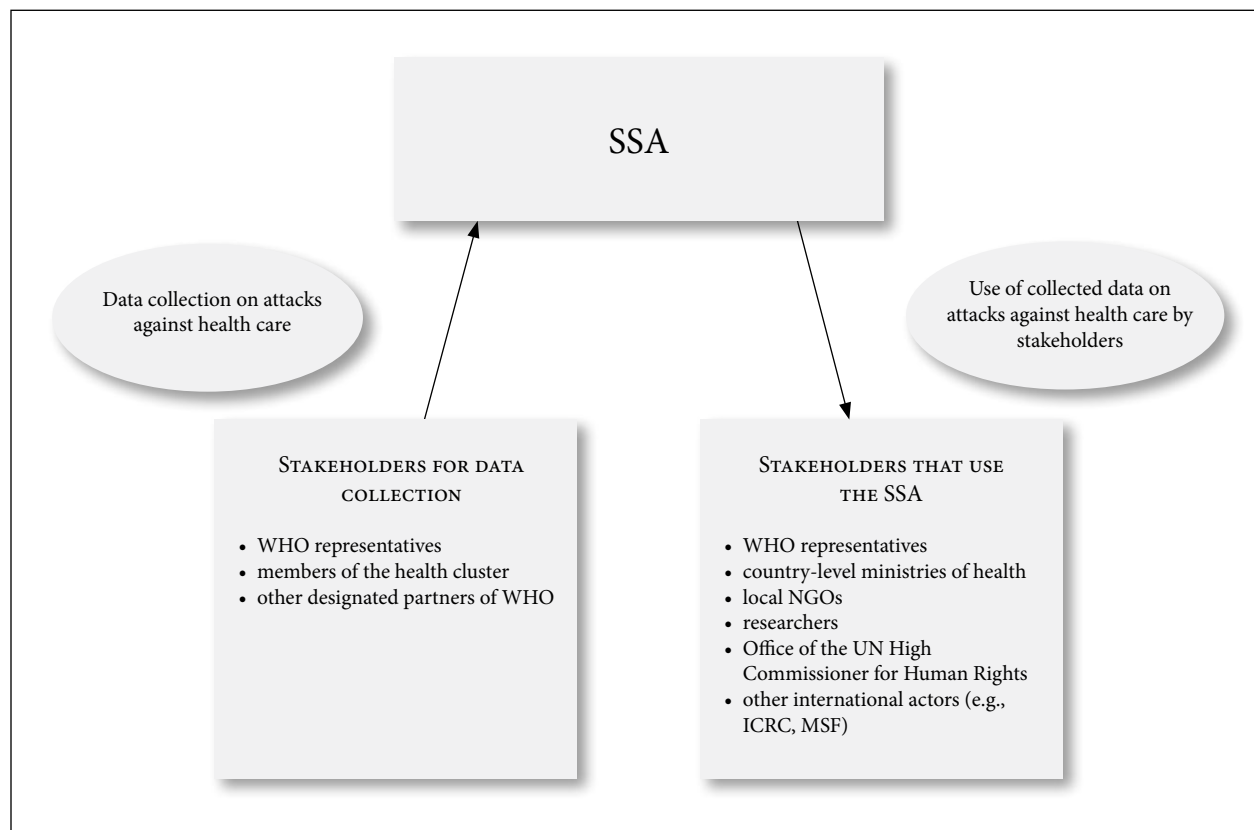
Through the collection and dissemination of data concerning attacks on health care, the SSA reflects a new mechanism for WHO to monitor such attacks, providing data that can facilitate international accountability for human rights violations.

Data collection

The SSA is designed to collect extensive data about attacks on health care and categorize these data according to the reliability of the source, providing a clear, consistent, and complete picture of the nature and effects of attacks in complex humanitarian emergencies. With WHO adhering to a transparent methodology for data collection, WHO's approved partners (those with a WHO Application Directory Service account or a WHO specific Web-based Information Management System account) can complete the SSA's web-based reporting form to provide WHO with the following standardized data:

- *description of the attack;*
- *description of immediate consequences to health service delivery;*
- *date of the attack and location (for example, name of town, facility, GPS coordinates);*
- *source of data (for example, identity or type of*

FIGURE 1. Stakeholders and the processes of data collection and data dissemination by the SSA



- source);
- health resources affected (for example, health facility, ambulance, health worker, patient);
- type of attack (for example, abduction, shooting, threat of violence);
- total deaths and injuries (by sex, age group, and type); and
- description of immediate follow-up actions to reestablish health services and support victims.⁴²

(Although anyone can create an Application Directory Service account, only approved partners can provide reports to the SSA.)

Figure 2 shows the first section of the online

collection form, which allows partners to describe the circumstances and impact of the attack. (Sections on “data sources” and “certainty level” do not appear in the partner organization reporting form, as the relevant WHO Country Office is expected to complete those sections in assessing the reliability of the information.⁴³)

In describing the attack, the SSA categorizes data based on the nature of the attack: type of attack, effects of the attack, and certainty of information about the attack. This systematic categorization of the collected data seeks to ensure that

FIGURE 2. Data collection form for SSA: Attack description section

The screenshot displays the 'SURVEILLANCE SYSTEM FOR ATTACKS ON HEALTH CARE (SSA) Administrator's Dashboard'. It includes a header with the WHO logo and a 'Report an attack' button. A central message box states: 'Only fill out if safe and secure to do so (names, locations or other sensitive information will be kept confidential and secure)' and 'Please fill out the form as completely as possible.' The form is divided into two main sections: 'Personal Information' and 'Attack Description'. The 'Personal Information' section contains a checkbox for 'I wish to remain anonymous', fields for 'Full Name', 'Phone Number', and 'Email', a dropdown for 'Affiliation/Organization', a 'I am' dropdown menu, an 'Other' checkbox, and a checkbox for 'I agree to be contacted for confirmation and/or further details'. The 'Attack Description' section features a 'Description' text area, an 'Immediate Impact' text area with a small example text, and a list of 'Affected health resources' with dropdown menus for 'Health care Facilities', 'Health care Transport', 'Health care Personnel', 'Health care Supplies/Assets', 'Health care Warehouse/Storage', and 'Health care Patients'. An 'Other' checkbox is also present at the bottom of this section.

reports submitted to WHO are as comprehensive as possible, facilitating comparative analysis. The SSA first categorizes an attack as either direct or indirect and targeted or not targeted.⁴⁴ Any report that is determined to be either direct or targeted in nature is automatically labeled as an attack on health care, with indirect and non-targeted events reviewed by WHO on a case-by-case basis.⁴⁵ Under these broad categories, the SSA provides for 15 specific categories of attack types, including arrest, militarization of a civilian health care facility, removal of health care assets, and violence with heavy weapons.⁴⁶

Through this standardized form—which collects the date, location, and nature of the attack, as well as health resources harmed—the SSA allows for a streamlined data collection process that can be implemented throughout the world, with reported information triggering WHO investigation and data collection.⁴⁷ The promise of the SSA is that all relevant data in complex humanitarian emergencies can be uniformly collected, allowing for comparisons over time and across countries.⁴⁸ Through the designation of an attack on health care focal point in each WHO Country Office (a position usually filled by the WHO incident manager, emergency manager, or health cluster coordinator), data from both primary and secondary sources can be investigated and harmonized through WHO staff with knowledge of the country context and then verified by WHO headquarters before publicly disseminating the data through the SSA.⁴⁹

In verifying the reliability of the data, WHO categorizes the collected data based on the source of the information, assigning each reported attack a level of certainty according to an established classification system, as detailed in Table 1: rumor, possible, probable, or confirmed.⁵⁰ While the SSA seeks to make public any attacks on health care as quickly as possible, this authentication process seeks to ensure the accuracy of the data, and thus the reliability of the SSA. Only after a report and its classifications have been cleared by the WHO Country Office, the attacks on health care focal point, and the WHO representative is the report disseminated through the SSA dashboard.⁵¹

Data dissemination

In publicly presenting the collected data on attacks on health care, the SSA dashboard interface, as seen in Figure 3, shares data on the number of attacks, the extent of death and injury, and the scope of countries and territories in which attacks have taken place.

While displaying aggregate data concerning attacks on health care, the SSA dashboard also provides a searchable database, with access to data on specific attacks, including categorized information on the country, date, and type of attack.⁵² By focusing on both the direct casualties and the secondary effects of attacks (such as the impact on medical transport, supplies, and facilities), the SSA shares a more complete understanding of the public health

TABLE 1. Source-of-information categorizations under the SSA

| Certainty-level category | Category description |
|--------------------------|--|
| Rumor | <ul style="list-style-type: none"> • Social media post (Twitter or Facebook) • Hearsay • Form submission from anonymous source |
| Possible | <ul style="list-style-type: none"> • Media report from local or international news source • Communication from an organization not defined in the partner group that an attack has been made against them |
| Probable | <ul style="list-style-type: none"> • One eyewitness accounts of the attack as told to one or more SSA partner(s) • Two secondary accounts (not eyewitnesses) of the attack as told to one or more SSA partner(s) |
| Confirmed | <ul style="list-style-type: none"> • Communication from an SSA partner that an attack has been made against them • One eyewitness account by someone from the SSA partner group • Two eyewitness accounts of the attack as told to one or more SSA partner(s) • Types and sources of information that would be graded as “probable,” plus a photo, video, or satellite image of the attack or its aftermath, or an international media or police report that provides clear evidence of the attack |

impacts of attacks on health care.

The SSA thereby provides data to the UN and other stakeholders to use as official records to characterize the trends of attacks, promote evidence-based advocacy, and design strategies to reduce their prevalence in complex humanitarian emergencies.⁵³ Compared with complementary NGO databases, as seen in Table 2, the SSA provides rapid dissemination of data in the public domain in addition to periodic reports, using a transparent methodology that is publicly available and a standardized approach that allows for analysis over time and across countries.⁵⁴

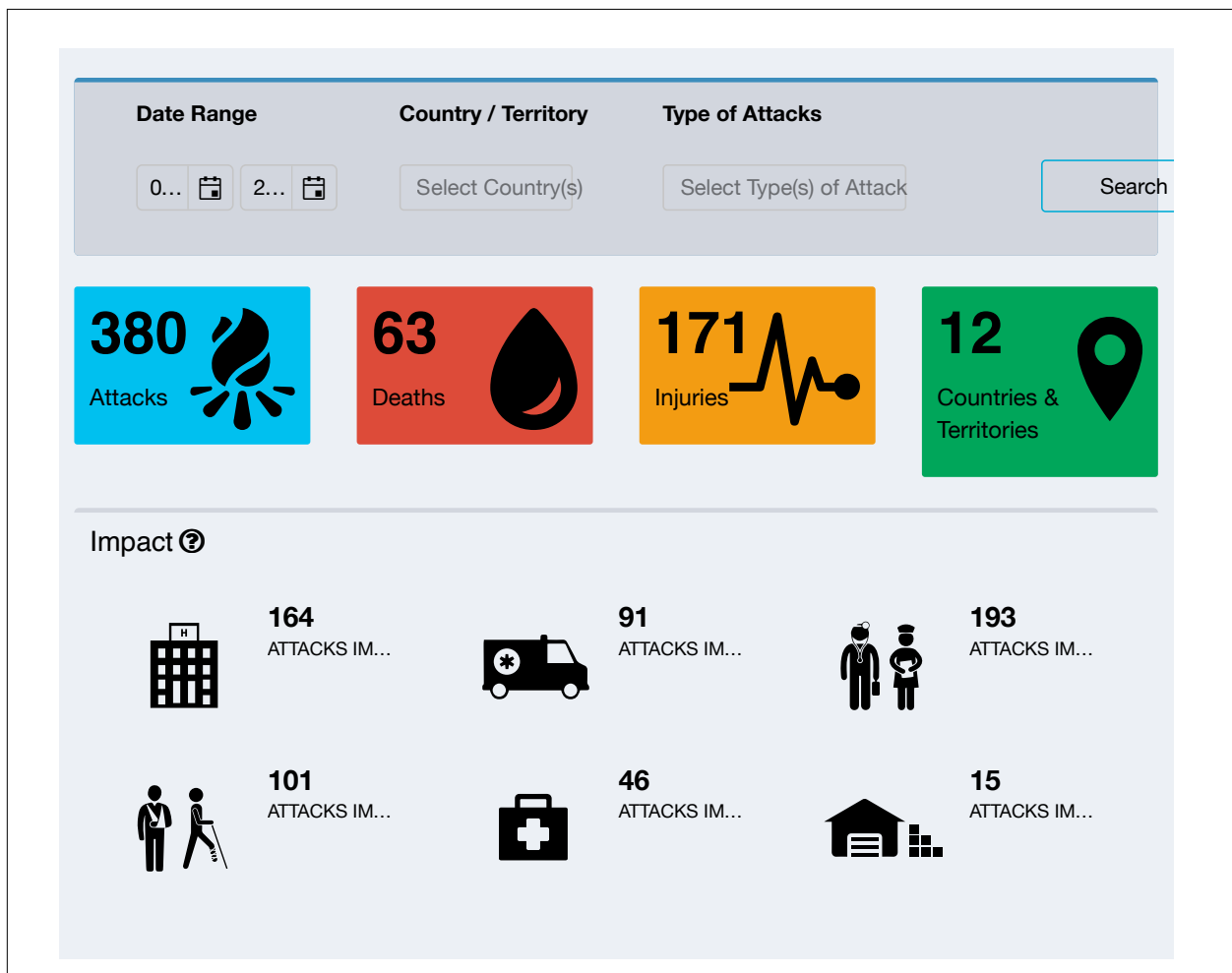
Where WHO does not make some details public within the SSA—citing security, verification, and safety reasons—Table 3 provides an overview of how data are categorized as either publicly

shareable or publicly non-shareable.⁵⁵ (WHO does not consistently collect or verify data that are not disseminated publicly under the SSA.) These limitations in disseminating details on the public platform can impact stakeholders in facilitating international accountability for attacks on health care.

International accountability

The public dissemination of data on attacks on health care is crucial in facilitating international accountability through independent advocacy, public pressure, and global governance. Ensuring that SSA data are transparently collected and publicly disseminated allows NGOs, partnering states, and international organizations to implement risk reduction and health system resilience measures.

FIGURE 3. SSA dashboard interface



Data monitoring thus provides a path for human rights accountability to protect health care from attacks. International monitoring and review institutions have evolved to lay a foundation for human rights accountability in global health.⁵⁶ Where fact finding and awareness-raising have long been powerful tools of human rights advocacy, public health data can serve as indicators of human rights violations, enhancing the visibility, objectivity, and credibility of human rights claims.⁵⁷ Clarifying the nature of attacks on health care, SSA data can be used as a basis for additional investigation to substantiate violations of human rights and for political advocacy to mitigate health harms through policy reforms. SSA monitoring is already being used to support the political advocacy of UN bodies such as the UN Office for the Coordination of Humanitarian Affairs.⁵⁸ In supporting global governance under international humanitarian law, data collection and dissemination can apply pressure on perpetrators of attacks and prevent future

attacks. Yet, it remains unclear whether monitoring attacks on health care through the SSA has been successful in facilitating accountability for human rights violations.

Facilitating accountability through monitoring

The SSA provides a foundation for monitoring attacks on health care, but refinements to this monitoring mechanism will be necessary for SSA data to be effective as a resource for stakeholders to facilitate human rights accountability. WHO continues to face barriers in collecting and disseminating necessary data, with political obstacles to collecting data at the country level, methodological challenges in reporting data from different sources, and institutional limitations in disseminating data to prevent attacks. Where the SSA is facing limitations in meeting WHO's objectives (with a precipitous drop in reported data in 2020 under-

TABLE 2. Comparison of the SSA with existing databases that monitor attacks on health care

| | Data in the public domain | Event-based continuous updates | Transparency of methodology |
|-----------------------------|---------------------------|--------------------------------|-----------------------------|
| ICRC | X | ✓ | X |
| MSF | X | ✓ | X |
| Physicians for Human Rights | X | ✓ | ✓ |
| Insecurity Insight / SHCC | ✓ | ✓ | ✓ |
| SSA | ✓ | ✓ | ✓ |

Note: ✓ indicates availability of a feature and X indicates non-availability of a feature

TABLE 3. Criteria for deciding whether information is disseminated publicly via the SSA

| Data that are made public | Data that are not made public |
|---|---|
| <ul style="list-style-type: none"> • Country of attack • Date and time of attack • Health resources affected by the attack • Type of attack • Type of facility impacted • Aggregate-level data on death, injuries, and removal of personnel • Level of certainty | <ul style="list-style-type: none"> • Province and city/town of attack • Identities of source information • Type of source data (eyewitness or not) • GPS coordinates of reported attacks • Name of health facility and affiliation • Description of attack, circumstances, and the impact on health services • Disaggregated data by sex, age, and personnel type • Follow-up actions taken |

mining the system's credibility), refinements in collecting and disseminating SSA data can better clarify the nature and the extent of attacks on health care systems, examine the consequences for health care delivery and public health, analyze global and context-specific trends and patterns of violence, and provide an evidence base from which to facilitate accountability for attacks on health care. Through these political, methodological, and institutional refinements to the SSA, WHO can work to reform data collection and disseminate data impactfully to protect health care in complex humanitarian emergencies.

Political obstacles to collecting data

Where the SSA is not seen as a political priority on the WHO agenda—leading to limited buy-in at the country level—reforms to integrate WHO country offices into the SSA, with resources to support not only data collection but also analysis of attacks, can address barriers to data collection, elevate the SSA on the country office agenda, and strengthen the capacity of SSA data as a resource to facilitate accountability for health and human rights. Country level buy-in is seen as limited due to both political and capacity constraints, with concerns that WHO country representatives must seek—above all else—to maintain effective working relationships with the ministry of health to promote other national health programs. Where SSA data collection may undermine national relationships, especially in countries suffering complex humanitarian emergencies, efforts to facilitate accountability for human rights violations may limit WHO diplomacy, threaten WHO staff safety, and weaken WHO health programming.

Thus, it will be crucial for the SSA to further integrate data collection into country level programming by providing high-level WHO support and dedicated data collection resources—highlighting the importance of the SSA as a public health priority and defending SSA data when member states challenge monitoring efforts. This high-level political support can support country office staff in the collection and categorization of relevant details not currently monitored under the SSA, including

details on the perpetrators (where ascertainable), types of weapons (for example, aerial bombing or tank attack), types of attacks (for example, criminal detention or kidnapping), and specific locations of attacks. Overcoming barriers in identifying perpetrators and weapons, the collection of more specific information concerning the type of attack would allow global and state partners to compare data meaningfully, utilizing these data to facilitate accountability.

Methodological challenges in reporting data

WHO must additionally address the methodological limitations of the SSA, as the methodology neglects the details of attacks that must be reported in order for SSA data to become an effective resource in facilitating accountability for attacks against health care. These methodological gaps are generally acknowledged to include a lack of contextual data in event descriptions, lack of data harmonization with other monitoring efforts, and lack of independent evaluation to assess data accuracy. Collecting information about the context of attacks will be crucial for situating an attack within the political, economic, and social reality of the relevant region or country. Considering this context can allow the SSA to account for impacts on health care that stem from the mere threat of violence. Where the SSA disseminates data only on realized attacks, it is increasingly clear that health care facilities may preventatively cease operations due simply to the fear of an impending attack, with effects on the health care system that WHO must monitor to facilitate accountability.⁵⁹

These methodological shortcomings require revision of the methodology or additional research efforts to monitor the contexts of attacks on health care, complemented by secondary data sources from organization partners and confirmed through independent assessments. Strengthening the credibility of WHO data reporting, WHO can look to harmonize its data with existing organizations (such as Insecurity Insight and coalitions such as SHCC) that already collect data related to attacks on health care—but often differ substantially from SSA data. Collaborative data sharing partnerships can

help WHO compare SSA data with other sources—understanding where methodological differences lead to reporting differences—while strengthening institutional partnerships for data collection and dissemination. To ensure the credibility of reported data, WHO can enlist an independent evaluation of SSA data and the data collection methodology, sharing recommendations publicly to support WHO and its partners in assessing the SSA's context specific and systemwide methodological weaknesses.

Institutional limitations in disseminating data

Finally, in disseminating data impactfully to prevent attacks on health care, there is an institutional imperative in global health governance to support efforts to facilitate accountability. Attacks with impunity are increasingly observed in complex humanitarian emergencies, from Tigray to Gaza, necessitating international accountability that moves beyond monitoring attacks through the SSA to engage with the perpetrators of attacks on health care. Yet, with WHO finding that the SSA lacks both the mandate and the capacity to identify perpetrators, concluding that World Health Assembly directed WHO simply to “raise awareness” of attacks, WHO's refusal to identify responsible parties in attacks on health care undermines efforts to engage with those who attack health workers, weakening efforts to prevent future attacks.⁶⁰ In supporting advocacy to mitigate attacks on health care, from top-down UN resolutions to bottom-up civil society protests, WHO must analyze trends in the context of reported attacks, frame preventive measures, and support perpetrator engagement.

Facilitating accountability through global health governance, institutional coordination is needed to improve the visibility of the SSA within WHO and throughout the UN, analyze data to support engagement with perpetrators, and strengthen the SSA as an effective mechanism to safeguard health and human rights. While preventive measures are understandably context specific, further analyses of the SSA data can increase the visibility of existing challenges, provide data to support advocacy, and push the global community to

consider policy reforms to prevent future attacks. In galvanizing global action, WHO must further strengthen the SSA to assess the health impact of attacks and release statements to condemn these health impacts. Developing research based on the SSA, providing resources to conduct in-depth case studies of the context-specific impact of attacks on health care, will be crucial to WHO leadership in complex humanitarian emergencies and accountability efforts to protect health and human rights.

Conclusion

There is international legitimacy in the data that WHO collects and disseminates through the SSA, but as WHO expands the implementation of the SSA in additional countries, it will be crucial that stakeholders build on its strengths in mitigating attacks on health care. Policy attention to attacks on health care has long followed a familiar pattern—rapid condemnation under international humanitarian law followed by extended neglect until another major attack occurs. In order to avoid such a reactive cycle of attention to health and human rights, the SSA must strengthen its monitoring to be effective as a resource to facilitate accountability. In confronting the threat of attacks against health care in complex humanitarian emergencies, WHO must address political obstacles, methodological challenges, and institutional limitations in SSA efforts to monitor the impact of attacks on health care, improving the effectiveness of the SSA as a mechanism to facilitate accountability for realizing health as a human right.

Acknowledgments

This article is dedicated to the memory of Lola Sweicarz Lewin (1924–2021), a loving grandmother, who survived the genocidal rage of the Holocaust and taught succeeding generations to build a better world for health and human rights. We are grateful for the dedicated research assistance of Hanna Huffstetler, who provided crucial research on human rights accountability as a foundation of public health protection.

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VIEWPOINT

Addressing the Boko Haram-Induced Mental Health Burden in Nigeria

ADEWALE OLUSOLA ADEBOYE

In Nigeria, the Boko Haram insurgency has opened up wide-ranging discussions regarding human security and human rights. The crisis has exposed the sheer neglect and near exclusion of people under mental distress from health facilities, despite the urgent need for adequate mental health support and care for those who have experienced extreme violence. If people are unable to receive mental health care, the crisis will likely lead to further violence and other human rights abuses. As well as ensuring that there are mental health care services available, government leaders must address the social determinants of mental health. This includes providing legal support to ensure justice for victims; promoting community enterprises to help build communal resilience; undertaking awareness and information campaigns on the value of mental health support interventions; and encouraging people to recognize that mental health is a human right. To achieve all of these things, new legislation and dedicated funding is needed.

I have worked for the past decade with multilevel local, national, transnational, and international stakeholders, including serving as the secretary and Anglophone West Africa focal representative in the Africa Working Group of the Global Action Against Mass Atrocities and, for a time, country coordinator for the Terrorism Research Initiative–Nigeria. Thus, I have long been concerned about the impact of these attacks on the population’s mental health and, accordingly, recognize the need to protect mental health as a fundamental human right. By applying mass atrocity prevention and human rights lenses to the unique public and mental health challenges of Nigeria, this Viewpoint beams a searchlight on ways to address mental distress after encounters with Boko Haram.

Boko Haram and its impact in Nigeria

Nigeria’s 12-year conflict with Boko Haram has devastated communities in the country’s northeastern states.¹ Boko Haram has targeted its attacks on both civilians and security personnel, damaging and destroying buildings and public infrastructure. Local communities have suffered grave human rights abuses as a result of the incessant raids.² These abuses include murder, abduction, sexual violence, forced labor, forced conscription of children, looting, and burning public buildings (such as schools), personal property (such as farmland), and, in some cases, entire villages.³ Since the beginning of the conflict, more than 43,000 people have died from Boko Haram violence.⁴ Those who have survived this violence are often left with enduring physical and mental trauma.⁵

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Mental health as a human right

The International Covenant on Economic, Social and Cultural Rights (ICESCR) asserts that “health is a fundamental human right indispensable for the exercise of other human rights where every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.”⁶ The African (Banjul) Charter on Human and Peoples’ Rights draws on language from the ICESCR and also mandates the health security of individuals as a human right.⁷ Nigeria ratified the United Nations Convention on the Rights of People with Disabilities in 2007 and its Optional Protocol in 2010, recognizing the importance of mental health.⁸ Human rights demands adequate and urgent care for survivors of trauma, especially in high-burden environments such as war zones or mass atrocity environments.

Despite these commitments to human rights, Nigeria lacks a national mental health policy. The World Health Organization estimates that over 2 million of the country’s near 200 million residents suffer from depressive and anxiety disorders.⁹ However, there are insufficient mental health workers in Nigeria to cater to the dispersed population, even without the burden of Boko Haram-induced mental distress. For example, in one of the northeastern affected states, Borno, 80% of local government areas have insufficient numbers of functioning health facilities.¹⁰ During periods of conflict or postconflict, heavier burdens are placed on every aspect of the public sector, thereby forcing facilities to compete against each other for reduced budgetary allocations.

Consequently, public health facilities and services in Nigeria, including mental health services, are in a poor state to respond to a crisis such as mass atrocity. Accessibility to mental health care services in the northeast is severely restricted, with mental health services and staff unable to meet the needs of individuals requiring attention.¹¹ In 2020, there were about 250 psychiatrists in the entire country: community mental health task-shifting pilot programs were limited to a few locations.¹² As a result, the impacts from trauma—such as post-traumatic stress disorder, depression, anxiety, and

drug dependence—go untreated. This exacerbates the harm that Boko Haram has inflicted on the community at large and increases the risk of perpetuating the cycle of violence.

Addressing social determinants and community relationships

To limit the long-term mental health impacts of Boko Haram violence, governments at the local, state, and national levels must protect and fulfill victims’ mental health rights, without discrimination. In a multidimensional, intersectoral response, Nigerian officials must reinforce support for the social determinants of mental health, recognizing that individual needs and community relationships are fundamental in promoting and protecting improved mental health and well-being.¹³

The lack of mental health services compounds survivors’ inability to adjust and cope with the losses and trauma they have experienced. Across most of the country, people who have experienced mental distress remain stigmatized and discriminated against. Personal and religious beliefs may cause survivors of these atrocities to reject mental health interventions. Government-led awareness and education campaigns at the local or community levels, and in partnership with religious institutions, could help promote the acceptance of mental health interventions.

Reparation, another important mitigating factor in healing, has not yet been addressed. The legal system needs to provide official recognition of victims’ need for justice and develop strategies to help people who have been kidnapped or injured by Boko Haram. Although testifying must be handled sensitively to avoid retraumatizing victims, the courts can provide justice and closure for those who have been harmed.

The suffering caused by Boko Haram is a collective loss, as well as an individual one. An injury to one community member injures all. While the community has experienced harm, the community can also be a source of healing. Cultural and community affiliations promote resilience in the form of family, cultural, religious, and traditional

associations. Training in skills acquisition and enterprises, such as soap making and sewing, has offered communities collective coping solutions to mitigate suffering.¹⁴ More such opportunities are needed.

Conclusion

The Boko Haram insurgency has exposed serious and substantive flaws in Nigeria's public health system. Nigeria has human rights obligations to address these failings, and must do so in a way that is consistent with the Convention on the Rights of Persons with Disabilities. The United Nations Human Rights Commission has been advocating for the domestication of this convention at state levels for some time, to promote the human rights entitlements of people exposed to Boko Haram atrocities. In particular, it is imperative that the National Assembly pass a mental health bill that, among other things, will lead to an increase in the number of mental health workers and to a reduction in discrimination and stigma.¹⁵ Local government and state emergency response teams could also advocate for such legislation. Mental health support in Nigeria, especially in the northeast, requires multidimensional and multidisciplinary approaches for research and practice that frame health issues within the broader context of the psychosocial well-being and rights of postconflict societies. It must provide justice, employment, and economic support, all of which contribute to sustained good mental health of individuals and communities.¹⁶

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Quantifying the Ripple Effects of Civil War: How Armed Conflict Is Associated with More Severe Violence in the Home

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Abstract

Both the fields of public health and that of human rights seek to improve human well-being, including through reducing and preventing all forms of violence, to help individuals attain the highest quality of life. In both fields, mathematical methods can help “visibilize” the hidden architecture of violence, bringing new methods to bear to understand the scope and nuance of how violence affects populations. An increasing number of studies have examined how residing in a conflict-affected place may impact one of the most pervasive forms of violence—intimate partner violence (IPV)—during and after conflict. This paper contributes to this effort by examining whether severe forms of IPV are associated with previous experience of political violence in one conflict-affected country: Liberia. Our findings indicate that living in a district with conflict fatalities increased the risk of IPV among women by roughly 60%. Additionally, living in a district with conflict fatalities increased the risk of a past-year injury from IPV by 50%. This analysis brings to light links between two of the most pervasive forms of violence—political violence and violence against women. The findings suggest that women residing in a district that is more highly affected by conflict, not only people experiencing direct trauma during conflict, may be at risk of increased violence long after peace is declared. These findings point to the need for targeted programs that address IPV postconflict.

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Introduction

Violence, including political conflict and interpersonal violence, accounts for a significant burden of injury and death worldwide.¹ For the purposes of this paper, political violence is defined as “the use of force by a group with a political purpose or motivation.”² Interpersonal violence is defined as “the intentional use of physical force or power, threatened or actual, against another person, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation.”³

Both the fields of public health and that of human rights seek to improve human well-being, including through reducing and preventing all forms of violence, to help individuals attain the highest quality of life. The right to health and the right to live a life free from violence are enshrined in human rights law and promoted by the World Health Organization (WHO).⁴ While addressing violence is core to both human rights and public health, each field leverages distinct approaches to understand the abuses that threaten human well-being.

One of the ways that human rights efforts have historically sought to mobilize action is through advocacy. In many cases, the images associated with atrocities—in media portrayals and through victim narratives—have played a key role in engaging global attention and action. Yet, feminist and post-colonial scholars have interrogated how “atrocities aesthetics” can distort our understanding, privileging certain forms of victimization while dismissing others.⁵ As noted by Randle DeFalco, “dominant socially shared understandings of what constitutes an atrocity are grounded in an aesthetic model of large-scale harm causation that is comprised of two key elements: spectacle and familiarity.”⁶ Media accounts can both amplify and distort human rights advocacy, narrating and re-narrating stories that play into comfortable understandings of what atrocities look like—a practice that can occlude an accurate understanding of how and where abuses occur.⁷

To address this challenge, a number of human rights organizations have sought to ground

advocacy narratives in systematic analyses of data, a practice that has become increasingly common in recent decades.⁸ The field of public health is founded on a strong tradition of conducting large-scale systematic efforts to quantify morbidity and mortality through population-based surveys, clinical records, rapid needs assessments, and other approaches. As each field grapples with the ability to collect and analyze ever larger data sets with increasingly sophisticated analytical techniques, they can learn from and complement each other.

Mathematical methods in particular can help “visibilize” the hidden architecture of violence, bringing new methods to bear to understand the scope and nuance of how violence affects populations. By helping lay bare patterns of abuse that may not conform to our understanding of “typical” atrocities, these approaches can represent a powerful tool to advance the twin pursuits of public health and human rights to recognize and address grave harms. Perhaps nowhere is this leveraging of empirical methods more important than for a form of violence that is notoriously hidden—gender-based violence (GBV).

GBV refers to any harmful act that is perpetrated against a person’s will and that is based on socially ascribed gender differences between males and females; it is one of the most prevalent forms of interpersonal violence and has been called one of the most pervasive forms of human rights violations worldwide.⁹ Globally, it is among the top 10 causes of disability-adjusted life years lost and disproportionately affects women.¹⁰ GBV not only carries severe physical, psychological, and social consequences but also keeps women from fully engaging in political and economic systems.¹¹

The past four decades have witnessed a belated recognition that addressing GBV is fundamental to protecting human rights. A succession of meetings and international commitments in the 1990s recognized the vital importance of violence prevention as a public health and human rights imperative.¹² One of the most common forms of GBV is intimate partner violence (IPV). WHO defines IPV as “behavior by an intimate partner or ex-partner that causes physical, sexual or psycho-

logical harm, including physical aggression, sexual coercion, psychological abuse and controlling behaviours.” As governments turned their attention the prevention of GBV, including IPV, there was a call for rigorous, population-based research that could provide an empirical foundation for action.¹³ This call mirrored a wider trajectory in the field of human rights to draw on epidemiological methods and population-based data to examine some of the most hidden forms of violence, particularly in conflict and crisis. Oskar Thoms and James Ron trace the influence of methods used to quantify the cost of conflict, noting that “epidemiologists are gradually demonstrating that most existing studies grievously underestimate war’s overall human cost by failing to capture its indirect and long-term impacts.”¹⁴

An increasing number of studies have begun examining how residing in a conflict-affected place may impact IPV during and after conflict.¹⁵ This paper aims to contribute to this continued effort by examining whether severe forms of IPV are associated with previous experience of political violence in one conflict-affected country: Liberia. The conclusion will explore the long-term repercussions of conflict for individuals and communities, and the implications for public health and human rights.

Beyond battle deaths: Quantifying the ripple effects of war

Increasingly, studies have documented the detrimental impacts of conflict, looking not only at excess mortality but also at a range of other health outcomes, including injury, trauma, and disease.¹⁶ A central conundrum, however, is that the chaotic nature of war has made the systematic examination of its human impact difficult or impossible. Christopher Murray et al. discuss how examining the health impact of conflict has fallen into a limbo between the fields of public health and political science and receives inadequate attention from both.¹⁷ However, new techniques to measure physical and mental health are changing existing understandings of the impact of war. A number of efforts have taken the first steps to estimate the direct and indirect effects of political instability in new ways.

Population-based surveys that draw on family health history and verbal autopsy have proven effective in documenting the impact of conflict in a number of countries, as have nesting mortality assessments within other planned assessments.¹⁸ These techniques have shown that indirect causes of death—such as inadequate access to water, sanitation, and health services—have accounted for most civilian deaths and have had a differentially large impact on children and early teens.¹⁹

Violence: From political conflict to interpersonal violence

One of the newest frontiers in understanding conflict involves quantifying how political violence may impact human aggression even after formal peace is declared. An increasingly rich body of literature documents the “contagion” of violence. Like diseases and many complex social phenomena, violence can be transmitted across individuals, groups, generations, and different levels of social organization.²⁰

Together, political violence and GBV, including IPV, represent two of the most pressing affronts to human rights and well-being throughout the world; understanding how these abuses are linked will help advance an understanding of how cycles of violence can potentially be disrupted.²¹ Globally, 35% of women globally have been victims of physical or sexual abuse during their lifetime.²² In turn, war accounts for roughly one-fifth of deaths globally.²³

IPV can be a major factor affecting the physical and mental health of individuals before, during, and after conflict.²⁴ Because it occurs in homes rather than in theaters of war and may be condoned or overlooked because of cultural norms, IPV is often far less visible than conflict-related sexual violence.²⁵ This form of abuse, however, may be more common than sexual violence perpetrated by armed actors during war.²⁶ Relatively few studies have examined how political violence at the community level may impact IPV, though this field is rapidly expanding to understand how residing in a conflict-affected place may impact IPV after peace has been declared.²⁷ However, previous re-

search from Liberia has shown that residence in a fatality-affected district in Liberia was significantly associated with a 50% increase in IPV and increases in nonpartner physical violence.²⁸

This paper aims to extend this body of work by examining whether severe forms of IPV are associated with previous experience of political violence. The multilevel analysis focuses on a single conflict-affected setting—Liberia—and leverages household-based survey data collected through Liberia’s Demographic and Health Survey (DHS) for IPV outcomes, and data gathered from the ACLED database for political violence exposures. Results are discussed in the context of the long-term impact of conflict on individuals and communities, and the implications for public health and human rights.

Liberia country profile

Situated in West Africa, Liberia is one of the continent’s smaller countries. In 1979, riots broke out in the country in reaction to rising prices of rice, economic stagnation, and increasing tension between the Americo-Liberian population and Indigenous groups.²⁹ The ensuing unrest launched the first Liberian war (1985–1996). From 1989 to 1997, according to national-level data, the countrywide conflict resulted in the deaths of over 150,000 Liberians.³⁰ In 1999, antigovernment fighting once again broke out. Rebel groups entered Liberia from neighboring countries and fighting became widespread in the following year.³¹ The Second Liberian Civil War (1999–2003) ended after international intervention, when a peace agreement was signed and rebel troops were demobilized. In both wars, combatants were both victims and perpetrators of human rights abuses, including rape, torture, and murder.³²

Study data and methods

Analytic sample

This study combines geo-coded information from two existing datasets: the Liberia DHS, which provides individual-level data on health and social outcomes in 2007—four years after the Liberian Civil War—and ACLED, which provides informa-

tion on the number of conflict events and fatalities occurring during Liberia’s civil unrest from 1999 to 2003.³³ We chose the 2007 Liberia DHS because it provides the first population-based data in Liberia after the conflict. While other DHSs are more recent, they represent a longer lag between the conflict and the outcomes we are seeking to understand. In the 2007 DHS, 7,092 of 7,448 women sampled completed the survey. Of these, a total of 4,913 women were sampled for the domestic violence module. Roughly 400 individuals were not given a geographic identifier in the DHS dataset, representing 8.4% of the sample, leaving 4,502 women. Of these 4,502 women, just over 80% (n=3,648) were administered questions about intimate partner violence because they reported being currently or formerly in a union. Over 98% of the sample (n=3,596 women) responded to this question and are thus eligible for inclusion in the analysis.

Severe intimate partner violence in the past 12 months

Ever-partnered women were classified as having experienced partner physical violence or partner sexual violence within the last 12 months if they replied “yes” to at least one item from Table 1 and responded that the violence occurred “sometimes” or “often” within the last 12 months.

Severe IPV is defined by WHO “on the basis of the severity of the acts of physical violence: being beaten up, choked or burnt on purpose, and/or being threatened or having a weapon used against you is considered severe. Any sexual violence is also considered severe.”³⁴ Those women who reported any of the forms of violence from items iv–vii were defined as having experienced severe IPV. Those women who responded having experienced any of the forms of violence from items viii or ix were defined as having experienced sexual IPV. This approach is in keeping with other studies that have looked at the severity of IPV.³⁵

Our project assessed IPV in the categories given in Table 1: no IPV, less severe IPV, severe IPV, and sexual IPV. WHO categorizes sexual IPV within the severe category; we assessed this form of violence separately from physical violence to deter-

mine whether there might be differences between sexual and physical IPV. This approach reflects the fact that IPV often escalates from less severe to more severe, either during the same altercation or over time. Looking at only one form of violence while excluding less severe forms of violence would result in untenably small sample sizes for the analysis. Women are classified according to the most severe form of violence they have experienced during the past year, with sexual IPV considered the most severe.

Injuries from intimate partner violence in the past 12 months

Of those women reporting having experienced IPV, women were given three questions that assessed three different sets of injuries: (1) cuts, bruises, or aches; (2) burns, eye injuries, sprains, or dislocations; and (3) deep wounds, broken bones, broken teeth, or any other serious injury. Women who responded “yes” to any of the three questions were classified as having experienced injuries from past-year IPV.

Primary predictor: Conflict exposure

ACLED defines a politically violent event as “a single altercation where often force is used by one or more groups for a political end, although some instances, including protests and non-violent activity, are included in the dataset to capture the potential pre-cursors or critical junctures of a conflict.”³⁶ The quantification of politically violent events in Liberia allows us to characterize conflict in the country through fatalities and events—the primary expo-

sure for this analysis.³⁷ Events are any political incident, including clashes, protests, riots, and battles that occurred during the 1999–2003 civil war. If an event resulted in any deaths, then the number of fatalities were recorded. Thus, all fatalities occur as a result of a political event, but every event does not necessarily result in fatalities. The conflict measures were aggregated at the district level. There are 61 districts in Liberia, which are administrative areas defined by the national government. Districts were chosen because they are large enough areas to have large numbers of individuals and have heterogeneity across their levels of conflict exposure.

Potential confounding variables

Potential confounding variables measured for each woman were selected based on theory as well as by those variables that have been found to be significantly associated with interpersonal violence.³⁸

Model specification

Multilevel regression models were used to quantify the associations between levels of IPV (multinomial model) and experience of IPV-related injury (logistic model) with district-level conflict. Models contained a random intercept defining the district. Separate models were constructed using the primary exposure and the two alternative conflict measures. All models included the potential confounding variables described above. To account for the complex survey design of the DHS, the survey weights for the DV module were included in all analyses.³⁹ Analyses were conducted with Stata/SE 14.0.

TABLE 1. Questions assessing intimate partner physical and sexual violence from Liberia’s 2007 Demographic Health Survey

| Does/Did your (last) husband/partner ever do any of the following things to you? | |
|--|---|
| Less severe partner physical violence | (i) push you, shake you, or throw something at you (ii) slap you (iii) twist your arm or pull your hair |
| Severe partner physical violence | (iv) punch you with fists or something harmful (v) kick you, drag you, or beat you up (vi) try to choke you or burn you on purpose (vii) threaten or attack you with a knife, gun, or other weapon |
| Sexual intimate partner violence | (viii) physically force you to have sexual intercourse with him even when you did not want to (ix) force you to do any sexual acts you did not want to do |

Results

Severe intimate partner violence

Of the 3,596 women asked about past-year IPV, 18.5% (n=665) stated they had experienced less severe IPV, 12.6% (n=454) reported severe IPV, and 8.3% (n=299) reported sexual IPV. As noted in the methods, violence often escalates from less to more

severe forms of IPV. This is borne out by the data below: 96% of women who experience severe IPV also experience less severe IPV. While sexual IPV does occur without physical IPV, roughly half of women experiencing sexual IPV also experience severe IPV (Table 2). The distribution of demographic characteristics of women across the different levels of IPV is given in Table 3.

TABLE 2. Prevalence of different forms of past-year IPV

| | N (% of total sample) | % of total also experiencing less severe IPV | % of total also experiencing severe IPV |
|--|-----------------------|--|---|
| No IPV | 2,178 (62.39%) | -- | -- |
| Less severe IPV only | 526 (15.07%) | 526 (100%) | -- |
| Severe IPV (including women who also reported less severe IPV) | 479 (13.72%) | 461 (96.2%) | 479 (100%) |
| Sexual IPV | 308 (8.82%) | 205 (17.2%) | 145 (47.1%) |
| Total | 3,491 | | |

TABLE 3. Distribution of demographic variables across different forms of IPV

| | | N= 3,371 | | | |
|----------------------------|-------------------------------|--------------|-----------------|-----------------|-------------|
| | | No IPV | Less severe IPV | More severe IPV | Sexual IPV |
| | | N (%) | N (%) | N (%) | N (%) |
| Age (N, mean) | | 2178 (33.2) | 526 (30.9) | 479 (30.5) | 308 (30.2) |
| Education | No education (ref) | 1213 (50.9%) | 267 (54.0%) | 258 (50.6%) | 156 (54.3%) |
| | Primary | 651 (31.1%) | 163 (32.4%) | 155 (36.4%) | 112 (31.0%) |
| | Secondary and above | 314 (18.0) | 95 (13.6%) | 65 (13.0%) | 40 (14.7%) |
| Religion | Christian (ref) | 1822 (88.0) | 463 (86.9) | 416 (79.9) | 246 (84.4) |
| | Muslim | 270 (8.4) | 44 (10.2) | 49 (11.7) | 36 (11.4) |
| | Other | 86 (3.6) | 19 (2.9) | 14 (8.4) | 26 (4.2) |
| Civil status | Married (ref) | 1315 (51.7) | 272 (49.9) | 239 (61.7) | 190 (57.6) |
| | Living together | 681 (40.5) | 213 (32.6) | 156 (27.6) | 85 (32.5) |
| | Widow/divorced | 182 (7.8) | 41 (17.5) | 84 (10.7) | 33 (9.7) |
| Partner education | No education (ref) | 589 (28.6) | 146 (27.3) | 126 (29.5) | 88 (28.0) |
| | Primary | 457 (20.2) | 103 (23.6) | 109 (23.5) | 70 (21.8) |
| | Secondary and above | 1079 (51.2) | 261 (49.1) | 226 (47.0) | 140 (50.2) |
| Age married (N, mean) | | 2178 (18.1) | 526 (18.0) | 479 (17.7) | 308 (18.2) |
| Wealth | Poorest (ref) | 580 (24.1) | 127 (24.8) | 119 (23.0) | 71 (25.7) |
| | Poorer | 522 (21.3) | 112 (23.2) | 111 (27.3) | 84 (23.8) |
| | Middle | 456 (20.2) | 106 (19.8) | 95 (22.1) | 68 (20.8) |
| | Richer | 367 (21.3) | 112 (20.1) | 101 (16.6) | 51 (18.0) |
| | Richest | 253 (13.1) | 69 (11.1) | 53 (11.0) | 34 (11.7) |
| Employment | Didn't work in past 12 months | 518 (29.0) | 152 (28.0) | 134 (24.5) | 75 (25.3) |
| | Worked in past 12 months | 1655 (71.0) | 372 (72.0) | 344 (75.5) | 231 (74.7) |
| Aggregate violence measure | No violent experiences | 682 (21.9) | 115 (20.9) | 100 (13.6) | 42 (26.9) |
| | Violent experiences | 1496 (78.10) | 411 (79.1) | 379 (86.3) | 266 (73.1) |
| Alcohol | Partner doesn't drink alcohol | 1532 (54.2) | 284 (49.1) | 235 (56.2) | 172 (64.0) |
| | Partner drinks alcohol | 634 (45.8) | 240 (50.9) | 244 (43.8) | 134 (36.0) |

Analysis comparing districts with and without conflict fatalities. Compared to women living in a district with no conflict fatalities, the unadjusted relative odds of women reporting less severe IPV versus no IPV were 2.24 times greater among women living in a district with conflict fatalities (95% confidence interval (CI): 1.60–3.13). A similar association is seen with regard to severe IPV: women reporting severe IPV versus no IPV were roughly two times greater among women living in a district with conflict fatalities compared to no fatalities (odds ratio (OR) 2.11, $p < 0.0001$). Sexual IPV has a more attenuated relationship than the other forms of IPV to the conflict predictor. For a district experiencing fatalities versus no fatalities, the odds of sexual IPV compared to no IPV are 1.5 times higher with marginal significance (OR 1.51, $p = 0.055$).

The adjusted relative odds of experiencing less severe IPV versus no IPV among women living in a district with no fatalities compared to a district with any conflict fatalities were 67% higher for women living in fatality districts compared to their counterparts living in fatality-free districts (aOR 1.67, $p = 0.01$).

Women living in a district with any fatalities were 59% more likely to experience severe IPV than their counterparts living in fatality-free districts compared to the referent group (aOR 1.59, $p < 0.001$). Being widowed or divorced (aOR 2.95, $p < 0.001$), having a partner who drinks alcohol (aOR 2.88, $p < 0.001$), and having any past violent experiences (aOR 1.89, $p < 0.001$) were also risk factors for this abuse. Each additional year of age (aOR 0.96, $p < 0.001$) was a protective factor.

Compared to women living in a district with no conflict fatalities, the adjusted relative odds of women reporting sexual IPV versus no IPV were 5% higher for women living in a district with conflict fatalities. However, this result was not significant (aOR 1.05, $p = 0.80$) (Table 4).

Because this analysis parses the outcome into four levels, the sample size was too small to run across cumulative conflict event years. However, the additional injury analysis below provides some insight into how cumulative levels of conflict may be related to IPV.

Injuries resulting from intimate partner violence

Of the 1,418 women who reported any form of past-year IPV, 1,397 answered questions about injuries resulting from that violence (97.8% response rate). From this sample, 30.2% ($n = 419$) reported having an injury resulting from IPV.

Analysis comparing districts with and without conflict fatalities. In the adjusted model, living in a district with conflict fatalities was associated with a 50% increase in IPV-related injuries (aOR 1.52, $p < 0.05$; Table 5). Other variables significantly associated with increased risk of injury were being widowed or divorced compared to currently married (aOR 2.67, $p < 0.0001$); having a partner who drinks alcohol (aOR 1.87, $p < 0.0001$); and having any previous experiences with violence (aOR 1.59, $p < 0.05$). Protective factors were having a partner with primary versus no education (aOR 0.67, $p = 0.01$) and being in the second-richest wealth quintile versus the poorest (aOR 0.59, $p < 0.05$).

Analysis of cumulative conflict event years. A similar pattern is seen when looking at the burden injury while using a different measure of conflict. After adjusting for all independent variables in the final model, each additional conflict year was associated with an 11% increase in injuries associated with IPV (aOR 1.11, $p < 0.05$) (Table 6).

Limitations

The cross-sectional nature of the DHS limits the ability to draw causal conclusions about the impact of conflict on IPV. However, the fact that conflict events preceded the measurement of the outcomes helps establish a temporal, if not causal, relationship. Additional literature presented here supports the hypothesis that conflict may contribute to post-conflict IPV; however, this paper does not make causal claims. Because our analysis draws on secondary data, we were not able to design a survey that elicits additional pertinent information for this analysis (for instance, personal exposure to political violence). The DHS approach to measuring IPV can also be problematic, for it asks only ever-partnered women about IPV even though women in informal

or unstable relationships may also be at risk of IPV, and possibly at higher risk. Additionally, direct reporting to an interviewer may lead to systematic underreporting of this abuse.⁴⁰ Expanding this analysis to additional countries and undertaking qualitative work to better understand the dynamics and mechanisms at play in postconflict contexts would further our understanding of these issues.

Discussion

The pursuit of human rights is to allow all humans—

regardless of age, sex, national or ethnic origin, or other status—to live a life of safety, dignity, and freedom.⁴¹ Political violence and GBV represent some of the gravest threats to human rights globally.⁴² In 1993, the United Nations Declaration on the Elimination of Violence against Women recognized violence against women and girls as a violation of human rights.⁴³ This global acknowledgement of women’s right to “equal enjoyment and protection of all human rights and fundamental freedoms” helped propel a recognition that GBV is unacceptable in all contexts.

TABLE 4. Multinomial model for past-year IPV with dichotomous district-level fatalities, unadjusted and adjusted associations

| Less severe IPV (no IPV as reference) | | | | | | | | |
|---|-------------------------------|--|--|--|-------------|-------------------|-------------|-------------|
| | | | | | N= 3,371 | | | |
| Unadjusted association of less severe IPV | | | | | | | | |
| | | | | | OR | P value | Low CI | High CI |
| | | | | | 2.24 | p<0.0001 | 1.60 | 3.13 |
| Adjusted association of less severe IPV | | | | | | | | |
| | | | | | aOR | P value | Low CI | High CI |
| Districts with fatalities | | | | | 1.67 | 0.01 | 1.12 | 2.48 |
| Age | | | | | 0.97 | p<0.001 | 0.96 | 0.98 |
| Number of children under 5 | | | | | 1.05 | 0.27 | 0.96 | 1.16 |
| Education | No education (ref) | | | | -- | -- | -- | -- |
| | Primary | | | | 1.19 | 0.28 | 0.87 | 1.65 |
| | Secondary and above | | | | 1.45 | 0.07 | 0.98 | 2.13 |
| Religion | Christian (ref) | | | | -- | -- | -- | -- |
| | Muslim | | | | 0.76 | 0.38 | 0.41 | 1.41 |
| | Other | | | | 0.85 | 0.45 | 0.56 | 1.29 |
| Civil status | Married (ref) | | | | -- | -- | -- | -- |
| | Living together | | | | 1.24 | 0.10 | 0.96 | 1.59 |
| | Widow/divorced | | | | 1.12 | 0.53 | 0.78 | 1.59 |
| Partner education | No education (ref) | | | | -- | -- | -- | -- |
| | Primary | | | | 0.79 | 0.07 | 0.62 | 1.02 |
| | Secondary and above | | | | 0.77 | 0.05 | 0.59 | 1.00 |
| Age married | | | | | 1.00 | 0.80 | 0.96 | 1.03 |
| Wealth | Poorest (ref) | | | | -- | -- | -- | -- |
| | Poorer | | | | 1.0 | 0.9 | 0.6 | 1.5 |
| | Middle | | | | 1.0 | 0.9 | 0.7 | 1.5 |
| | Richer | | | | 1.1 | 0.6 | 0.7 | 1.6 |
| | Richest | | | | 0.9 | 0.8 | 0.5 | 1.7 |
| Employment | Didn't work in past 12 months | | | | -- | -- | -- | -- |
| | Worked in past 12 months | | | | 0.91 | 0.53 | 0.69 | 1.21 |
| Aggregate violence measure | No violent experiences | | | | -- | -- | -- | -- |
| | Violent experiences | | | | 1.79 | p<0.001 | 1.25 | 2.56 |
| Alcohol | Partner doesn't drink alcohol | | | | -- | -- | -- | -- |
| | Partner drinks alcohol | | | | 2.16 | p<0.001 | 1.72 | 2.72 |

For decades, scholars and advocates had challenged long-held beliefs that GBV was an inevitable and inherent by-product of war.⁴⁴ The declaration helped enshrine this belief in global doctrine. With an increased understanding of GBV during conflict came a recognition that some of the worst and most pervasive forms of violence during war included violence in the home.⁴⁵ Yet, we still have an incomplete understanding of how GBV changes during conflict, and how these changes persist after war has formally ended.

This paper represents a new contribution to

the literature examining whether the most severe forms of IPV are associated with previous experience of political violence. Living in a district that experienced conflict fatalities during war can increase the risk of experiencing severe and less severe forms of physical IPV, and being injured from IPV, in the postconflict period. Living in a district with any versus no conflict fatalities increased the risk of both less and more severe forms of IPV by roughly 60% for each form of violence compared to the referent group (no IPV).

Additionally, injury from IPV may serve as a

TABLE 4. *continued*

| Severe IPV (no IPV as reference) | | N= 3,371 | | | |
|--------------------------------------|-------------------------------|----------|----------|--------|---------|
| Unadjusted association of severe IPV | | | | | |
| | | OR | P value | Low CI | High CI |
| | | 2.11 | p<0.0001 | 1.65 | 2.70 |
| Adjusted association of severe IPV | | | | | |
| | | aOR | P value | Low CI | High CI |
| Districts with fatalities | | 1.59 | p<0.001 | 1.18 | 2.15 |
| Age | | 0.96 | p<0.001 | 0.94 | 0.97 |
| Number of children under 5 | | 1.06 | 0.30 | 0.95 | 1.19 |
| Education | No education (ref) | -- | -- | -- | -- |
| | Primary | 1.09 | 0.48 | 0.86 | 1.38 |
| | Secondary and above | 0.97 | 0.91 | 0.62 | 1.54 |
| Religion | Christian (ref) | -- | -- | -- | -- |
| | Muslim | 1.07 | 0.80 | 0.62 | 1.88 |
| | Other | 0.56 | 0.21 | 0.23 | 1.39 |
| Civil status | Married (ref) | -- | -- | -- | -- |
| | Living together | 1.04 | 0.81 | 0.73 | 1.49 |
| | Widow/divorced | 2.95 | p<0.001 | 2.08 | 4.17 |
| Partner education | No education (ref) | -- | -- | -- | -- |
| | Primary | 1.12 | 0.58 | 0.75 | 1.68 |
| | Secondary and above | 0.92 | 0.50 | 0.71 | 1.18 |
| Age married | | 0.99 | 0.47 | 0.95 | 1.02 |
| Wealth | Poorest (ref) | -- | -- | -- | -- |
| | Poorer | 1.12 | 0.61 | 0.72 | 1.76 |
| | Middle | 1.01 | 0.95 | 0.68 | 1.51 |
| | Richer | 1.22 | 0.30 | 0.83 | 1.79 |
| | Richest | 1.04 | 0.92 | 0.48 | 2.24 |
| Employment | Didn't work in past 12 months | -- | -- | -- | -- |
| | Worked in past 12 months | 0.91 | 0.41 | 0.72 | 1.14 |
| Aggregate violence measure | No violent experiences | -- | -- | -- | -- |
| | Violent experiences | 1.89 | p<0.001 | 1.41 | 2.54 |
| Alcohol | Partner doesn't drink alcohol | -- | -- | -- | -- |
| | Partner drinks alcohol | 2.88 | p<0.001 | 2.25 | 3.70 |

vital, but underreported, measure of the impact of violence in the home. Living in districts with any conflict fatalities increased the risk of a past-year injury from IPV by 50% ($p < 0.05$). There was also an evident dose-response relationship: for each additional year that a district experienced at least one conflict event, the odds of a woman reporting an injury from IPV increased by 11% (OR 1.11, $p < 0.05$).

Research from Uganda, Thailand, Peru, Burma, Cote D'Ivoire, and Liberia has found that women who have higher levels of conflict-related abuses also report higher levels of IPV victimiza-

tion during and after conflict.⁴⁶ This study adds to the growing literature on the links between violence that has begun to make evident the connection between political violence and postconflict IPV—and draws out additional information on how the most severe forms of IPV might be exacerbated. The findings from this and previous studies clearly show the subtle “ripple effects” of conflict on one of the most hidden forms of violence: IPV. Recognizing that violence may endure in communities after political conflict officially ends has implications for postconflict policy decisions, humanitarian

TABLE 4. *continued*

| Sexual IPV (no IPV as reference) | | N= 3,371 | | | |
|--------------------------------------|-------------------------------|----------|-------------|--------|---------|
| Unadjusted association of severe IPV | | | | | |
| | | OR | P value | Low CI | High CI |
| | | 1.51 | 0.055 | 0.99 | 2.29 |
| Adjusted association of severe IPV | | | | | |
| | | aOR | P value | Low CI | High CI |
| Districts with fatalities | | 1.05 | 0.80 | 0.71 | 1.56 |
| Age | | 0.95 | $p < 0.001$ | 0.94 | 0.97 |
| Number of children under 5 | | 1.00 | 0.97 | 0.88 | 1.14 |
| Education | No education (ref) | -- | -- | -- | -- |
| | Primary | 1.34 | 0.06 | 0.99 | 1.81 |
| | Secondary and above | 1.13 | 0.63 | 0.69 | 1.87 |
| Religion | Christian (ref) | -- | -- | -- | -- |
| | Muslim | 1.22 | 0.41 | 0.76 | 1.94 |
| | Other | 2.34 | 0.01 | 1.30 | 4.22 |
| Civil status | Married (ref) | -- | -- | -- | -- |
| | Living together | 0.65 | 0.04 | 0.43 | 0.97 |
| | Widow/divorced | 1.55 | 0.10 | 0.92 | 2.63 |
| Partner education | No education (ref) | -- | -- | -- | -- |
| | Primary | 0.91 | 0.58 | 0.65 | 1.27 |
| | Secondary and above | 0.78 | 0.11 | 0.57 | 1.06 |
| Age married | | 1.03 | 0.05 | 1.00 | 1.06 |
| Wealth | Poorest (ref) | -- | -- | -- | -- |
| | Poorer | 1.46 | 0.07 | 0.97 | 2.19 |
| | Middle | 1.39 | 0.13 | 0.90 | 2.15 |
| | Richer | 1.36 | 0.23 | 0.82 | 2.26 |
| | Richest | 1.50 | 0.10 | 0.92 | 2.43 |
| Employment | Didn't work in past 12 months | -- | -- | -- | -- |
| | Worked in past 12 months | 1.07 | 0.68 | 0.77 | 1.49 |
| Aggregate Violence Measure | No violent experiences | -- | -- | -- | -- |
| | Violent experiences | 3.23 | $p < 0.001$ | 1.89 | 5.54 |
| Alcohol | Partner doesn't drink alcohol | -- | -- | -- | -- |
| | Partner drinks alcohol | 2.19 | $p < 0.001$ | 1.60 | 2.98 |

response, and public health efforts.⁴⁷

The 2020 Global Peace Index describes a world emerging from the conflicts that have characterized the past decade, but moving toward continuing instability and uncertainty. Current conflicts are characterized by those same factors that are drivers of violence for women—not only during conflict but after: chronic poverty, a vacuum of state and civil institutions, poor access to health care and education, low levels of state accountability, and the risk of continuing instability. Without a better understanding of how two fundamental threats to human rights—war and GBV—are interlinked, we will be less prepared to address ongoing instability globally.

Conclusion

The past two decades have highlighted synergies between the fields of public health and human rights.⁴⁸ One vitally important area of convergence is in the understanding of how best to document, prevent, and address violence, particularly during conflict and its aftermath. Large population-based studies and increasingly sophisticated statistical techniques have allowed us to improve our understanding of risk factors and impacts of violence and have shaped policies and the deployment of resources around this issue.⁴⁹

The current analysis shows links between two of the most pervasive forms of violence—political violence and violence against women—and suggests that women residing in a district that is more

TABLE 5. Association of injuries related to IPV with dichotomous district-level fatalities

| | | N= 1,334 | | | |
|----------------------------|-------------------------------|----------|---------|--------|---------|
| | | aOR | P value | Low CI | High CI |
| Districts with fatalities | | 1.52 | <0.05 | 1.04 | 2.23 |
| Age | | 1 | 0.693 | 0.99 | 1.02 |
| Number of children under 5 | | 0.89 | 0.108 | 0.78 | 1.02 |
| Education | No education (ref) | -- | -- | -- | -- |
| | Primary | 0.99 | 0.947 | 0.73 | 1.33 |
| | Secondary and above | 1.1 | 0.503 | 0.84 | 1.43 |
| Religion | Christian (ref) | -- | -- | -- | -- |
| | Muslim | 1.12 | 0.573 | 0.75 | 1.69 |
| | Other | 0.94 | 0.837 | 0.49 | 1.77 |
| Civil status | Married (ref) | -- | -- | -- | -- |
| | Living together | 1.18 | 0.268 | 0.88 | 1.57 |
| | Widow/divorced | 2.67 | <0.001 | 1.88 | 3.80 |
| Partner education | No education (ref) | -- | -- | -- | -- |
| | Primary | 0.67 | 0.01 | 0.49 | 0.91 |
| | Secondary and above | 0.88 | 0.4 | 0.65 | 1.19 |
| Age married | | 0.98 | 0.21 | 0.94 | 1.01 |
| Wealth | Poorest (ref) | -- | -- | -- | -- |
| | Poorer | 0.99 | 0.98 | 0.69 | 1.45 |
| | Middle | 1.1 | 0.64 | 0.75 | 1.60 |
| | Richer | 0.59 | 0.01 | 0.39 | 0.87 |
| | Richest | 0.79 | 0.35 | 0.49 | 1.29 |
| Employment | Didn't work in past 12 months | -- | -- | -- | -- |
| | Worked in past 12 months | 0.84 | 0.32 | 0.60 | 1.18 |
| Aggregate violence measure | No violent experiences | -- | -- | -- | -- |
| | Violent experiences | 1.87 | <0.05 | 1.09 | 2.32 |
| Alcohol | Partner doesn't drink alcohol | -- | -- | -- | -- |
| | Partner drinks alcohol | 1.59 | <0.05 | 1.49 | 2.36 |

highly affected by conflict, not only people experiencing direct trauma during conflict, may be at risk of increased violence long after peace is declared. These findings point to the need for targeted programs that address IPV after a conflict. This form of violence may become elevated and persist at higher levels for years after war, especially in highly

war-affected areas.⁵⁰ Understanding the long-term impact of war is vital for effective and sustained recovery, yet there has been little scholarship on the enduring consequences of political violence. Assessing how violence may persist and morph after war is critical, since it may impact a country's ability to achieve sustained peace.

TABLE 6. Association of injuries related to IPV with cumulative district-level conflict events

| | | N= 1,334 | | | |
|----------------------------|-------------------------------|----------|---------|--------|---------|
| | | aOR | P value | Low CI | High CI |
| Event years (0-5) | | 1.11 | 0.03 | 1.01 | 1.22 |
| Age | | 1.00 | 0.71 | 0.99 | 1.02 |
| Number of children under 5 | | 0.90 | 0.11 | 0.78 | 1.02 |
| Education | No education (ref) | -- | -- | -- | -- |
| | Primary | 0.98 | 0.89 | 0.72 | 1.32 |
| | Secondary and above | 1.09 | 0.54 | 0.83 | 1.42 |
| Religion | Christian (ref) | -- | -- | -- | -- |
| | Muslim | 1.11 | 0.63 | 0.73 | 1.67 |
| | Other | 0.93 | 0.83 | 0.49 | 1.78 |
| Civil status | Married (ref) | -- | -- | -- | -- |
| | Living together | 1.17 | 0.30 | 0.87 | 1.56 |
| | Widow/divorced | 2.64 | p<0.001 | 1.86 | 3.77 |
| Partner education | No education (ref) | -- | -- | -- | -- |
| | Primary | 0.67 | 0.01 | 0.50 | 0.91 |
| | Secondary and above | 0.87 | 0.38 | 0.64 | 1.18 |
| Age married | | 0.98 | 0.20 | 0.94 | 1.01 |
| Wealth | Poorest (ref) | -- | -- | -- | -- |
| | Poorer | 0.99 | 0.95 | 0.68 | 1.44 |
| | Middle | 1.09 | 0.66 | 0.74 | 1.59 |
| | Richer | 0.58 | 0.01 | 0.39 | 0.87 |
| | Richest | 0.78 | 0.34 | 0.47 | 1.30 |
| Employment | Didn't work in past 12 months | -- | -- | -- | -- |
| | Worked in past 12 months | 0.84 | 0.31 | 0.60 | 1.18 |
| Aggregate violence measure | No violent experiences | -- | -- | -- | -- |
| | Violent experiences | 1.58 | 0.02 | 1.09 | 2.30 |
| Alcohol | Partner doesn't drink alcohol | -- | -- | -- | -- |
| | Partner drinks alcohol | 1.88 | p<0.001 | 1.49 | 2.37 |

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Teaching Truth in Transitional Justice: A Collaborative Approach to Supporting Colombian Educators

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Abstract

The pursuit and acknowledgment of the truth of past atrocities and human rights abuses are critical processes in transitional societies. While truth commissions have become a central part of achieving these goals, there has historically been minimal attention to the role of teachers and students in this work. Critical and thoughtful teaching about the past conflict, however, may help prevent the reoccurrence of atrocities, promote acknowledgment and accountability of the past (which, in turn, fosters psychosocial healing), and support the construction of a peaceful society. In this paper, I detail a research collaboration with Colombia's truth commission to aid its pedagogical efforts to develop effective resources and support Colombian educators' instruction about the truth of past atrocities. I first draw on the literature to demonstrate the potential for education—and, specifically, teachers—to support the goals of truth commissions. Then, I describe the Colombian context and this specific collaboration. Finally, I end by presenting preliminary findings from surveys of teachers across Colombia and detailing future directions.

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Introduction

In the aftermath of widespread human rights abuses, transitioning nations face multifaceted challenges. Healing must occur at and across various levels—individuals, groups, and society—by addressing the past while upholding psychosocial health, structural reform, and human rights. Education systems, often themselves complicit in past conflict, have increasingly been considered a critical part of transitional justice, including in the prevention of renewed violence. Schools, and the implicit and explicit curricula in them, hold potential for promoting truth and accountability for past atrocities while laying the groundwork for young people's involvement in building a society that respects the rights of all and prevents renewed atrocities.¹ The absence of effective education about the past can increase the risk of collective forgetting, truncated psychosocial healing processes, and backsliding into conflict.² Policy and programming in transitional societies, however, tends to overlook how mental health and psychosocial healing is woven into the fabric of education and into the roles that educators play as mediators, healers, and community members.³

In this paper, I detail a research initiative to better understand Colombian teachers' perspectives and positionality. This project—a collaboration between the Colombian truth commission, a Colombian nonprofit foundation, and myself—explores not only the potential for education to prevent further atrocities but also some mental health concerns linked to transitional processes. The Colombian context offers a prime opportunity to consider teachers' unique role in managing the psychosocial implications of past atrocities, preventing future ones, and coping with their own experiences.

A primary goal of this project is to contribute to the development of effective teaching resources and supports for Colombian educators to instruct about the truth of past atrocities. Generally, it also has the potential to aid in collective psychosocial healing and affirmation of human rights after violence and widespread violations. Many students, teachers, and their families have been impacted

by the conflict, which is linked to high rates of posttraumatic stress disorder, anxiety, depression, and other challenges.⁴ The individual and collective processes of healing inevitably enter schools, with teachers playing a mediating role. For this reason, the collaborators have come together to better understand Colombian teachers' thinking, processing, and psychosocial well-being. Below, I first draw on the literature to discuss education and educators in relation to the goals of truth commissions, mental health, and the prevention of future atrocities. Then, I describe the Colombian context and this specific collaboration. Finally, I end by presenting findings from a pilot survey of teachers across Colombia and detailing future directions.

The focus on transitional

I present a theoretical-based argument for focusing on teachers and their perspectives and then offer preliminary findings from the first step in a collaborative research project. This work is integrally intertwined with the recent context in Colombia: an involved peace process, an institutionalized and multipronged initiative to uncover and clarify the past, and political wrangling over related peacebuilding efforts. The lessons from this work can inform other contexts, including societies with eras and histories of past violence, injustice, and human rights abuses without official transitional justice processes. Still, it is important to acknowledge the differences and explain why I focus on transitional processes in this paper. Based on a collaborative foundation, this project is rooted in understanding the role of educators and their perspectives in relation to institutionally driven processes of constructing and teaching historical memory. Transitional justice implies a state-led effort to engage, through established institutions, with narratives and legacies of the past.⁵ While lessons can be learned from one context to another, transitional contexts cannot be conflated with contexts where national institutions are not engaged in processes of constructing historical memory or invested in bridging the gaps between this official work and the orientations and positionalities of educators. The

current project is driven by a broad question rooted in these dynamics: *How do educators understand the work of truth commissions, as well as their role and positionality in educating about past injustices?* The ultimate goal is to inform the pedagogical work of the Colombian truth commission, even though there are broader implications, which are addressed in the final section.

Defining truth and the role of truth commissions

Within transitional justice, the definition of truth is much debated and raises many issues.⁶ Broadly identified as a fundamental first step in reconciliation and healing, truth in transitional societies can generally be understood as referring to a process of gathering and recording various actors' experiences and interpretations of past events.⁷ Generally, truth commissions—state-sponsored mechanisms for collecting information about human rights abuses and victims and perpetrators' stories—have been recognized as important official processes for promoting accountability and reestablishing human rights because they “break the silence about widely known but unspoken truths.”⁸

Efforts to compile and disseminate truth can contribute to individual and collective healing. The collection and validation of survivors' stories recognizes their dignity, reaffirms their shared humanity, and creates a space for agency by highlighting resistance and resilience.⁹ These steps may contribute to addressing victims' emotional and mental health challenges; this recognition of their experiences and affirmation of their human rights can support psychosocial recovery.¹⁰ There may also be benefits in terms of reconciliation and the prevention of renewed conflict.¹¹

Truth commissions, however, do not uniformly or in isolation advance healing across multiple levels.¹² Other contributing factors include cultural, systemic (such as strength of democracy), structural (such as economic reforms), and individual (such as experience of conflict and psychological predispositions) elements.¹³ Furthermore, truth-telling may have negative impacts: there is evidence that truth

commissions without other transitional justice mechanisms can harm human rights, and public truth sharing may have detrimental individual-level psychosocial consequences.¹⁴ Finally, peacebuilding and the postconflict era are long-term processes, which means that beyond commissions' truth-seeking work, there are challenges in truth-telling: implementing recommendations, creating lasting and significant memorials, and constructing historical memory across generations.¹⁵

Truth and education: Healing, mental health, and accountability

Truth-telling challenges are integrally tied to schools in transitional societies. Importantly, schools can be spaces for the perpetuation of violence and for socializing young people into problematic social attitudes and norms while reifying inequities and injustices.¹⁶ Many transitional and postconflict societies are plagued by structural obstacles that inhibit critical, careful reform of educating about the past; and often, a lack of consensus on how to teach a nation's history leads to the privileging of civics or human rights education instead.¹⁷ Schools are also often in flux politically and socially, with changing priorities and resources that may complicate the stable building of historical narratives and education about the past.¹⁸ Still, education offers a potentially fruitful opportunity to support the work of truth commissions.

An explicit curriculum can offer a direct point of intervention for truth commissions in their postconflict reconstruction work. First, the teaching of the past—of a nuanced and critical truth emerging from a multiplicity of perspectives—can contribute to preventing future abuses.¹⁹ A commission's work can be carried on through opportunities in schools to talk about truth reports. This integration not only brings these issues to future generations but also promotes public discourse about causes, consequences, and healing processes.²⁰ Furthermore, teaching about diverse individuals' experiences of past conflict can affirm their human rights. The voices solicited and the ways they are presented can address instruments such as the Convention on

the Elimination of Discrimination against Women and the Declaration on the Protection of Women and Children in Emergency and Armed Conflict.²¹ Building on these possibilities, education and educators have both forward- and backward-facing roles.²²

As part of the forward-facing role, education can contribute both to conflict and to peacebuilding through socialization, teaching and explicit instruction, and reifying or contesting social inequities. Both “overt” and “hidden” curricula—that is, explicit material and instruction, as well as school culture and interactions—convey norms and lessons to students.²³ From these experiences, children and adolescents form understandings of who is valued in society, how to relate to others, and in-group/out-group designations and relations.²⁴ Schools are critical spaces for promoting change and healing precisely because they are intertwined with the roots of conflict and the intergenerational transfer of knowledge and norms.²⁵ Minors spend much of their time in schools, which serve for many as the first and primary interaction with social systems and the state.²⁶ These experiences have the potential to promote values, civic engagement, and actions that challenge injustice and promote healing.²⁷

The backward-facing charge of education and educators involves the legacies and histories of the past. To be effective, transitional justice processes must support individual healing and reconciliation, as well as collective processes with groups and communities.²⁸ Schools are a microcosm of these broader processes: students, teachers, and administrators carry their past experiences with them and hold identities that are inherently based on the group dynamics often linked to atrocities and their psychosocial impacts. Yet the recognition of trauma and need for support is missing in much of the discourse about how education can inform the construction of peaceful futures.²⁹ Much of the work of addressing the mental health needs of students—who may be victims, perpetrators, or family of either category—falls to teachers, who themselves also carry their own traumas and mental health needs.³⁰ The importance of these educators has

been highlighted in theoretical literature but is often overlooked in policies, programming, and empirical studies.³¹

The role of teachers

As conveyers of both overt and hidden curricula, teachers are key actors in the socialization of future generations and are mediators between societal processes of transitional justice and young people’s psychosocial development.³² Supporting teachers as potential promoters of truth involves acknowledging the complexity and nuance of their positionality. In transitional societies, there is often considerable pressure on teachers. They may be expected to serve as educators while also being expected to take on other emotionally demanding roles they have not been trained for, such as psychologists, guidance counselors, and conflict mediators. Having lived through violence and operating in potentially unstable presents, teachers may worry about safety in teaching official narratives or be coping with their own experiences.³³ Possible psychological challenges include a feeling of discomfort as leading agents of change, doubt about their abilities to change attitudes or understandings, and biases or predispositions.³⁴

The need to consider the positionality and mental health of teachers in transitional settings plays out in the scant literature focused on their perspectives. Studies have shown that history teachers in South Africa experience intense emotional burdens as they consider touching on difficult topics about apartheid. Some teachers described these lessons as too painful, possibly harmful for themselves or their students, or as eliciting in them personal feelings of guilt.³⁵ One teacher asked, “We worry about learners, but we should be worrying about ourselves. What is teaching doing to us?”³⁶ In the Balkans, a study on teachers highlighted other anxieties and emotional burdens experienced by teachers, who expressed feeling unsafe discussing the past in the classroom and finding a balance between their own emotional connection to the past and what they had to teach.³⁷

Historically, truth commissions have seldom explicitly and proactively engaged with schools or

considered the mental health of students and teachers in relation to educating about past atrocities. Recently, however, some truth commissions are engaging with the educational sector, though the nature of these collaborations varies considerably and seldom involves mandates to produce materials and provide psychosocial supports for teachers.³⁸

The Colombian truth commission was given a mandate to support pedagogy about the past, reconciliation, and the prevention of future atrocities. While the commission is not explicitly focused on the mental health of teachers or their role in supporting that of their students, these issues emerge from a consideration of teachers' perspectives on this pedagogy.

Colombian context

Colombia's history is marked by multiple and interconnected forms of violence and human rights abuses. The modern era of violence is often cited as beginning in 1948 with the assassination of a populist presidential candidate, Jorge Eliécer Gaitán. This act sparked *La Violencia*, a period of heightened violence between the Conservative and Liberal political parties. *La Violencia* ended in 1958 with a power-sharing agreement that alienated other political actors. Along with other social and geopolitical dynamics, this pact factored into the emergence of several armed leftist revolutionary groups. Violent political conflict has remained constant, though the forms, dynamics, actors, and drivers of violence have varied. Across these decades, human rights violations have been committed extensively and systematically by various actors.³⁹

Since the 1980s, different presidential administrations have held multiple negotiations with armed groups, and these processes have included smaller commissions to investigate specific acts of violence.⁴⁰ From 2012 to 2016, the government of then-president Juan Manuel Santos held negotiations with the oldest and most prominent armed group, the Revolutionary Armed Forces of Colombia (FARC). The resulting accords included a mandate to establish *La Comisión para el Esclarecimiento de*

la Verdad, la Convivencia y la No Repetición (the Commission for Truth, Coexistence, and Nonrepetition) to investigate acts of violence, the causes and systematic factors that have fostered human rights violations, the human and social impact of the conflict, and the collective responsibility of all actors. This commission, formed in December 2018, was directed to focus on vulnerable groups (such as Afro-Colombians, Indigenous peoples, and women) and develop pedagogical materials and programming.⁴¹ Importantly, civil society and government entities have also taken on the task of uncovering and constructing truth. One of the most comprehensive accounts of the extent and experiences of violence is *Basta Ya* (roughly, "Enough is Enough"), a report released in 2013 by the National Center for Historical Memory that cited 220,000 casualties and over 6 million displaced people.⁴²

Experiences with violence have been linked to a host of emotional and psychological struggles in Colombia, and broadly, rates of mental health problems are high.⁴³ Among children and adolescents, government reports indicate elevated rates of trauma and needs for mental health counseling.⁴⁴ While there have been no systematic analyses of emotional well-being among Colombian teachers, they have been identified by the United Nations and others as targets of violence.⁴⁵ Though no direct connection has been drawn, these experiences likely factor into educators' increasing levels of stress, depression, and other mental health issues.⁴⁶

Teaching truth in Colombia

Nature of the collaboration

In 2019, the truth commission began to gather stories and analyze the armed conflict, while also developing a strategy to educate teachers about its work and create materials to support teaching about the armed conflict. This focus motivated a collaboration between the commission, *Fundación Compartir* (a Colombian nonprofit organization with a mission to build a more equitable society), and myself. Our goals were to better understand educators' current knowledge of the truth commission, the challenges of teaching about truth, and

how best to support teachers—both in terms of educational resources and psychosocial support—in this work.

Planning meetings included discussions of the truth commission's efforts to inform Colombians about its activities; networks and possible school partners; and research questions and methodological approaches. The different perspectives coalesced around the commission's primary short-term goal: to open spaces for educators at all levels to discuss and think about the challenge of incorporating the final report into their curricula. This aim drew on practical political ends, as well as key issues identified in previous literature (for example, extolling the importance of integrating and carrying forth truth commissions' work through education, the mediating role of teachers, and the mental health challenges that educators face in transitional societies).

A multistep, mixed-methods process was designed in line with the commission's workplan schedule. The collaborators decided to prioritize understanding teachers' perspectives and the unique challenges faced by teachers as intermediaries between national transitional processes, students' psychosocial health and development, and their own mental health in working with questions of conflict, victimization, and truth. Systemic factors underscored the importance of attentiveness to local dynamics. While national mandates must be officially followed by schools, each school decides how it will comply.⁴⁷ Administrators and teachers have previously resisted curricula and resources developed by the Ministry of Education or institutions in the capital, which may not be attuned to local contexts. This disconnect is not only about content, material, and power.⁴⁸ Younger generations' understandings and experiences of the conflict is tied to local factors (for example, in their community or specific teachers) and social positioning (such as socioeconomic status and gender).⁴⁹ Depending on where they live, some adolescents are more likely to be or know direct victims or still encounter other armed actors operating with impunity.⁵⁰

The diverse contexts complicate how national mandates or curricular resources may be received

or implemented at the local level. One cautionary example comes from a 2015 peace education law that was implemented through a centrally imposed process that marginalized teachers' voices and perspectives.⁵¹ Considering these cases, we decided jointly to prioritize understanding Colombian teachers' perspectives on truth, the commission, and the teaching of its work.

An iterative, multi-step process

The final process we developed collaboratively involves multiple steps over time to engage with teachers' thinking about these topics. Centralizing teachers and their psychological processes is an emerging area of attention in transitional societies. This collaboration offers an experience of deeply engaging and committing to incorporating the voices of educators into national mechanisms. Still, our work is in progress. Below I detail the three phases of the project and then present the findings from the first phase (the one that has been completed to date) to demonstrate the utility of this approach and lessons learned.

The first phase—a pilot online survey that was completed in 2019 and 2020—is described in detail below and informs future steps. As a second phase, the team will select a subset of schools serving diverse populations. Visits to these schools will include interviews with teachers who participated in the online surveys of the first phase to further probe their thinking about truth and education, as well as to engage in conversations about preliminary analyses of the online surveys. These discussions will add to the project's ecological validity, as well as help clarify needs and obstacles identified by teachers through the online survey.⁵² Visits will also incorporate students' voices; focus groups will be conducted with a random sample from each school to explore how students understand truth, as well as how they have experienced and formed understandings of the past conflict and its reverberations in the present.

The project's final phase will center on the creation and implementation of pedagogical materials. The online surveys, interviews, and focus groups described above will inform the commission's de-

velopment of materials, as well as complementary workshops, online activities and resources, and other supports for teachers. When these materials are released, we will return to the teachers and schools that previously participated, while also striving to include other voices. This final activity will involve reassessing teachers' needs and obstacles to teaching about truth and studying how students process and respond to these discourses.

Each step has been purposefully designed to more effectively promote the integration of education into the complexities and nuances of truth in transitional justice. The online survey built connections with teachers and a preliminary understanding of conceptions of truth and the obstacles to teaching about it. It will be complemented by in-depth interviews and student perspectives to create a fuller picture of current thinking, the psychosocial well-being of educators and adolescents, and needed supports. Lastly, the return to these participants during implementation underscores an iterative evaluation that will inform the truth commission's pedagogical strategies. Overall, we designed this research to be in line with the evolving dynamics of the Colombian context and the truth commission's work.⁵³

Our pilot project: Surveying teacher perceptions

Our research began in 2019 with an online survey of teachers across Colombia. Existing networks were used to engage a broad range of educators, with a final sample of 122 teachers from over 50 schools. The schools included institutions in all 10 of the truth commission's regional areas, with the greatest representation from Antioquia, Cordoba, and "coffee country" (21%); the Caribbean region (13%); and the central region of Boyacá, Cundinamarca, Tolima, and Huila (13%). The sample was 53% female. The majority (54%) identified as mestizo (of mixed Spanish and Indigenous descent), while 7% stated they were Afro-Colombian, and about 5% stated that they were mestizo and Afro-Colombian. About three-quarters of the sample reported that the communities served by their school were deeply affected by the conflict; however, teachers were not asked to self-report if they were victims.

The survey questions were developed collaboratively to provide insights for the truth commission's efforts to support pedagogy and prevent the repetition of atrocities, as well as to offer preliminary insights into teachers' psychological processing and feelings about teaching about the armed conflict. The survey consisted of three sections: demographics, a set of 12 close-ended questions with five-point Likert scale response options, and a set of seven open-ended questions. Close-ended items were designed collaboratively to assess broad patterns in respondents' understandings of the commission's work, efficacy related to teaching about peace and truth, and beliefs about student and community attitudes concerning these topics. Items included the following: "I feel informed about the work of the Truth Commission," "In my class, I feel that I can incorporate themes of historical memory and armed conflict in Colombia," and "My students have become indifferent to the issues of the armed conflict." Open-ended questions probed the armed conflict's impact on participants and their schools, their understandings of truth and the commission, and what they felt they needed to teach about Colombia's conflict. Mental health was not directly asked about because of the commission's concern about alienating participants. Still, there were related topics, such as possible challenges in teaching about the armed conflict. The interviews—a more intimate format where I will be able to build trust with teachers—will also more explicitly address mental health by exploring educators' thinking about their roles in teaching about the past.

I first analyzed the data and then shared preliminary findings with the commission and Fundación Compartir for discussion, further development, and ecological validity. Close-ended questions were used to provide general background information about respondents and their perspectives, and so only descriptive statistics were considered. Though demographic information was collected, location was determined using the truth commission's territorial classifications. These broad categories encompass distinctively different local contexts (varying by rural/urban, socioeconomic status, and so forth) that prevented detailed

subgroup analyses. Nonetheless, this information will be considered when choosing follow-up sites through maximum variation sampling.⁵⁴ Open-ended responses were analyzed using thematic analysis with NVivo software.⁵⁵ In detailing the key takeaways across these analytic processes, my aim is not just to present empirical data but to demonstrate the connection between our preliminary findings and next steps.

Findings

The analysis was divided into four areas: understanding of truth, knowledge about the truth commission, participants' understanding of their roles as educators, and their thoughts on teaching about truth (including challenges and desired resources).

Definitions of truth

The teachers we surveyed defined truth predominantly as facts articulating what happened in the past. Some participants succinctly and clearly presented this perspective. For example, one wrote, "It's a statement of facts." Others added more nuance, stating that there were clear parameters but that truth could be contested. For example, one respondent defined truth as "a position on an event that is not put into doubt by other versions or beliefs. Even though some people say that truth in some cases is relative or that there isn't an absolute truth, there are certain indisputable criteria in most situations." Facts were part of a broader pattern of defining truth as objective. Some respondents directly made this link, such as one who stated, "knowledge of the facts as they happened in an objective manner." Objectivity was not always explicitly mentioned, sometimes arising implicitly in respondents' emphasis on accuracy: "It is historical memory of past events exactly as they happened."

Another theme was the importance of truth in society and its potential positive impacts, with no participants explicitly noting negative effects or contesting truth's importance. Positive impacts were at both broader societal levels and for individuals. Exemplifying the former, one teacher wrote

that truth was "a necessity for any society," while another responded that it "makes things right for humankind and for society." For the latter, one teacher answered that truth "presents the information that victims yearn for about the death or disappearance of their loved ones." Others explicitly referred to the importance of truth for victims' mental health because it recognizes and clarifies what they experienced. These various perspectives generally pointed toward participants suggesting that the pursuit of truth is beneficial at one or multiple levels in a society, including individuals' psychosocial well-being.

Lastly, a smaller group offered a different perspective on truth, portraying it as a value-laden coherence between attitudes and actions. They did not define truth as a record or process but rather as linking thoughts, actions, and treatment to more abstract orientations. To this end, one teacher stated that "truth is to be coherent in how a person thinks, feels, and expresses themselves about something they have lived through," while another answered, "it is what you do conforming with what you think and believe." The values themselves were not specifically listed; instead, these respondents invoked moral frameworks abstractly. While there was variability in the exact terms used—for example, feelings, values, beliefs—an underlying thread was that truth is more than facts and encompasses coherence between one's attitudes and actions.

Knowledge of the commission

In relation to the truth commission, teachers demonstrated varying levels of knowledge. Only 10% of respondents agreed that they felt informed about the commission, while a third indicated disagreement. In the open-ended responses, the sample was generally split into two relatively even-sized groups (about 40% each): those who had clear and developed understandings and those who stated they knew little or nothing. The first group clearly articulated a purpose for the commission. Some offered paragraph-long, developed descriptions, while others responded more succinctly: "constructing the country's historical memory" or "knowing the causes and consequences about

events of the past.” In the other group, many teachers simply answered “nothing” or “very little,” and others indicated they did not even know where to find this information. Given the online nature of the survey, participants could have researched the commission online while crafting their responses, suggesting that even fewer might have previously been knowledgeable about its work.

Roles as educators

A second aim was to build better understandings of how teachers envisioned their role in teaching about Colombia’s conflict. Respondents generally reported valuing teaching about truth and feeling able to contribute to these efforts. The overwhelming majority (80%) responded that they felt it was important that students know history from diverse points of view. Similarly, a majority agreed that they could incorporate history into the material they teach (60%) and could be a peacebuilder in their schools (70%).

For perceptions of contextual factors, respondents generally indicated that students were open and supportive but that broader dynamics were more complicated. None of the teachers disagreed that students were interested in talking about peace, while only 5% responded that they and their students could not help prevent the repetition of the armed conflict. Participants were more divided on whether their community had become indifferent to issues related to the armed conflict: 33% agreed and 36% disagreed. Additionally, just over a third indicated feeling that teaching about the armed conflict was risky in their local context.

Teaching about truth

The last area of analysis was challenges in teaching about truth and what resources respondents would like to have as support. In terms of resources, participants primarily indicated interest in digital resources and videos, which some described as “engaging”; others noted requiring technological infrastructure (such as projectors). The nature of the content was also mentioned in some responses: testimonies, visits from victims and other actors, and videos of victims’ stories.

Another group of respondents listed accompaniment from the commission or government, requesting a coach, psychologist, or other “human resource” to support them in teaching the commission’s final report. As an example, one participant requested “a trained professional who can initiate the process smoothly and then can accompany the teachers and the educational community in general as they take it over.” This participant was from the Antioquia region and described their local community as deeply affected by the conflict, which was according to them still present in “minds of those who lived it.” Other participants who expressed similar sentiments came from contexts immersed in current violence and crime, as well as other communities that participants described as disconnected and apathetic to the armed conflict.

The mention of interpersonal support by some participants connected to challenges that teachers identified in thinking about teaching the commission’s report. Two themes emerged in this respect: raising awareness was a primary need and difficult task, and forces at various levels prevented the transformation in thinking that is necessary. First, some participants explicitly or implicitly referred to *sensibilización* (awareness or sensitivity). Their role was part of a broader challenge to “disseminate the results of the commission.” Others specifically mentioned raising awareness in their schools, such as “making students aware of the subject and getting them to reflect on it.” Educators expressed that students were interested in learning about these themes both in contexts where teachers described their community as being affected by the conflict and in contexts where they said it was not. An interconnected concern was how to motivate students to want to learn more about this topic. Helping students become aware of the truth commission’s report involves more than simply conveying information within it. One teacher identified a challenge as “trying to teach about this topic dynamically to inspire in students an interest in learning about it,” while another wrote, “getting students interested in the importance of knowing history as a basis for building a better society.” Importantly, both of these teachers, and those who espoused this view

more generally, identified their school contexts as not affected by the armed conflict.

Second, teachers—particularly those who identified conflict as having impacted the communities they serve—emphasized the challenge of enacting the change required to effectively teach about the truth of the conflict. This endeavor entails a different way of educating and thinking for many Colombians. Participants described numerous forces opposing it: political opposition, other armed actors, lack of faith in the government, and inertia in daily life. In terms of teachers themselves, teaching about truth of Colombia's conflict requires intentionality, reflection, and moving beyond usual classroom structures and curriculum. One respondent from a conflict-affected area in the central region of the country wrote of the need for teachers to “re-orient their practice to focus on reflection,” while another from a similar area of Antioquia described the importance of “breaking with set paradigms, educating with an orientation towards forgiveness, respect, and recognizing the perspectives on events from various actors in the conflict.” This attention to a change in mindset among teachers mirrored other respondents who identified more generally the difficulty of changing the mindset of Colombians. This phrase—*cambiar el chip*—was invoked in reference to teachers, students, families, and citizens in general.

Takeaways

Overall, this analysis provides preliminary insights into how the truth commission should work with teachers in their unique role of supporting psychosocial well-being and preventing the repetition of atrocities. First, the complexity of responses about truth and the challenges that teachers identify demonstrate that teachers are not just conduits for curricula. They are individuals embedded within particular contexts who are actively psychologically processing and responding to their experiences. They demonstrated concern about sociopolitical dynamics and preconceptions about truth that may need to be engaged. Furthermore, some respondents acknowledged that a genuine engagement with these issues would entail reflection on and a

reorientation of the role of teachers. This work is inherently tied to identity, positionality, and mental health, as teachers would have to reconcile not only with the past but with their own understandings of education and their purpose as educators. Other scholars have noted that such changes can impact teacher's emotional health and psychosocial well-being.⁵⁶

A second thread was these teachers' feeling of efficacy, even while acknowledging the difficulty of their task. Participants noted feeling that students were receptive and that they were able to contribute to peace and teach about history despite the complexity of this challenge. Their work, particularly in conflict-affected contexts, requires raising awareness and making change in the face of significant material and psychological obstacles: lack of adequate infrastructure, attitudes in the community (such as indifference to peace or distrust of government), the need to reconceptualize pedagogical practice, and anxiety over safety. These significant challenges point to the need to better understand and support the mental health of teachers, who are intermediaries in transitional societies: though they may feel able and motivated to teach about the past as part of efforts to prevent future atrocities, this work is mentally and emotionally demanding. Research with teachers in other transitional contexts has also highlighted safety concerns affecting their psychosocial well-being, while investigations of Colombian teachers' mental health has indicated that many already feel overwhelmed in their job.⁵⁷

Building on these dual pressures, some respondents from conflict-affected areas explicitly indicated the need for psychological and personal supports. Taken on the whole, these responses can be understood as demonstrating that these participants were aware of the emotional and mental challenges of teaching about truth, including the lived and possibly traumatic experience of the past and teachers' need for psychosocial and educational accompaniment. Teaching about truth, for many of these teachers, thus encompasses the actual content, “the surrounding reality,” and the psychosocial well-being of students, teachers, and the community.⁵⁸

Conclusion

In this paper, I have described a research collaboration aimed at supporting the Colombian truth commission's school-based pedagogy, as well as our pilot survey of educators. Our project's motivational foundation was acknowledging and attending to teachers' intermediary positions between transitional justice and future generations within a framework of education as a potential space for supporting human rights through healing, accountability, and prevention after mass atrocity. The first phase of research of this collaboration has demonstrated that teachers' positionality and mental health are salient concerns regarding the effective incorporation of the Colombian truth commission's work into the educational sector. Specific challenges include recognizing the uniqueness of local contexts, motivating students, confronting established pedagogical orientations, and understanding broader social dynamics. While teachers are important intermediaries in the work related to truth, education, and human rights in transitional societies, these elements must be addressed in fostering this potential. Identifying and addressing these areas will help the Colombian commission as it moves forward in its efforts to promote healing, foster a harmonious society where human rights are upheld, and ensure that past atrocities are not repeated.

Our findings on teachers' definitions of truth provide fruitful ground for this work in Colombia, with implications for postconflict societies and others that seek to use education to address violence and human rights abuses of the past. While some participants described truth as objective and singular, many espoused more nuanced perspectives that touched both on values and on everyday behaviors and attitudes. These perspectives extend beyond official processes of gathering and accounting diverse experiences about what occurred, which have been much of the focus in relation to truth in postconflict societies.⁵⁹ In making the link to pedagogy, there may be opportunities to harness the construction and teaching of truth for a more holistic development of students. As noted by these participants, however, changing the perspectives

and orientations of educators, administrators, and broader communities is difficult. Therefore, a specific point of intervention could be to work with educators on their conceptions of truth and what it means to reimagine their role to encompass the formation of critical, engaged future citizens. Such an opportunity for future development builds on connections between history education and civic development but adds a particular focus on shaping teachers' conceptualizations and orientations.⁶⁰

This work must be attentive to broader contexts and sociopolitical trends as well. As evident in the responses of teachers in our pilot study, educators and schools do not operate in sociopolitical vacuums. Entering 2020, the Colombian president, Iván Duque, was openly against the peace accords, and the numbers of dissident ex-FARC members were growing.⁶¹ These sociopolitical dynamics will have implications for teachers' mental health and ability to support their students, for increased security risks, retraumatization, and new atrocities will add to the substantial load already carried by Colombian teachers. Therefore, one lesson from this work is the need for continual and iterative engagement with educators. Efforts to support the work of truth commissions must evolve in accordance with changing circumstances, political pressures, and resulting impacts on teachers and their educational communities.

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Societal Healing in Rwanda: Toward a Multisystemic Framework for Mental Health, Social Cohesion, and Sustainable Livelihoods among Survivors and Perpetrators of the Genocide against the Tutsi

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Abstract

The genocide against the Tutsi in Rwanda left the country almost completely devastated, with tremendous consequences for mental health, social cohesion, and livelihoods. In the aftermath of such extreme circumstances and human rights violations, societal healing should be conceptualized and approached based on a multisystemic framework that considers these three sectors—mental health, social cohesion, and livelihoods—as well as their interactions. The aims of the present study are twofold: (1) to review evidence on multisystemic healing initiatives already applied in Rwanda using fieldwork notes from interviews and focus groups, alongside relevant scholarly and gray literature, and (2) to propose a

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scalable multisystemic framework for societal healing in Rwanda that builds on existing innovations.

Within a participatory action research methodology, we used a grounded theory approach to synthesize fieldwork findings and compare them with literature to generate a set of principles for multisystemic recovery in Rwanda. Recognizing the strengths and limitations of the current mental health system and other initiatives, including sociotherapy and collaborative livelihood projects, we propose a scalable and rights-based multisystemic approach for recovery and resilience that would target mental health, social cohesion, and sustainable livelihoods within an integrative cross-sectoral framework, thus reducing the risk of post-genocide conflict.

Introduction

Starting in the late 1950s, Rwanda intermittently experienced periods characterized by community level conflict between the ethnic divisions of Hutu and Tutsi. Social tensions and discrimination policies continued after Rwanda gained formal independence from Belgium in 1962 and gradually led to a mass exodus of the Tutsi minority population to neighboring countries.¹ Extensive effort was made to ease tensions, including international mediation, culminating in an August 1993 peace agreement signed in Tanzania.² However, starting in April 1994, for over 100 days Rwanda was immersed in a brutal state-sponsored genocide instigated by extremist factions within Hutu leadership. According to the Rwandan National Commission for the Fight against Genocide, the genocide resulted in the death of 1,070,014 Tutsis and moderate Hutus, while almost two million persons were accused of having participated actively in the genocide (population 6 million at that time).³ The genocide included highly local violence, as victims often lived in the same villages as perpetrators.⁴ Extremist propaganda fueled sexual violence during the genocide against the Tutsi. As a result, 350,000 women and young girls, as a lower-bound estimate, were subjected to rape, torture, sexual slavery, and mutilation.⁵ The Tutsi-led Rwanda Patriotic Front brought an end to

the genocide after defeating the Hutu militia in late July 1994. Rwanda's political and socioeconomic infrastructure had been destroyed, while the country was left devastated, especially in the areas of social cohesion, mental health, and livelihood sustainability. Fearing reprisals or seeking to escape accountability, more than 2.5 million Rwandans fled to neighboring countries in the aftermath of the genocide.

According to the Rwanda Ministry of Health, a large segment of the Rwandan population experienced severe mental illness after the genocide. Numerous studies were conducted in the years following the genocide to establish prevalence rates for posttraumatic stress disorder (PTSD) and other clinical disorders among the survivor population, with estimates of PTSD prevalence in early post-genocide years ranging from 45% to 54%.⁶ More than two decades after the genocide, mental health challenges appear to persist for a large proportion of survivors. The 2018 Rwanda Mental Health Survey conducted by the Rwanda Biomedical Centre revealed a high prevalence of several disorders both in the population of survivors and in the general population. Most commonly reported were major depressive disorder (found in 35% of genocide survivors and 12% of the general population) and PTSD (found in 27% of genocide survivors and 3.6% of the general population).⁷ In

line with these findings, a recent meta-analysis of 19 original studies conducted in the country found that the proportion of genocide survivors who had PTSD was 37%.⁸ When considering that perpetrators and survivors were often people from the same village, the damage extended beyond mental health, human capital, infrastructure, and available community resources, to severe societal wounds. The impact on society and economy and the severe magnitude of trauma in Rwanda resulted in what might be termed as “collective trauma” or “traumatized nation.”⁹ Collective and historical trauma are prevalent in populations that have experienced war, displacement, genocide, and poverty, causing considerable distress across whole communities and interference with functioning in multiple areas of educational, work-related, and social activities.

Historical genocidal trauma, combined with socioeconomic adversities, represents severe threats to development and mental health. Social cohesion, or its absence, has been implicated in the etiology and recovery from both physical and psychological illnesses.¹⁰ Additionally, a significant correlation has been reported between income deprivation and low social cohesion with poor mental health.¹¹ The United Nations Special Rapporteur on the right to health advocates that good mental health cannot exist without human rights, peace, and security. While the currently prevalent biomedical model of mental health focuses predominantly on individual determinants of mental distress, by emphasizing, for instance, the role of neurochemical imbalances and maladaptive personality traits, advocates of rights-based approaches, such as the Special Rapporteur, argue that a greater emphasis should be placed on the social determinants of mental illness. Notably, the Special Rapporteur argues that mental distress is caused primarily by contextual factors that include human rights violations, such as violations of the rights to life, food, housing, education, work, development, nondiscrimination, and equality.¹² Denial of such rights leads to experiences of trauma, fear, isolation, and despair which, from a biomedical perspective, can meet the diagnostic criteria for mental illness and trigger an attempt to

cure such disorders at the individual level—even though the factors that have led to such adverse psychological experiences are primarily social and political in nature. The case of Rwanda, where a significant burden of ongoing mental distress has been detected among survivors of the genocide against the Tutsi, provides strong evidence in support of the Special Rapporteur’s position: more than two decades after the genocide, the severe human rights violations it entailed constitute social determinants of a significant mental illness burden that is still felt by a substantial proportion of the Rwandan population.

Conceptualizing multisystemic recovery and resilience as a rights-based approach for mental health in post-genocide Rwanda

To the extent that the mental health burden experienced in Rwanda today can be attributed to the experience of the genocide and its consequences across multiple social and economic systems, it is reasonable to assume that efforts to restore mental health in affected communities through a purely biomedical approach would likely fall short of the objective due to not addressing the social determinants of psychological distress, such as extreme poverty, social isolation, and ongoing community polarization. A general principle in resilience science is that multisystemic adversities need to be met with multisystemic solutions.¹³ Addressing mental health issues that accompany societal wounds while developing community livelihoods and strengthening local social cohesion could promote resilience and contribute to a more complete recovery. From a systems perspective, individuals, households, communities, and higher-level institutions are considered to be mutually evolving and adjusting to meet oncoming challenges. All these diverse layers of society are required to achieve system-wide resilience.¹⁴

There are several plausible mechanisms through which multisystemic interventions might influence mental health. These include psychosocial processes (for example, enhancement of self-es-

teem, community support, and respect), adoption of health-promoting activities and norms in the community, and increased social organization and trust levels that encourage the utilization of existing mental health services while directly contributing to psychological well-being.¹⁵ In addition, diversity and sustainability of livelihoods have been shown to be essential for social sustainability, as measured through key indicators of social cohesion, inclusion, and gender equality.¹⁶ Finally, UNICEF studies have shown that providing humanitarian assistance and basic livelihoods to displaced or vulnerable populations predicts better health, including mental health and higher levels of well-being.¹⁷

Approaching mental health from a multisystemic perspective is not just empirically sound but also consistent with a rights-based perspective. According to the Special Rapporteur on the right to health, mental health interventions should acknowledge social and economic determinants of mental illness and address these through multisectoral policies and programs. In contrast, an excessive medicalization of mental health, combined with a singular emphasis on the individual level, can serve as an excuse to violate social and economic rights while labeling the resulting psychological distress as mental illness.¹⁸ Therefore, only a multisystemic approach to recovery and resilience—where rights in one domain (for example, the right to development or the right to peace and security) are understood to beget rights in other domains (for example, the right to mental health)—can be considered to be consistent with a rights-based approach.

Adopting a rights-based lens of multisystemic recovery and resilience, as outlined above, the present study has a twofold aim. First, we seek to review existing initiatives in Rwanda for multisystemic recovery and societal healing. In its efforts to overcome the extreme challenges posed by the genocide against the Tutsi, Rwanda has become a breeding ground for innovation and leadership within the field of multisystemic recovery. Understanding such efforts can provide essential insights into multisystemic recovery and resilience processes, with potential applications in other conflict-affected

or genocide-affected countries. The study's second aim is to propose an integrative and scalable public health framework for multisystemic recovery and societal healing in Rwanda, building on local innovations while strengthening them with evidence-based practices that have already been validated in other contexts. While the immediate objective is to propose scalable solutions to be implemented across the various districts of Rwanda, it is our hope that the proposed framework can have broader utility within the field of post-conflict and post-genocide recovery and resilience.

Methods

Participatory action research framework

This study adopts an action research approach.¹⁹ Action research begins with an effort to understand the facts of a situation within the context in question, leading to planning and action to address the problem (that is, implementing a targeted intervention) and then reflecting on the result of the action. All research activities within this Rwanda-specific study were designed to pursue tangible solutions to real-world problems and were outlined in the following action agenda: (1) determine how Rwanda can be assisted in transitioning beyond the legacy of the genocide in ways that simultaneously address genocide-associated mental health challenges and disrupted social cohesion while contributing to livelihoods development and poverty mitigation, and (2) determine how these solutions build on the progress already made in order to provide a scalable framework that can reach and benefit the majority of Rwandans.

Participatory action research is a variant of action research that brings in community stakeholders as co-directors of the research process.²⁰ In this study, the stakeholders involved included the formal mental health sector, government-appointed commissions that focus on societal healing and reconciliation, municipal authorities in districts that were severely impacted by the genocide, and international partners with a strong interest in supporting Rwanda's transformation. Numerous consultations with such stakeholders took place

over five field missions to Rwanda between May 2019 and October 2020.

Field-based service mapping

In support of the participatory process described above, we conducted interviews and focus groups to map out the field of services currently provided in Rwanda within the domains of mental health, social cohesion, and sustainable livelihoods. We then discussed our findings with participating stakeholders, further informing the direction of the action research process.

Participants and recruitment

We recruited 31 participating service providers from various organizations based in Kigali (Rwanda's capital) and Bugesera (a district south of the capital). Bugesera was chosen as the area of focus for the fieldwork based on guidance from participating senior stakeholders. Bugesera was among the hardest hit during the period of the genocide; therefore, any future intervention program for multisystemic recovery and resilience would be more credible and promising for countrywide scaling if it were first shown to be effective in the particularly challenging context of Bugesera. Senior project stakeholders recommended which service providers should be interviewed, suggesting organizations (governmental, nongovernmental, or private) that were actively providing services in the domains of mental health, social cohesion, or sustainable livelihoods. Executives and other staff from these organizations had the choice to participate through individual interviews or focus groups. Participants included, among others, clinical psychologists, trauma counselors, public health professionals, development specialists, dialogue facilitators, and community workers.

Materials

We used unstructured interviews due to the flexibility they offer and to allow for the generation of qualitative data through the use of open questions. Moreover, this approach offered time and space for participants to talk in depth and express themselves in their own words, which helped us obtain a better

sense of respondents' experiences and perspectives. To explore current gaps in service provision, we made sure to ask participants about service gaps, beneficiary needs, potential areas of improvement, and recommendations for practice and policy.

Interview procedure

All interviews and focus groups took place at a mutually agreed-on and convenient place and time. Individual interviews lasted 30 to 90 minutes, while the duration of focus groups was 120 to 180 minutes. Field notes were taken by three authors. To mitigate unforeseen risks, we have protected participants' identities in the reporting of results.

Ethical considerations

The study design was reviewed and received ethical clearance from the Rwanda National Ethics Committee, which is registered under the US federal-wide assurance for the protection of human subjects for international institutions.

Review of relevant scholarly and gray literature

We also reviewed scholarly and gray literature about policy frameworks and available services for mental health, social cohesion, and sustainable livelihoods, sharing our insights with community stakeholders within the action research process. The literature under review was based on electronic database searches in PubMed, PsychArticles, and Google Scholar. Our review aimed to scope the body of literature and identify gaps in services while mapping the available evidence. We accessed the following reports through the above websites: the 2019 report on healing practices by the National Unity and Reconciliation Commission; the report on future drivers of growth in Rwanda, which was prepared by the government of Rwanda and the World Bank Group; and the mental health strategy report published by the Rwandan Ministry of Health.²¹ We also reviewed relevant international scholarly and gray literature on global emerging practices to identify advances and innovations that could be applied in the Rwandan context.

Developing a grounded theory for multisystemic recovery and resilience in Rwanda

Data from the participatory action research process was analyzed and interpreted to propose a grounded-theory framework for multisystemic recovery and resilience in Rwanda, to be validated by community stakeholders. Grounded theory is described by its founders as “a theory derived from data, systematically gathered and analyzed through the research process, which is structured but still flexible.”²² It is considered a method for “creating conceptual frameworks through building inductive analysis from the data.”²³ Purposive acquisition of relevant data through all methods described earlier was followed by open coding to assign meaning to the data, followed by theoretical sampling to collect additional data that would enrich the emerging framework. The outcome of this process was twofold: first, a conceptual taxonomy of existing innovations in post-genocide Rwanda and, second, a set of principles to enrich, systematize, and scale up existing efforts for multisystemic recovery and resilience across all Rwanda districts.

Results: Toward a conceptual taxonomy of existing innovations for multisystemic recovery and resilience in post-genocide Rwanda

One of the most remarkable insights from the research process as a whole is the breadth and scope of innovation for multisystemic recovery and resilience in Rwanda—but also specifically in Bugesera district. This innovation appears to cut across the formal and informal sectors at the national and district levels, while frequently combining methods and approaches from the mental health, social cohesion, and livelihoods domains. Various aspects of this multidimensional effort are outlined below.

The post-genocide emergence of a sophisticated mental health sector in Rwanda

The genocide left a significant proportion of the population suffering from posttraumatic stress

and other mental health disorders, with almost no services to meet this unprecedented mental health emergency. Thus, the development of a fully functioning mental health sector soon became a priority of the Rwandan government. After an initial stage of building up core capacities at the national level, the focus rapidly shifted to decentralizing the mental health system to the district level, to more effectively reach beneficiaries.²⁴ By 2012, Rwanda had established a functioning referral hospital in its 30 districts, each coordinating a network of up to 20 primary health centers at the sector level. These infrastructure development efforts have been complemented by a mentoring and enhanced supervision framework, which has strengthened monitoring and evaluation practices while enabling the implementation of clinical protocols.²⁵ Preliminary results from these evaluations have identified the need for a better diagnostic assessment for depression, posttraumatic stress, and alcohol-related disorders.²⁶ Concerning genocide perpetrators, targeted psychotherapeutic interventions were generally missing or applied in small-scale studies only for research purposes, while local mental health professionals’ training and education systems were still insufficient.²⁷ In 2019, the Ministry of Health upgraded the Rwanda Health System Package to include guidelines on psychological interventions conducted in health centers.²⁸ However, the absence of an integrated mental health strategy that would operate across the public sector and nongovernmental organizations limited the potential of such interventions to achieve mental health outcomes at scale. Cognizant of these challenges, the government formulated an updated national mental health strategy for 2020–2024, which is compatible with a rights-based multisystemic approach. It highlights the need to integrate recovery with social inclusion and recommends organizing campaigns to reduce mental health stigma in communities while encouraging the private sector’s engagement in efforts to reintegrate individuals with mental health disorders, following their treatment at district-level mental health units. Currently, the private sector utilizes mainly individual integrative psychotherapeutic approaches that include narra-

tive exposure therapy, trauma-informed therapy, cognitive behavioral therapy, humanistic therapy, functional analysis of behavior, psychoeducation, and art-based therapy. Within the state sector, implementing the mentoring and enhanced supervision framework at health centers has resulted in the development of care packages for individuals struggling with schizophrenia, bipolar disorder, major depressive disorder, and epilepsy. These assist mental health providers in delivering more targeted interventions at the individual level.²⁹

While the mental health care system has made tremendous efforts to support recovery in post-genocide Rwanda, there are still challenges ahead.³⁰ A medicalized mental health care model still prevails, with patients seeking mental health care typically being referred for individual treatment at district-level hospitals. Western approaches in conceptualizing mental health provision in Rwanda have limited the scaling up of the services provided and resulted in a “treatment gap” between the people who need care and those who receive care. Compounding this challenge is the severe shortage of fully trained mental health personnel. For instance, by 2019, only 12 psychiatrists were registered in Rwanda, and no child psychiatrists were reported as practicing. Another factor that contributes to the treatment gap is the possible unwillingness of sufferers to utilize individual one-on-one treatment services, which appear to be a poor fit for collectivist sub-Saharan African cultures, where most issues and challenges of daily life are addressed in the context of group-based processes at the community level.³¹

One possibility for addressing Rwanda’s mental health treatment gap might be to emphasize group-based, resilience-oriented psychological interventions. Such approaches could simultaneously address scalability challenges (since the limited number of mental health professionals would be in a position to serve a greater number of beneficiaries) and issues related to the cultural acceptability of interventions. To take one example, an invitation to participate in a group-based intervention to strengthen psychological resilience might not raise the same concerns about being stigmatized

as a mentally ill person or being expected to discuss sensitive personal issues with an unknown professional as would a traditional Western-style one-to-one clinical intervention. In this regard, emerging evidence-based approaches in group-based therapy programs that focus on skills and resilience could also inform practices in Rwanda. For example, the McLean Hospital in Boston, United States, implements a Behavioral Health Partial Hospital Program, which is focused primarily on group therapy for individuals with various co-occurring mental disorders. The treatment program builds participants’ psychological skills and resilience, simultaneously focusing on ameliorating cognitive, emotional, and social processes implicated in developing and maintaining mental health symptoms. This flexible treatment approach is set up in an outpatient, partial hospital setting, which is cost- and time-effective, while the diversity of skills taught in the program reinforces community reintegration after discharge.³²

Sociotherapy as a hybrid intervention that cuts across psychological trauma healing and rebuilding of community trust

In Rwanda, community-based sociotherapy has been used as a hybrid intervention that integrates psychological trauma healing with rebuilding community trust and resilience.³³ Within a group setting that actively encourages the participation of both perpetrators and survivors in the same healing space, participants are given the opportunity to go through various phases of transition. Distinct sequential stages of the healing process include “safety,” “trust,” “care,” “respect,” “new life orientation,” and “memory”. The approach has often been described as promoting psychological and community resilience through shared storytelling.³⁴ Participants in sociotherapy are groups of 10–15 people who meet weekly for three hours, covering 15 sessions in total, with the support of two facilitators selected from the same community. Evidence shows that sociotherapy leads to improvements in interpersonal and community tolerance and trust while contributing to the mitigation of mental health symptoms. More than 20,000 Rwandans are

estimated to have participated in different variants of sociotherapy since the approach became popular in the early 2000s.³⁵

However, because the focus of sociotherapy groups is not directly mental health, social reconnection objectives might be hampered for those presenting with more severe mental health problems or those with limited cognitive, emotional, and interpersonal skills. At the same time, the National Unity and Reconciliation Commission has recognized a need to assess sociotherapy more systematically and has noted that healing should be provided as an intervention with greater regularity, not only during the genocide commemoration period.³⁶

Practical reconciliation in Rwanda through collaborative livelihood initiatives

One additional critique that has been levied against sociotherapy is that it might not adequately address practical livelihood challenges. In regions where the socioeconomic fabric and human capital have been devastated due to the genocide, often resulting in extreme poverty, a singular focus on meeting survivors and perpetrators' social and psychological needs runs the risk of putting participants into a situation where relapse is likely. Thus, in recent years, greater emphasis has been placed on ensuring that psychosocial processes related to sociotherapy are complemented with hands-on, collaborative livelihood initiatives, which lead to income generation for the whole community. In this way, graduates of sociotherapy groups have an opportunity to capitalize on the skills and relationships that they have developed through sociotherapy. The livelihood initiative, therefore, has positive effects on both the social cohesion and mental health of its participants.³⁷

Such an integrated understanding of livelihoods development and social cohesion has been formally acknowledged in Rwanda's "Vision 2020," which prioritizes poverty reduction through rural development, increased productivity, and youth employment.³⁸ Inspired by contact theory, the strategy assumes that collaborative contact in the context of a community-based livelihoods initiative could be

an effective pathway to strengthen social cohesion after the genocide, especially between survivors and perpetrators.³⁹ In this regard, the formation of "reconciliation villages" has been a notable initiative for integrated socioeconomic development and peacebuilding. In these communities, survivors and perpetrators are invited to coexist while being given resources, skills, and opportunities for cooperative economic enterprises.⁴⁰ Through engaging together in livelihood projects of all kinds, the previous, trauma-associated identities of survivor and perpetrator gradually become less salient, while citizens have an opportunity to rediscover each other through their present- and future-oriented socioeconomic roles and identities.⁴¹

The promising concept of utilizing collaborative livelihood initiatives as a pathway to simultaneously achieve social cohesion and local economic growth is not unique to Rwanda. Having reviewed numerous such initiatives around the globe, Ana Maria Peredo and James Chrisman have proposed a comprehensive theoretical framework for community-based enterprises (CBEs) as an alternative form of social and economic organization for communities experiencing social and economic stress.⁴² CBEs build on preexisting social capital, skills, and natural assets in the community. Once initiated, such enterprises further strengthen social and human capital while serving as incubators for downstream independent entrepreneurship. However, CBEs are not without their challenges. In one review of community enterprises in the Songkhla Lake Basin of Thailand, several management problems were identified, particularly in marketing, finance, accounting, production, information systems, product design, and cost control.⁴³ While understandable, given the informal context in which such enterprises emerge, these are real challenges that must be addressed if CBEs are to become a mainstream solution to promote social cohesion and socioeconomic development in Rwanda.

Multidimensional approaches for the reintegration of convicted genocide perpetrators into their home communities

Genocide perpetrators are a large subgroup of the

Rwandan population, and their reintegration is considered crucial for social cohesion. An ethnographic study demonstrated that ex-prisoners who return home feel lost, carry the label of *genocidaire*, and are in an awkward position since they cannot become a part of the social world.⁴⁴ Other studies have also reported high levels of posttraumatic stress, emphasizing the need to facilitate the perpetrators' family relationships while providing mental health interventions to assist reconciliation.⁴⁵ Yet another critical dimension of the reintegration process is the need to prevent recidivism and ensure that the return of former perpetrators to their home communities does not lead to the retraumatization of survivors or to the reemergence of societal dynamics that had enabled the genocide.

While several organizations and government entities contribute to different aspects of prisoner care and community reintegration, some notable approaches deserve special mention. Prison Fellowship Rwanda (PFR), a local nongovernmental organization that is affiliated with Prison Fellowship International, is implementing a broad-based multidimensional approach to the reintegration of former genocide perpetrators. The PFR approach includes, among others, psychosocial support and behavioral activation while perpetrators are still incarcerated; motivational interviewing to assess readiness to engage in a reconciliation process; coaching through the process of experiencing remorse for the genocide and seeking forgiveness from survivors; civic education to orient perpetrators into the new post-genocide sociopolitical realities of Rwanda; the acquisition of vocational skills; family reintegration; and the socioeconomic integration of released prisoners through participation in collaborative livelihood initiatives.⁴⁶ Dignity in Detention Rwanda (DIDE), also a local nongovernmental organization, has a similar approach to PFR but with a more specific emphasis on the needs of detained women and youth. DIDE programs include the distribution of food, access to health services and education, skills development, human rights advocacy, and cooperatives aimed to help families of detainees become economically active.⁴⁷ While the initiatives of PFR and DIDE for prisoner

reintegration in Rwanda are inspiring and effective, they are not yet the mainstream standardized approach by which prisoner reintegration occurs in Rwanda, nor have they been fully incorporated into relevant policy frameworks of the formal sector, even though efforts are currently being made toward that end.

Ongoing efforts to prevent the intergenerational transmission of trauma

While most healing efforts in the 25 years since the genocide focused on supporting direct survivors of the genocide, challenges related to the next generation, particularly children born to survivors or perpetrators of the genocide, have received increasing attention in recent years. Recent studies have shown that the offspring of survivors have a nearly threefold higher risk of PTSD compared to the general population (16.5% prevalence versus 6.2%), suggesting the presence of mechanisms that contribute to the intergenerational transmission of trauma.⁴⁸ Such findings are contributing to deliberations on how to mitigate the risk for intergenerational transmission of trauma and other mental health problems, but also on ensuring that intergroup tensions and pre-genocide conflict dynamics do not reemerge in the next generation.⁴⁹

The developmental challenges experienced by descendants of survivors and of perpetrators are distinct but equally significant. Children born to survivors are likely to have been raised in an environment where the extended family network had been devastated by the genocide, with few or no mentally healthy adults to support their development, regular exposure to memories or commemorations of the genocide, and fears of renewed persecution. In contrast, children born to perpetrators were often raised under conditions where one or both parents were incarcerated. On many occasions, children grow up with the false belief that their parent's case was one of unjust imprisonment, contributing to sentiments of anger and bitterness against society.⁵⁰

Interventions to support children of survivors and children of perpetrators are multifaceted, though not yet commensurate to the challenge at

hand. Some approaches include the establishment of youth clubs, where principles for peaceful living are taught while youth from all backgrounds can develop bonds of friendship and solidarity; individual and group psychotherapy, where young people can process traumatic memories while developing more secure identities; vocational counseling and guidance, to support genocide-affected youth in making responsible life choices; intergenerational dialogue, to heal the rift that is often experienced between post-genocide youth and their survivor or perpetrator parents; entrepreneurship programs, to encourage youth from all backgrounds to form enduring friendships and partnerships; and parent training programs, focused on vulnerable populations affected by the genocide.⁵¹ While this is an impressive array of tools to support youth adaptation in post-genocide Rwanda, the greatest challenge is that most have not yet been systematized or tested for effectiveness, nor are they provided at a scale that is adequate to address population needs.

Toward a scalable public health framework for mental health, social cohesion, and sustainable livelihoods in Rwanda

The review of existing initiatives for multisystemic recovery and resilience in post-genocide Rwanda, outlined above, reveals a rich and dynamically evolving tapestry of initiatives, which display a high degree of complementarity and potential when it comes to developing a multisystemic, rights-based approach to mental health and societal healing. While recent and emerging developments within the formal mental health sector can play an important role in addressing biomedical and other individual determinants of mental distress, the social determinants of mental distress can more effectively be mitigated through community-based approaches, such as sociotherapy and collaborative livelihoods initiatives. At the moment, the challenge for Rwanda is not a shortage of societal healing efforts but rather an unregulated plethora of highly diverse and multidimensional initiatives by different actors at varying levels of sustainability and scale. From a public health perspective, the

main challenges to a cohesive public health framework for multisystemic recovery and resilience revolve around standardization and coordination, both of which are essential prerequisites for scaled-up and sustainable service delivery. Ultimately, the unspoken objective of such scaling efforts is genocide prevention. Just like the 1994 genocide struck at the heart of every community of Rwanda, destroying lives, livelihoods, and the social fabric, so must the recovery effort achieve equivalent scale, so that every community and household in the country can have the opportunity to heal from the multidimensional impact of the genocide. Achieving impact at scale is an essential prerequisite for an intervention to be considered rights based: in the absence of scalability and access by all, therapeutic interventions can inadvertently reinforce preexisting patterns of inequity by leaving the most vulnerable behind.⁵² Furthermore, a multisystemic approach to societal healing that simultaneously targets the protection of the rights to mental health, development through economic collaboration, and security through reconciliation is more likely to achieve sustainable social change for all segments of the population.

After contrasting the current state of affairs in Rwanda against its aspirations for societal healing and socioeconomic growth, we propose the following theoretical principles for a rights-based public health approach to societal healing:

Principle 1: Standardize protocols and approaches across sectors and initiatives

Currently, there appears to be a dearth of standardized protocols or approaches accepted as a “gold standard” within the various subdomains of societal healing (for example, in sociotherapy or prisoner reintegration). Without such agreed-on and standardized protocols, it is difficult to test the effectiveness of interventions and therefore determine what, precisely, should be scaled up within the context of a rights-based public health approach to societal healing. The standardization of protocols and approaches would require coordination between existing service providers and a willingness to empirically validate current approaches,

such as through randomized trials with wait-list control groups. A key benefit of having standardized approaches is that it would greatly simplify professional training in ways that would eventually enable scaled-up service delivery. Sociotherapy could be an early target for standardization, given the extensive literature that has been developed around this approach over the past 20 years. This would require close collaboration between the several nongovernmental organizations that are implementing different variants of sociotherapy, so that they can agree on a consensus approach or, at the very least, make explicit the divergences and similarities between alternative approaches.

Principle 2: Blend local innovations with emerging international practices

The scope and intensity of local innovation for societal healing in Rwanda over the past two decades is remarkable. Much of this innovation, for instance in the mental health sector, has occurred through the filtering of international practices through the lens of Rwanda's social and cultural context. In other efforts, such as the development of sociotherapy and of collaborative livelihood initiatives for social cohesion, innovation was inspired by Rwandan community-based culture, with international tools brought in to provide more cogent expression to Rwandan home-grown solutions. This confident blending of what is most valuable from Rwanda's culture with what is most beneficial from relevant international practices can and should continue. Specific directions for future blending include learning from international group-based mental health treatment approaches to strengthen the Rwandan mental health sector in culturally appropriate ways, as well as learning from international practices in community-based entrepreneurship to strengthen the effectiveness and strategic relevance of collaborative livelihood initiatives in Rwanda.

Principle 3: Strengthen the coordination of service delivery, particularly at the level of sectors and local communities

As has been noted throughout this study, societal healing in Rwanda's case requires services and

initiatives across different sectors and levels—from psychosocial support, sociotherapy, and livelihood initiatives at the village level to clinical interventions for mental health at the sector or district level. It is essential to ensure effective coordination to maximize service complementarity while minimizing overlap. A potentially effective formal mechanism for coordination could be provided through the existing decentralized health sector system. This includes health centers at the sector level (typically staffed by psychologists and nurses), health posts at the cell level, and community-based psychosocial workers at the village level. While this network is part of the formal health sector, it can also serve as a coordination hub for additional societal healing efforts provided by the nongovernmental or private sector.

Principle 4: Develop standardized screening, assessment, and referral systems to prescriptively allocate beneficiaries to matching interventions

Given the multisystemic nature of recovery and resilience efforts in Rwanda, appropriately allocating beneficiaries to the interventions they can most benefit from (for example, sociotherapy, a clinical mental health group that focuses on skills and resilience, a family-based intervention, or a collaborative livelihood initiative) is a challenge that must be carefully considered and addressed. The establishment of appropriate assessment-to-allocation systems would help ensure that scarce human and financial resources are optimally allocated in ways that maximize overall impact. Through appropriate community mapping and screening methods, it may be possible to determine what mix of services should be made available in any specific community and which community members should be invited to participate in each program.

Principle 5: Establish a sustainable funding system to enable decentralized multisectoral service delivery for societal healing

Financial resources for societal healing in Rwanda are currently provided through a patchwork of funding streams, from government funds that are disbursed through the annual government budget

to international grants provided directly to nongovernmental organizations, to services that are self-funded by individual and institutional beneficiaries. While this is not necessarily problematic, it can be an obstacle to sustainability and scaled-up delivery. As protocols, assessment systems, and coordination systems become standardized, it might become feasible to offer a more comprehensive range of societal healing services under a national insurance framework. Within such a framework, funding could be available so that beneficiaries and providers can engage with one another regardless of whether providers originate in the public, private, or nongovernmental sectors. This would further ensure the provision of rights-based mental health care, an integral aspect of health care for all.

Conclusion

This paper outlines several notable innovations that have emerged in Rwanda through its efforts for recovery and resilience in the aftermath of the genocide against the Tutsi. At the current juncture, moving toward a public health framework for addressing mental health and societal healing could be the soundest approach to systematize, consolidate, and scale existing gains. Such a public health approach would require extensive collaboration between formal government and nongovernmental service providers, as well as a creative synthesis between local innovations and emerging international practices. The effort should be scholarly and evidence driven, diligently reflecting on theories and mechanisms of change, but at the same time pragmatic.

While Rwanda's challenges have been extreme in their intensity, the multidimensional impact of violent conflict and genocide on mental health, social cohesion, and sustainable livelihoods is, unfortunately, a widespread global phenomenon. From this perspective, several countries can learn from Rwanda's decades-long effort toward multisystemic recovery and resilience. Adopting a multisectoral rights-based public health approach for societal healing is a prospect that should merit

serious consideration in any country emerging from violent conflict or genocide.

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Disclaimer

All views, thoughts, and opinions expressed in this article belong solely to the authors and cannot be ascribed to our academic institutions, Interpeace, or any of the stakeholders who were consulted in Rwanda.

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PERSPECTIVE

We Cannot Win the Access to Medicines Struggle Using the Same Thinking That Causes the Chronic Access Crisis

GAËLLE KRIKORIAN AND ELS TORREELE

Abstract

The inequity in access to COVID-19 vaccines that we are witnessing today is yet another symptom of a pharmaceutical economy that is not fit for purpose. That it was possible to develop multiple COVID-19 vaccines in less than a year, while at the same time fostering extreme inequities, calls for transformative change in the health innovation and access ecosystem. Brought into the spotlight through the AIDS drugs access crisis, challenges in accessing lifesaving medicines and vaccines—because they are either not available or inaccessible due to excessive pricing—are being faced by people all over the world. To appreciate the underlying framing of current access discussions, it is important to understand past trends in global health policies and the thinking behind the institutions and mechanisms that were designed to solve access problems. Contrary to what might be expected, certain types of solutions intrinsically carry the conditions that enable scarcity, rationing, and inequity, and lead us away from ensuring the right to health. Analyzing the root causes of access problems and the political economy that allows them to persist and even become exacerbated is necessary to fix access inequities today and to design better solutions to ensure equitable access to health technologies in the future.

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Introduction

The access to medicines (A2M) movement as we know it today materialized in the late 1990s, in the context of an out-of-control epidemic, rooted in the injustice of having a breakthrough medical innovation—antiretroviral combination therapy against HIV—that could turn AIDS from a fatal disease into a chronically manageable one, available in wealthy countries and largely inaccessible in countries hardest hit by the epidemic.¹

Although times and circumstances are different, we can see similarities with the current inequities in access to COVID-19 vaccines across the world. Understanding how the debates on access to medical innovation and related policy changes developed over the past two decades is useful to appreciate the nature and arguments of current access discussions. It should inspire reflection on strategies for improving access to the various health technologies we need to curb the COVID-19 pandemic, without repeating mistakes from the past or engaging in strategies that further anchor an untenable status quo.

Evolution of A2M activism and mainstreaming of access solutions

A growing reliance on market-based ideology underlying access solutions

Early HIV/AIDS treatment activism in the late 1990s and early 2000s was deeply rooted in health and human rights claims that access to lifesaving medicines was a right for everybody, challenging the premise that medicines could be regarded, and traded, as luxury commodities.² Patients, health and rights activists, and health professionals in countries like South Africa, Thailand, and Brazil mobilized allies globally to challenge pharmaceutical companies and governments to put lives before profits and use accessible generic medicines instead of expensive brand name products.³ In a few years, they successfully shifted the narrative and power dynamics around access to AIDS medicines.⁴ Access to HIV diagnosis and treatment, thanks

to the availability of generic antiretroviral drugs (ARVs), became a core element of the response to the epidemic.⁵

If rights-based treatment activism contributed to profoundly changing the political economy and reality of access to medicines in particular for HIV, tuberculosis, malaria, and a few neglected tropical diseases, there were also other forces at work that affected global health structurally. Initial solutions spearheaded by activists and policy makers in developing countries provided a constitutional right to health and challenged the monopoly powers of pharmaceutical corporations over a country's sovereign right and ability to provide lifesaving generics for its population. While successful at the domestic level, such approaches were often seen to threaten the global world order, in particular global trade, and were gradually overtaken by a more technocratic, less contentious, and more business-friendly approach that relied on voluntarism by donors and the pharmaceutical industry and focused mainly on low-income countries (LICs, a World Bank-invented grouping of countries based on macroeconomic indicators, not people's health needs).

Designed to work in the margins of the prevailing global pharmaceutical economy, this approach aimed to create donor-supported markets to supply selected pharmaceuticals to the poorest.⁶ Donor funds were channeled toward newly created institutions that promoted one-size-fits-all policy solutions, mainly market push and pull mechanisms to ensure large-scale supply at reduced prices. These include demand creation and supply diversification through geographically limited voluntary licensing, scaling up and concentrating production capacity to benefit from economies of scale, generic competition, and demand pooling, among others.⁷

For instance, the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria was created in 2002 to allow scale-up of the early rights-based HIV treatment programs by paying for health technologies at agreed-on lower prices and for their rollout in countries. It was followed by other international initiatives with variable status (including govern-

ment initiatives, United Nations institutions, and public-private partnerships) focused on either the demand or supply side of the medical commodities market. These include the US PEPFAR initiative for HIV/AIDS, the Clinton Health Access Initiative, Unitaid, and Gavi, the Vaccine Alliance, all dedicated to financing, negotiating, and facilitating the procurement and deployment of treatments, diagnostics, and vaccines for neglected populations. In parallel, multiple not-for-profit product development partnerships were created to address the lack of research and development (R&D) for diseases that did not constitute an attractive market for pharmaceutical companies. These included the TB Alliance, Medicines for Malaria Venture, International AIDS Vaccine Initiative, Foundation for Innovative New Diagnostics, and the Drugs for Neglected Diseases Initiative, among others.

This approach allowed the “global health community”—comprising donors and the assembled actors mentioned above—to respond to some of the most urgent access challenges in an ad hoc way, without confronting the overall pharmaceutical business model. Designed as exceptions within a globalized trade and market environment, the solutions were focused on specific gaps and did little in other disease areas that remained neglected, or for populations who remained excluded from access to key medical tools. In particular, people living in middle-income countries—home to 75% of the world’s population, including many of the most vulnerable—were typically excluded from the pricing and supply exceptions created for LIC markets.

The same approaches, and the same global health actors, have so far dominated the COVID-19 discussions and approach to equitable access, with the Access to COVID-19 Tools Accelerator (ACT-A) and COVAX as central mechanisms to accelerate access to COVID-19 health technologies for developing countries.⁸ A dose of charity associated with the traditional market approach risks once again diverting us from the profound moral, political, and economic questioning of the way we finance, govern, and ensure the development and use of essential health tools.

Intellectual property as the cornerstone of market-based solutions

Health policies during the 2000s were designed under a double premise: on the one hand, the positivist belief that technological innovations, particularly biomedical ones, are key to solving all health problems (as we also see today for the COVID-19 response) and, on the other, the prevailing ideology that framed access problems as punctual “market failures” within a globalizing trade environment in which the supply of technologies, including medical ones, was best left to the private sector. At the intersection of both, stringent intellectual property (IP) protection rules were established as an unsailable principle.

The gradual rollout of the 1995 World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property Rights had globalized new IP protections as minimal norms, undermining the ability of countries such as India to produce generics unless explicitly authorized.⁹ While the 2001 Doha Declaration had confirmed countries’ rights to prioritize protecting public health over IP in what was seen as a major victory by civil society and developing countries, enforcing this right remained mostly elusive under the tremendous pressures exercised by countries hosting the major pharmaceutical corporations.¹⁰

With the globalization of the IP regimen, the pharmaceutical industry gained unprecedented control over medical R&D priorities and over the resulting health products, for which they could charge monopoly prices. Since this economic model was considered to work well in delivering medical innovation for populations in wealthy countries (even if at high prices) and in building a prosperous pharmaceutical industry, it was largely left unchallenged. The access inequities it created for people living in less well-off countries were considered as collaterals that could be addressed through ad hoc solutions based on donor goodwill and market shaping. In line with these geopolitical power dynamics, the voluntary Medicines Patent Pool was created as part of global health institutions to broker licenses between corporations and generic companies that would be allowed to supply LICs

and a number of middle-income countries.¹¹ Meanwhile, some developing countries not benefitting from these mechanisms would discreetly make use of their right to use compulsory licenses, avoiding publicity to minimize retaliation and addressing health issues mostly in areas where civil society had exposed access problems.¹² As we see in the ongoing debates around COVID-19 vaccines, especially around the World Trade Organization IP-waiver, most policy makers in wealthy countries still believe or defend the idea that benevolent solutions such as voluntary licenses and the COVID-19 Technology Access Pool can be solutions for fundamental inequities and structural monopoly power (ab)use.¹³

A new global health order whose solutions are reflecting its governance

By the end of the 2000s, a new donor-shaped “global health architecture” or “global health order” was established. While multilateralism was still prominent in the 1990s and the 2000s, with world leaders ready to put health on the international political agenda (for example, the 2001 United Nations General Assembly Special Session on HIV/AIDS and the 2006 G8 Summit on emerging infectious diseases), newly created international organizations that work alongside but separately from the United Nations system—such as the Global Fund, Gavi, Unitaid, and the likes—multiplied. This new global health architecture relied on a central role given to the private sector, primarily the multinational pharmaceutical industry and a handful of large generic producers, as the supplier of health technologies. The primary role of the public sector became to fix the market failure through financing and shaping the market to incentivize this private sector, often according to its conditions. The new preferred modus operandi became public-private partnerships. Their governance typically takes the form of a multistakeholder board that validates large orientations (with a marked presence of philanthropic donors such as the Gates Foundation and Wellcome and of pharmaceutical industry representation, despite potential conflicts of interests) and a secretariat that designs and implements

policies on a day-to-day basis.¹⁴

The public-private partnership model assumes that the commercial sector is not only adequate but also more effective than the public sector in serving the public interest. Based on an assumed “win-win” scenario, often developed by management consulting firms funded by the Gates Foundation, public resources are deployed to subsidize pharmaceutical market segments to make them profitable for the private sector.¹⁵ Importantly, the companies remain largely in control over the availability and pricing of health technologies through intellectual property rights and regulatory monopolies. This new preferred modus operandi is both popular and largely unquestioned, despite significant gaps in democratic oversight and a general deficit in transparency around the deals, the modes of collaboration between private and public entities, and the use of financial resources.¹⁶

Not surprisingly, there has been a large influx of private sector professionals, from management consulting firms to former bankers and pharma executives, to staff the new initiatives and institutions created under the global health architecture, which has infused even more market thinking into global health. This has culminated into the now-dominant assumption that the market-based mechanisms developed to ensure access to selected health technologies for LICs are adequate solutions, financially sustainable, and scalable to all developing countries, provided that “innovative financing” can be found to keep money flowing to support these “markets.”

Although the pharmaceutical industry was directly challenged in the early days of the A2M movement for pursuing profit at the expense of people’s health and lives, it seems to have successfully repositioned itself from being (part of) the problem to being an integral part of the solution, including influencing public health policies. In the context of COVID-19, pharmaceutical companies have been heralded by many for the rapid development of effective vaccines, while their CEOs are directly discussing with head of states about funding, production, and purchase in private bilateral meetings. At the same time, availability and access

to these vaccines has remained highly inequitable, in part because companies insist on retaining their monopolies and refuse to share technologies, despite many contributions of public research and massive public investments and de-risking, including through advance purchase commitments.¹⁷

Meanwhile, solutions divide countries into two categories—donors and recipients of aid—with consequent power dynamics. The donors determine which countries are “eligible” to benefit from the solutions they created, and under which conditionalities. The voices of “recipient” countries and the concerned populations are largely absent in the design and governance of the new global health order. The continued demands by developing countries for systemic solutions to address structural inequities and the dominance of the market over health rights and socioeconomic justice remain largely ignored. A brief look at the design and governance of ACT-A and COVAX reveals the same fundamental flaws, as countries’ calls for more autonomy and technological resilience to develop and manufacture their own solutions are growing louder, especially from African leaders.¹⁸

Exploring new avenues to secure access to health products

Going beyond market-based solutions

Increasing financial incentives and monopoly rights for the private sector to make the market work better for global health has not prevented the multiplication of “market failures” and therefore public health failures. Over the past ten years, it has become apparent that access to medicines is no longer just a problem of “poor people in poor countries.” Most high-income countries are facing access challenges, in particular for new lifesaving treatments sold at such high prices that even the richest social security systems cannot provide them to all their citizens in need. Claims for affordable treatment access are now being raised by patients and medical practitioners globally and for multiple diseases (hepatitis C, diabetes, cancers, etc.), while policy makers are struggling to stand up against the global pharmaceutical industry.¹⁹ There are also

demands for truly needs-driven R&D that delivers adequate health technologies for unmet or new medical needs, such as antimicrobial resistance and emerging infectious diseases (including Ebola, Zika, and COVID-19).²⁰

In recent years, we have also begun seeing instances of pharmaceutical companies choosing to not register or sell their product in some countries because doing so is not financially attractive enough, despite clear medical needs and demand for the product.²¹ This supply control by companies over where to make products available has become a daily reality with COVID-19 vaccines and other medical technologies needed for pandemic control. Through monopolies on products, technology platforms, and manufacturing capacity, companies are deciding to whom to sell their technologies. Taken together with wealthy countries competing to hoard most of the world’s vaccine supply to vaccinate their own populations first, many of the poorest countries—and even the international mechanism COVAX—are unable to purchase vaccines in a timely way, even if they have the money.²²

Supply gaps and market failures are also increasing for health products considered not profitable enough to continue production. The availability of medicines and diagnostics required in small volumes is being increasingly threatened, as is the case for many neglected diseases such as tuberculosis, sleeping sickness, leishmaniasis, and diphtheria. We are also seeing shortages of old and inexpensive yet essential medicines, such as penicillin and cotrimoxazole.²³ In the context of the COVID-19 pandemic, we have witnessed global shortages of key antibiotics (such as amoxicillin and doxycycline), morphine, and basic reagents for diagnostics.²⁴ At various points since the start of the pandemic, even if one wanted to buy these, they are simply not available or have already been sold to the highest bidder. This has led to calls for considering essential medicines strategic products that every country or region should be self-sufficient in and for creating nonprofit- and government-controlled production to ensure this.²⁵

These emerging tensions are questioning the efficiency, cost-effectiveness, and fairness of the

dominant system. Another extraordinary example of unjustified control by pharmaceutical companies that affects patients worldwide is the rising prices of previously cheap—yet lifesaving—medicines, such as insulin, where a few corporations control the market for their mutual benefit and are able to increase prices year after year to the detriment of many people with diabetes who can no longer afford the treatment.²⁶ Seeking to challenge this status quo, a group of scientists is exploring small-scale community-based open source production of insulin.²⁷ In a similar move to increase access to overly expensive medicines and circumvent monopolies, doctors and pharmacists are looking into bedside magistral production as a way to provide personalized medicine.²⁸

The COVID-19 crisis has added to the growing understanding that the scarcity of many essential medicines, vaccines, and raw materials is not inevitable but rather the consequence of policies and decisions from the industry and governments. On the one hand, pharmaceutical companies have wielded unrivaled power to determine the scope and direction of medical innovation and to decide who gets access and under which conditions. On the other hand, states, relinquishing their power to exert their health sovereignty, agree to rely on the private sector for the provision of these essential health tools. They thus became dependent on a handful of producers and a globalized supply that cannot fulfill all existing needs, chose to adopt economic and industrial policies that prioritized business interests over the needs of their populations and health systems.²⁹

Business-as-usual is not an option; we must break the deadlock

Wishing to replicate past successes, health advocates have pushed for broadening the scope of existing solutions to encompass additional diseases and health technologies and to expand the set of “eligible” countries for the exceptions created in earlier years. This has been welcomed by some of the organizations embodying those solutions, as they see it as an opportunity to expand their mandate and scope of activities across disease areas or

to new territories and be able to tap into additional funding sources for sustainability. This applies for instance to Gavi, the Coalition for Epidemic Preparedness Innovations, the Global Fund, the Foundation for Innovative Diagnostics, and Unitaid, which positioned themselves as key players in the design, setup, and functioning of ACT-A together with the Gates Foundation and Wellcome. The same players are now advocating for ACT-A’s evolution into a permanent epidemic response infrastructure.³⁰

But the replication and routinization of ad hoc and donor-driven solutions, bringing more and more public health areas under the control of self-declared global health institutions that focus on narrowly defined biomedical solutions, does not necessarily suit all current and future health challenges or take into account existing shortfalls or pitfalls of these mechanisms. It also does not address the governance gaps that exist in many international organizations that function more like untransparent public-private partnerships than institutions whose policies are dictated by public interest. Because countries’ ability to set priorities and develop an integrated health policy are often hampered and skewed by donor subsidies and their priorities, there are growing voices from “beneficiary” countries calling for increased agency and participation, if not leadership and autonomy, in designing the solutions they deem most fit to promote the health and well-being of their populations—a movement that also includes #DecolonizeGlobalHealth.³¹

For the ongoing COVID-19 pandemic, it is clear that the established global health architecture is unable—and ill suited—to work out relevant and equitable solutions for the developing world, as exemplified by ACT-A and its well-intended but so far ineffective COVAX facility, held hostage to supply restrictions by companies and the vaccine nationalism from those who created it in the first place.³² Voluntary proposals that keep developing nations captive to the willingness of corporations and wealthy countries to access lifesaving public health tools are being increasingly criticized.³³ The political tensions on an IP waiver on COVID-19-re-

lated technologies at the World Trade Organization are reopening an old battle that raged during the HIV epidemic 20 years ago between developing countries challenging monopolies on medical technologies and the wealthy countries defending the pharmaceutical corporations located in their countries.³⁴ However, the COVID-19 vaccine scarcity affects people everywhere, rendering the flaws of the monopoly-based yet highly subsidized pharmaceutical economy visible to more people, and making it obvious that limited exceptions to the IP regimes (for a few patents, for one virus, for a few months, and so forth) will not fix the problems.

The COVID-19 crisis illustrates the critical role of public contributions in the research, development, production, and deployment of medical innovations for global public health.³⁵ The inequities in vaccine access that we are seeing due to the fact that control over such innovations was left in the hands of a few private companies highlights the colossal unbalance that exists between the public health interest and private profits. They illustrate how public resources are used without adequate checks and balances to ensure public value, and fail to prevent growing inequalities in access, even in the wealthiest countries.

Tinkering in the margins of the status quo is unlikely to be successful. The market-based health, pharmaceutical, and medical innovation policies that our governments designed are unable to generate the relevant health technologies and make them available—at an affordable price—to all who need them. Therefore, we need transparent R&D and access policies and governance that are no longer captive to the current, Western-driven global health order. The design of needs-driven research and production of pharmaceuticals could be organized to deliver health commons, not market commodities, making the best of public capacities and setting up transparent and fair collaboration with the private sector for the public interest.³⁶

Conclusion

The inability of the current health innovation and access ecosystem to provide equitable access to

lifesaving technologies has never been so clear. The conditions that made it possible to develop multiple COVID-19 vaccines in less than a year, while at the same time fostering extreme inequities in access and disregarding human dignity and the right to health, call for transformative change in the pharmaceutical economy.

Reforming R&D, production, and availability of pharmaceuticals in the public interest must rely on the following key elements:

- Rebalance the power dynamics between public and private actors in the medical innovation ecosystem and redesign the governance of knowledge and financial resources to prioritize the public interest over private and financial interests. This will require an end-to-end approach to medical innovation and access, as well as full transparency over economic and scientific inputs and outputs throughout the innovation-to-access chain, for which the World Health Assembly's 2019 transparency resolution is a pivotal starting point.³⁷
- Establish adequate governance mechanisms for issues ranging from R&D to access that reflect the reality of medical innovation as a collective effort and of public health as a fundamental democratic and human rights matter. Such governance must be participative and inclusive of all concerned actors, including health professionals, users of health systems, civil society groups, governments, other payers and funders, researchers, and industry. For global governance mechanisms, there should be a particular emphasis on Global South representation.
- Shape economic, industrial, and financing policies in line with health policies, and design them with the explicit purpose of delivering solutions to address people's health needs in equitable ways.
- Embrace the idea that one size does not fit all. Instead, the diversification, deconcentration, and devolution of health innovation and manufacturing must be catalyzed, allowing for locally and regionally driven solutions adapted to specific health needs and contexts, and fostering

countries' agency, resilience and autonomy in improving the health of their own communities.

These elements form a solid basis for a new health innovation ecosystem charged with providing access to health products to the populations who need them, in fulfilment of the rights to health and to the benefits from scientific advancement, which are rooted in the principles of equity, nondiscrimination, and transparency. They can also help shape governance and financing models that are fit for purpose to reach this objective, as well as an economic model that is sustainable for health systems.

Importantly, they would change the political economy against which the right to medicines is currently articulated, removing the risk of undermining health equity. Courts in a number of countries have explicitly recognized that human rights impose obligations on states to find solutions to the provision of even high-cost medicines. For example, a high court in India has stated that "no government can wriggle out of its core obligation of ensuring the right of access to health facilities for vulnerable and marginalized section[s] of society ... by saying that it cannot afford to provide treatment for rare and chronic diseases."³⁸

In conclusion, we need to reassert the purpose of medical innovation so that it aims to improve people's health outcomes everywhere, including through equitable access to adapted health technologies, and actively shape the innovation ecosystem toward achieving that goal. This will allow us to develop out-of-the-box solutions that revisit the articulation between industrial and health policies, including financing. Such solutions must also reimagine the governance of medical R&D and access between different public and private actors, and include individual citizens as co-creators of solutions to improve their health.

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Addressing the Risks That Trade Secret Protections Pose for Health and Rights

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Abstract

Human rights frameworks afford everyone the right to health and the right to enjoy the benefits of scientific progress and its applications. Both come together to create state obligations to ensure access to medicines and other health technologies. Though the impact of patents on access to high-quality, affordable medicines and health technologies has been well described, there has been little attention to the impact of trade secrecy law in this context. In this paper, we describe how trade secrecy protection comes into conflict with access to medicines—for example, by preventing researchers from accessing clinical trial data, undermining the scale-up of manufacturing in pandemics, and deterring whistleblowers from reporting industry misconduct. The paper proposes measures to diminish the conflict between trade secrecy and health that are consistent with international law and will advance health without undermining innovation.

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Introduction

The right to health is widely recognized in international treaties,¹ and every state has ratified at least one of the several international agreements that recognize it.² The affirmative right to health necessarily entails access to medicines and other health technologies such as vaccines and diagnostics, as recognized by international bodies and domestic courts alike.³ (In this paper, we use the shorthand “access to medicines” to refer to access to a variety of health technologies, including vaccines and diagnostics.) Access to medicines, in turn, requires institutional and legal arrangements that ensure that appropriate medicines are developed, tested, and made available equitably and at affordable prices.

Realizing health rights, as one of us has emphasized, requires interventions in law and political economy.⁴ Political economy approaches to law recognize that law constructs markets and that the shape law gives to markets implicates values of equality and democracy—for example, by shaping who has access to health technologies. Intellectual property law is a key component of how law structures markets in, and access to, scientific advances. Patents, for example, are legally granted temporary monopolies that create both incentives for the development of medicines and barriers to affordable medicines. Safeguarding the right to health requires the international community and individual states to balance, adjust, or even override intellectual property provisions.

A great deal of work has been done to illuminate the relationship between patents and access to medicines. But the role that trade secrecy law, another type of intellectual property, plays in limiting access to quality and affordable medicines has received far less attention. An emerging literature has begun to explicate how the protection of trade secrets and confidential corporate information creates barriers to data and information that the public has vital interests in accessing, including information about voting technologies, criminal justice and surveillance technologies, and environmental hazards. This opaqueness compromises important public interests in democratic accountability and public health and safety.⁵ This paper adds to that

literature, detailing how trade secrecy can also impede access to information that is needed to ensure quality, affordable medicines, thereby burdening the public’s right to health and its right to enjoy the benefits of scientific progress and its applications.⁶ As we describe, trade secrecy may be invoked in a manner that prevents public access to clinical trial data, drug pricing data, evidence of corporate wrongdoing, manufacturing information needed to decentralize production, or biologic resources important to treatment and vaccine development.

Access to these resources is particularly acute now, while the world is struggling to respond to the COVID-19 pandemic. On October 2, 2020, India and South Africa submitted a communication to the Council for Trade-Related Aspects of Intellectual Property Rights (TRIPS) of the World Trade Organization (WTO) proposing a waiver of sections 1, 4, 5, and 7 of part II of the TRIPS Agreement in order to support measures to prevent, treat, and contain COVID-19.⁷ The proposal suggests waiving protections of undisclosed information, described in TRIPS section 7. This is of special importance due to the rapid development of treatments and vaccines for COVID-19, and the dramatic global disparities in access to these technologies. Although the public made extraordinary investments in private companies’ vaccine research and development, details of clinical trial data and government contracts remain secret. For example, when immense public pressure led to the release of US vaccine contracts in November 2020, the public learned that the Johnson & Johnson contract explicitly allowed the company to keep secret “production/manufacturing know-how, trade secrets, [and] clinical data.”⁸ Similarly, the European Commission’s first two publicly released vaccine contracts include generous redactions of alleged “confidential information,” including the price per dose, the amount paid up front, and the rollout schedule.⁹ We show why access to information that companies may (rightly or wrongly) designate as trade secrets can be important for public health, why the problem is becoming more acute, and how states can interpret or revise trade secrecy protections to enable them to promote access to medicines.

The rise of trade secret protections

Trade secrecy law generally protects information that is secret, commercially valuable because it is secret, and subject to reasonable efforts to protect its secrecy. Trade secret protections are distinct from patents and copyrights. In certain ways, they are weaker: unlike patents, trade secrets are not protected from independent invention, and they can be used or disclosed if they are discovered by “fair” means. In other ways, they are stronger: both patents and copyright protection are limited to a specific number of years, but trade secret protections can be indefinite. Companies can claim trade secret protection without any registration, and the scope of these rights often become clear only after litigation. Trade secret protections are also not subject to clear exceptions and limitations, such as the “fair use” right in copyright.

The history of trade secrecy law is obscure and disputed, and no major body of scholarship summarizes the transnational evolution of trade secret protection. Broadly speaking, however, protection for trade secrecy follows an arc similar to other forms of intellectual property, growing stronger in many jurisdictions in recent decades.¹⁰

One difficulty tracing the evolution of trade secrecy law around the world is the wide array of ways that states protect trade secrets. Many common law legal traditions, for example, have long protected certain kinds of business information through the rubric of unfair competition law or contract law.¹¹ A competitor stealing information from another could be liable in tort, and an employee who reveals a secret they promised to protect could be liable in contract. Over time, courts have expanded these rights—for example, by implying contracts in certain settings and by preventing the use of trade secrets by some third parties who obtain them improperly. In civil law settings, commercial secrets have commonly received protection under regulation and statute, such as general laws protecting fair competition.¹² Many Asian countries have historically protected trade secrets through informal norms and business relationships rather than through legal means. Countries have thus not always had—and still today do not necessarily

have—a special domain of “trade secrets law.” In India, for example, commercial secrets are not protected as such, but can be protected via the law of contracts and misappropriation. In Germany, trade secrets are protected in a general fair competition statute. In Malaysia, the law of confidence generally governs confidential commercial information, while in Chile the only reference to trade secrets is in criminal law provisions.

In the United States, however, there are a few clear inflection points that show the increased strength of this area of law. Until the 1980s, the leading source of guidance for courts was the Restatement (First) on Torts, which made it clear that trade secrets were protected only in tort, as a violation of “of relationally specific duties,” and did not reflect any “right of property in the idea.”¹³ In 1984, however, the US Supreme Court declared that trade secret rights were indeed a kind of property for the purposes of the US Constitution and thus could be protected from unlawful “takings” of private property—meaning that a government that improperly revealed a trade secret would be required to pay compensation.¹⁴ Early cases in the US and the First Restatement often treated the core information protectable by trade secrecy as technical information about industrial processes and formulas.¹⁵ Today, the US legal framework, shaped largely by the Uniform Trade Secrets Act, defines the scope of trade secrets far more broadly, as covering any “information” that is commercially valuable, secret, and subject to reasonable efforts to keep it secret.¹⁶ In 2016, the US Congress additionally passed the Defend Trade Secrets Act, expanding the law again by providing federal jurisdiction for cases involving the misappropriation of trade secrets. After advocacy regarding the conflict of trade secrets with public interests in access to information, the law also incorporated limited “whistleblower” protections, limiting criminal and civil liability for those disclosing a trade secret pursuant to reporting a suspected violation of the law.¹⁷

In combination with the rise of information technologies and the “informationalization” of the economy, these shifts have had substantial implications. Businesses in the United States can now

claim as their property not just secret formulas but an almost limitless range of information and data, even if such claims might not hold up in court. The implications for public access to information are formidable. In 2001, for example, a US appeals court held that a state could not require the public disclosure of all of the ingredients in cigarettes, even if this disclosure might benefit public health, unless the state first paid the company for “taking” its trade secrets.¹⁸

The 1980s and 1990s also marked a moment when the United States and other wealthy countries made strengthened intellectual property law a significant trade priority, pressing developing countries in particular to adopt stronger intellectual property rights.¹⁹ The WTO’s 1995 TRIPS Agreement played a significant role here. All members of the WTO must adhere to it, and violations of TRIPS are actionable in dispute resolution. Trade sanctions are also possible where countries do not bring their law into compliance.²⁰ Under article 39 of TRIPS, countries must provide protection for “undisclosed information,” provided that the information is sufficiently secret, “has commercial value because it is secret,” and has been “subject to reasonable steps under the circumstances” to keep it secret. Drafters refrained from using the term “trade secret” to avoid associations with any particular legal system, and the requirement of protection for “undisclosed information” does not require a US-style trade secrets law.²¹ International commitments thus give countries many flexibilities with respect to how they implement protection.²²

Wealthy countries have regularly sought to increase protections for trade secrets in bilateral and multilateral agreements.²³ For example, the recent United States-Mexico-Canada Agreement, the result of the renegotiation of the North American Free Trade Agreement, includes “the most robust protection for trade secrets of any prior [US] agreement.”²⁴ It obligates parties to provide both civil and criminal remedies for the misappropriation of trade secrets, judicial procedures to prevent the disclosure of trade secrets during litigation, and corresponding penalties. These measures were not required by earlier instruments such as TRIPS. The

agreement also makes it more difficult for regulators to seek “confidential business information” from commercial entities for certain products.²⁵ This and other bilateral and multilateral agreements contribute to the rising floor of international trade secrecy protections.

As noted above, there do remain meaningful cross-jurisdiction differences in the scope of trade secret protections. But continued trade pressure and efforts to attract foreign investment have led to a recent wave of standardization, with major laws protecting trade secrets recently passed around the world, including in China, Thailand, Taiwan, and Japan.²⁶ The European Parliament and Council adopted a directive in 2016, which requires all European Union (EU) member states to amend their existing laws to comply with a minimum level of trade secrecy protection. Importantly, the directive provides some room for local variation in implementation and also provides exceptions to the enforcement of trade secret laws where, for example, disclosure of the trade secret was for purposes of reporting wrongdoing or protecting a “legitimate interest recognized by Union or national law.”²⁷

Uses of trade secrets and consequences for access to medicines

As the scope of protectable trade secrets has expanded, companies have claimed trade secret or trade secret-like protections for many types of information relevant to health. The consequences for the ability of all people to access safe and affordable medicines are significant.

Clinical trial data

Understanding the safety and efficacy of medicines on the market is crucial for public health.²⁸ Pharmaceutical companies regularly collect safety and efficacy data, including individual participant data, metadata (such as trial protocols for interpreting results), and summary-level data.²⁹ Health regulators require companies to submit clinical trial data to assess the safety and efficacy of proposed medicines. (Fewer data may be required for technologies such as diagnostics, and there is no clear regulatory

framework yet for newer technologies such as health apps.) Companies do, however, commonly invoke trade secret protections to prevent or limit the disclosure of data to outside researchers or the public.

Keeping such data secret has significant consequences. First, regulators are often understaffed and under pressure to approve medicines quickly, and they sometimes make mistakes. Without access to clinical trial data, researchers cannot verify or investigate a medicine's claimed benefits and risks. There are many examples where serious—sometimes deadly—side effects, or a lack of efficacy, were revealed only many years after a drug has been on the market, because clinical trial data were kept secret from researchers. Prominent examples include rofecoxib (Vioxx), estrogen hormone therapy (Prempro), and extended-release oxycodone (OxyContin).³⁰

Clinical trial secrecy can also obstruct the proper operation of health technology assessments, which contribute to health care provision and reform. Health technology assessments “provide a range of stakeholders ... with accessible, usable and evidence-based information to guide decisions about the use and diffusion of technology and efficient allocation of resources.”³¹ For example, they are used to make recommendations about the proper pricing of medicines and how to channel funds toward research that will have the most value for patients. However, health technology assessments can only function when they have sufficient information about the drugs and devices they are assessing.

Researchers can also make new uses of clinical trial data where they are available, such as to predict how subgroups will respond to a medicine or to understand the natural course of a disease. In the case of COVID-19 vaccines, for example, access to clinical trial data and post-market surveillance data may help researchers understand more about COVID-19 infection and immune responses, as well as ask new questions about the safety and efficacy of the vaccines.³² Strong advocacy around access to data has had a significant impact in this context. US regulators released detailed summaries—although

not all data—about vaccines during the regulatory process, and companies have published key trials relatively quickly. These measures have helped scientists understand and debate their efficacy and have likely bolstered public trust in regulatory processes and vaccines.

Access to study protocols is critical for allowing researchers to interpret trial results and to evaluate whether a study's design can produce the information needed. For example, when several companies testing COVID-19 vaccines, after public pressure, voluntarily agreed to release the secret protocols for their studies, this allowed researchers to evaluate the endpoints used, enabling debate about how well the vaccines will protect against transmission and not just against severe disease. When protocols are public, it is also possible to identify improper “outcome switching” or “data dredging,” which occurs when researchers change the primary outcome measures during the analysis stage from those identified in the study protocol to those that make their study results appear more favorable.³³

Second, inhibiting public access to clinical trial data undermines the development of new drugs. Under the current regime, companies and regulators need not disclose the existence of, much less the data from, failed or abandoned preclinical studies and clinical trials.³⁴ This practice drives up the costs of drug development and undermines innovation because researchers cannot “learn from the failures of previous medical products in subsequent research programs.”³⁵ Lack of access to this information may result in unnecessary and unethical human and animal experimentation as companies remake and retest unsuccessful compounds.

Engineering and manufacturing data

Even after patent and data exclusivity periods for drugs expire, trade secret protections permit pharmaceutical companies to keep the precise composition or manufacturing process for medications confidential. This effectively slows the release of generic competitor drugs by preventing their reliance on existing engineering and manufacturing data. As a consequence, drug companies can pre-

serve monopolies on medications that are difficult to reverse engineer.

Trade secret protections can effectively lengthen exclusivity periods for biological medicines in particular. In the case of “small molecule” medicines, which are synthesized in chemical reactions, a researcher can chemically reverse engineer the product. However, biologics, a newer group of medications that are often grown in or derived from living organisms, are more difficult to replicate. Biologics, composed of complex protein or other macromolecules and compositions, are comparatively difficult to produce, and their efficacy and safety depend on the specific conditions of their manufacture.³⁶ To produce follow-on biologics, researchers would benefit from access to manufacturing information, which includes the specific cell line used, the host organism from which the cells were taken, the variable introduced to arrive at the final cell line selection, the method of optimization for the culture medium, the production environment used to grow the cells, and the procedure for isolation and purification of the relevant protein, among other data.³⁷

Access to these alleged trade secret resources and information would also lighten the regulatory burden and therefore hasten consumers’ access to critical medicines. Health regulators treat biosimilars differently from small-molecule medications. For example, the US Food and Drug Administration (FDA) currently approves biosimilars only if testing demonstrates that they are sufficiently biosimilar to the original product.³⁸ However, these time-consuming testing requirements could be simplified if regulators could be confident that the biosimilar was produced with high fidelity to the originator’s production. The licensing of trade secrets can allow production under the originator’s regulatory approval, and information exchange can also enable independent production of biological generics or biosimilars. Without access to alleged trade secret biologic resources and production information, the approval of biosimilars can take longer, leading to higher prices for originator products.³⁹ This ultimately drives up the cost of health care and reduces patients’ access to critical, cutting-edge biological

vaccines and treatments for conditions, including rheumatoid arthritis, anemia, multiple sclerosis, and cancer.⁴⁰ Given the importance of the rapid scale-up of COVID-19 vaccines around the world, many have advocated for the need for the transfer and licensing of manufacturing information in this context.⁴¹

Trade secret protections may also be used to inhibit access to engineering and manufacturing data for vaccines and diagnostics, such as those critical to resolving the ongoing COVID-19 crisis.⁴² Most diagnostics, such as those used for rapid testing for the virus, “are being developed commercially and with proprietary technology,” meaning that concerns about proprietary barriers to scale-up are particularly acute.⁴³ And while a great deal of public funding is being dedicated to developing vaccines and therapeutics, there does not appear to be any concerted effort on the part of funders to insist on either open access to resulting data or the sharing of trade secrets to ensure the possibility of competitive manufacture.⁴⁴ To resolve this pandemic, a coordinated effort must be made to increase capacity for testing, tracing, vaccinating, and treating, particularly among developing and the least developed countries. Sharing data and manufacturing know-how for diagnostics and vaccines will be crucial for enhancing production and ultimately mitigating the harms of the COVID-19 pandemic. Trade secrecy laws obstruct these efforts.

Data related to artificial intelligence

Artificial intelligence will likely permit important advances in health care in the coming years and decades. A subset of artificial intelligence known as “machine learning” uses computer algorithms to analyze large amounts of data, to identify patterns, and to use these patterns to make predictions. The technology is already widely deployed to determine who receives health and disability benefits, to improve patient outcomes, to connect eligible patients to clinical trials, and to promote drug development.⁴⁵

Without access to the algorithm and its underlying raw data, it can be difficult to identify problems with these systems. This is a serious

concern, because despite the perception of these systems as “intelligent,” well-known biases can affect them.⁴⁶ Access to algorithms and training data not only allows for better evaluation but also allows researchers with public health priorities in mind to improve these technologies. Yet companies may invoke trade secrets to guard predictive algorithms, related artificial intelligence and machine learning techniques, and the large datasets that these require to function.

Drug pricing data

Pharmaceutical companies have invoked trade secret protections and trade secret-like protections to limit access to various types of financial information, including drug prices, research and development costs, manufacturing costs, and details regarding financial arrangements. In the United States, for example, companies have litigated against transparency laws that sought to require them to make the prices of their medicines known to the public (when they might otherwise remain obscured by secret rebates or other deals). Collectively, we refer to these as “drug pricing data” because they are all relevant to the matter of fair pricing. The consequences of protecting this information are significant. A lack of transparent pricing information fuels high drug prices, while obscuring the research and development costs limits our ability to calibrate innovation policy and to identify price gouging.

Information about wrongdoing

Whistleblowers are individuals—commonly employees—who reveal secret corporate information in order to hold companies accountable for causing public harm. In some jurisdictions, trade secret law recognizes an exception when the disclosure involves “information that is relevant to public health or safety, or to the commission of a crime or a tort, or to other matters of substantial public concern.”⁴⁷ However, such exceptions may provide little solace to whistleblowers. In practice, “potential whistleblowers face a gauntlet of legal impediments, indoctrination policies, financial risks, and workplace and social pressures discour-

aging reporting of illegal conduct.”⁴⁸ For example, in the United States, employees have been found liable for misappropriation for giving corporate files to their attorneys, even in instances where they were seeking to disclose illegal conduct.⁴⁹

The stakes for establishing robust whistleblowing exceptions are high: insufficient protections coupled with broad trade secrecy law can pose a risk to public health. Without these protections, employees may not disclose misconduct or errors made by health care providers or firms.

Harmonizing trade secrecy law with the right to health

Proponents of trade secrecy protections contend that these protections encourage innovation by limiting the flow of proprietary information. However, many of the kinds of data being claimed as trade secrets are not clearly trade secrets.

One problem, to which some of the solutions we describe below are addressed, is that trade secret law is very fact specific, making it hard to rule out the possibility of trade secret protection for any particular kind of information. However, it is important to recognize that close scrutiny often reveals trade secret claims to be inappropriate and that careful studies have concluded that trade secret law, properly understood, does not protect many categories of information relevant to health. For example, although courts in the United States have at times accepted the idea that prices can be trade secrets with little analysis, there are good arguments based on the theory and purpose of trade secrets law that the price alone should not be afforded such protection. One argument is that price is simply a deal point representing the culmination of adverse negotiations between buyers and sellers and is not “an origin point for future development.”⁵⁰ Concealing prices does not further innovation; it simply undermines the capacity of competitors to provide competitive pricing—hardly a purpose of trade secrecy.⁵¹

Many types of clinical trial data should also not be properly considered trade secrets. Most safety and efficacy data, for example, will not confer an

advantage to competitors of the relevant kind—they cannot, for instance, be used to market another product or to reduce the costs of a competitor.⁵² The data might be privately valuable to the originator because they would reveal its product as harmful, but that is not the kind of value that trade secrecy law protects. Notably, the European Medical Association (EMA) has recognized in data-sharing regulations that many kinds of safety and efficacy data, such as trial endpoints, statistical methods, and adverse event information, are not protected confidential commercial information.⁵³ The EMA has also concluded that clinical trial protocols do not qualify.⁵⁴ US courts have held the same, noting that they contain “no information about secret formulas or rare treatment methods” and do not identify innovative procedures or techniques.⁵⁵

Timing can also influence whether the disclosure of information would produce a competitive harm. For example, releasing research and development costs after sending the relevant product to market would be unlikely to produce a competitive disadvantage.⁵⁶ In addition, the disclosure of aggregated data is unlikely to result in competitive harm.

How, then, can states create or expand safeguards against overly expansive trade secret protections? Three areas deserve particular attention. First, states should guard against the entrenchment of trade secrets as human rights or constitutional rights and reject attempts to enshrine stronger trade secrets law in international law, particularly without adequate and explicit protection of safeguards. Second, states should protect the public’s interest in health data by limiting trade secret law and allowing it to be overridden where public health benefits are salient. Third, countries should adopt robust whistleblower safeguards.

Avoiding the entrenchment of trade secret protections

Trade secret law has not been upwardly harmonized in international law to the same degree as other kinds of intellectual property. It will be important for countries to maintain policy space to modify and adjust domestic trade secret law, particularly given how rapidly information technologies are

evolving and the broad scope of trade secret law today.

Like other forms of intellectual property, trade secret rights are predominantly held by corporations and do not have the status of human rights, nor should they. These rights emerged out of practices that protected commercial morality and fairness between business competitors, and they have no grounding in the rights reflected in international human rights treaties.

States should also consider carefully the implications of treating trade secrecy as a form of property subject to protection under domestic constitutional law. The US experience shows that treating trade secrets as constitutionally protected property creates real risks for the publicity of health information, as in the tobacco case mentioned above. If trade secrets are protected as property, states are more limited in their ability to require the sharing of health data to improve outcomes or to develop new technologies, for example, because they may only do so after compensating the originator. Trade secret law is also plausibly understood more as a means to regulate behavior in the commercial sphere—a kind of tort or unfair competition law—rather than a right that is “good against the world” that should properly be deemed “property” for constitutional purposes. It is also not obvious that judicial review and mandatory compensation are essential to protect private interests: states can voluntarily afford compensation to companies when needed to protect incentives without judicial mandates.

Allowing public interest exceptions to trade secrecy

Public interest exceptions to trade secrecy can help ensure that data can be shared to benefit public health. These exceptions can be codified in at least four ways: first, states can require the proactive disclosure of health information where there is no conflict with trade secrecy law; second, states can exclude information from the scope of trade secret protections; third, states can adopt “balancing tests” that allow the release of trade secrets where the public’s interest outweighs private harm; and

fourth, states can use post hoc techniques such as intellectual property “pools” and compensation schemes to overcome barriers to data sharing.

First, mandatory, proactive disclosure requirements for certain health and safety information can advance the public interest. The scope and timing of these disclosure requirements can be carefully tailored to balance industry interests and public health concerns. For example, in the United States, as part of a settlement in a lawsuit brought by Public Citizen, the FDA began releasing key advisory committee materials, such as safety and efficacy data and FDA reviews of new drug applications, on its website 24 hours before advisory committee meetings.⁵⁷ Previously, these materials were accessible to the public only after a drug was approved. The careful timing requirements on these mandatory disclosures allow interested parties to participate meaningfully in committee meetings, while also negating industry arguments that disclosure will unduly benefit competitors. The United States also releases a substantial amount of summary data via a website called ClinicalTrials.gov, under a statutory mandate that requires such data to be shared. The data involved—summary information about trials underway and their results—are general enough that companies have not argued that the law “takes” their property or improperly discloses trade secrets. A great deal of important summary information that would otherwise be held in secret has been disclosed in this fashion. A key requirement for this disclosure is a regulatory requirement for data sharing from the private company to regulators; countries should ensure that the right to market medicines is contingent on the transfer of relevant data to regulators and should make clear that they will disclose such information to the public as needed to protect public health.

Proactive disclosure statutes can also be styled to create a presumption of transparency rather than confidentiality. Vanessa’s Law, adopted in Canada in 2014, requires manufacturers to release certain clinical trial data and provides the minister of health discretion to release additional information (including confidential business information) without the drug maker’s consent, if the minister

“believes that the product may present a serious risk of injury to human health.”⁵⁸ While Vanessa’s Law and its amendments provide procedures for companies to object to disclosures, the public’s interest is presumptively safeguarded.⁵⁹ There must also be efforts to monitor how laws providing for mandatory disclosure are implemented at the regulatory level.

Second, excluding certain public health information from the scope of trade secret protections can advance the public interest. Some information can be released, as described above, because it does not meet the definition of a trade secret. But states can also amend existing trade secret laws to broaden the ability to safely disclose information, wherever it would benefit health and safety. A narrower definition of trade secrets that excludes information of public interest could help enable more information to be disclosed through public information requests and limit measures that companies might take to threaten whistleblowers. It may also disincentivize companies from filing gratuitous trade secrets lawsuits. An exclusion of health and safety information from the proprietary scope of trade secrecy also resolves concerns that mandated disclosures constitute illegal government takings.

Third, affording public health weight in balancing tests can advance the public interest. Many countries already incorporate public interest overrides or balancing tests into their information access laws. The aforementioned EU directive explicitly allows for EU or national rules that require the public disclosure of trade secrets for the purpose of protecting the public interest.⁶⁰ In the United Kingdom, the Freedom of Information Act “subjects its ‘commercial interests’ exemption to a public interest balancing test: a public authority may only refuse to provide confidential information if it believes that, ‘in all the circumstances of the case, the public interest in maintaining the exemption outweighs the public interest in disclosing the information.’”⁶¹ Similarly, in India, the Right to Information Act of 2005 stipulates that protected information may be disclosed once a “competent authority is satisfied that larger public interest warrants the disclosure of such information.” The law further states that “a

public authority may allow access to information, if the public interest in disclosure outweighs the harm to the protected interests.⁶²

Countries that do not have such balancing tests should consider adopting them. In the United States, for example, the Freedom of Information Act lacks clarity on when the public interest should be balanced against private rights. US courts regularly weigh the public interest when parties seek to withhold information under exemption 6 (personal privacy interests) and exemption 7 (governing information collected for law enforcement purposes). Recent cases arguing that the same balancing applies under exemption 4, which governs trade secrets and confidential commercial information, are currently pending in courts.⁶³

Fourth, developing mechanisms such as involuntary licenses or intellectual property “pools” can override previously established in appropriate situations. If data have already been declared protected as trade secrets, post hoc approaches for disclosure may be necessary.

Where such data need to be pooled from many sources, governments can seek to create voluntary or mandatory “pools” that organize the terms under which such data will be shared. Recently, for example, the president and minister of health of Costa Rica wrote to the World Health Organization, urging it to “undertake an effort to pool rights and technologies ... useful for the detection, prevention, control, and treatment of the COVID-19 pandemic.”⁶⁴ This effort would make available via voluntary contribution all relevant research and other information related to the COVID-19 response without conventional intellectual property barriers, in order to encourage “follow-on” research and fast-track development of emerging technology.⁶⁵ The pool also ideally would provide manufacturers license to use needed data once a working technology is found.⁶⁶ States may also need to revise their laws to enable the entrance of generics and biosimilars where compulsory licenses on patents and data have been issued, but data exclusivity barriers exist. This post hoc approach to pooling trade secrecy information (among other intellectual property) may be particularly import-

ant in emergencies, when longer-term solutions may be impractical and a focus on particular technologies may be justified. However, a large-scale voluntary waiver of numerous intellectual property protections may work only when there is near universal consensus regarding the urgency of the public health interests at play, and non-voluntary sharing may be required.

Outside of pools, narrower mechanisms such as involuntary licenses for the disclosure of specific information, similar to compulsory licenses available in patents, should also be made available. These licenses can be granted whenever public health events arise that make the disclosure of data necessary, despite previous judgments or declarations regarding their protected status. This is especially important when the use of such data would lead to more accessible medical products, such as is the case with biosimilar or bioequivalent drugs and vaccines, which often rely on clinical trial data from originator drugs during the approval process.

Compensation can be afforded in these cases, where disclosure is to or for the benefit of competitors. For example, in some instances when regulators have allowed test data to be relied on by subsequent entrants to a market, they have also established liability schemes to ensure some limited payment to those who funded the creation of the data.⁶⁷ These schemes both dampen opposition from originator companies and address concerns about takings in the rare cases where these might have merit.

Strengthening whistleblower protections

In order to safeguard access to safe and affordable medicines, trade secrecy law must provide sufficient protections for whistleblowers. A model whistleblower protection regime would (1) include a reasonable belief standard and cover both illegal conduct and wrongdoing; (2) reduce the risk of negative consequences for whistleblowers; and (3) provide for infrastructure, resources, and reporting channels that facilitate disclosure.⁶⁸

Laws should facilitate disclosures by anyone who has a reasonable belief that they may expose illegal conduct or wrongdoing—even where disclo-

asures may contain trade secrets.⁶⁹ The reasonable belief standard helps ensure that whistleblowers do not bear too heavy a burden of proof. For example, the EU directive protects the disclosure of information that the whistleblower perceives as either illegal conduct or wrongdoing, in contrast to US federal law, which protects the disclosure only of illegal conduct. The EU standard protects those without legal expertise and those who seek to report unethical behavior that harms the public interest.

Whistleblower protections must also ensure the welfare of those making disclosures. Whenever possible, whistleblowers should be allowed anonymity to prevent workplace retaliation. Interim relief from courts is also necessary where workplace harassment does occur. To alleviate risk further, when disclosures fail to meet a reasonable belief standard, the law should not provide for onerous remedies against whistleblowers, as these disincentivize disclosures that may be valuable to the public.

Regulatory protections for whistleblowers are meaningful only if accompanied by infrastructure and resources that support disclosure. Organizations and individuals that facilitate whistleblowing—such as attorneys and nongovernmental organizations—must be afforded the same protections as whistleblowers themselves. Employees must also be informed of their rights as potential whistleblowers and must have access to pro bono legal representation when needed.

Addressing counter-arguments: International obligations and innovation

The measures promoted above will neither contravene international law nor unduly undermine innovation. As described in the first section, international law requires that states implement trade secrecy protections in a manner tailored to protect the right to access essential medicines. The TRIPS Agreement provides individual states broad leeway in interpreting the purposefully flexible requirements to prevent “undisclosed information” from being used “in a manner contrary to honest

commercial practices.”⁷⁰ Nothing in article 39.2 prohibits states from creating exceptions to trade secrecy protections, appropriately narrowing trade secret protections, or mandating the sharing of trade secrets where this would benefit health and competition. TRIPS also includes broadly stated purposes, for example noting in article 8 that members may “adopt measures necessary to protect public health,” “promote the public interest,” and “prevent the abuse of intellectual property rights” as long as the measures are otherwise consistent with the agreement.⁷¹ Article 7 also makes clear that intellectual property rights should be implemented in a manner that “contribute[s] to the promotion of technological innovation and to the transfer and dissemination of technology, to the mutual advantage of producers and users of technological knowledge and in a manner conducive to social and economic welfare, and to a balance of rights and obligations.” To that end, not only do these proposed measures comply with TRIPS, but they also facilitate the realization of some of the agreement’s core principles.⁷²

In addition, state practice suggests that many of the measures we propose are considered by members to be consistent with the TRIPS Agreement. Various states have already adopted public interest measures similar to those recommended by this paper. For example, the FDA, the EMA, and Health Canada already proactively disclose certain clinical trial data. The laws of several countries—including England, Scotland, and India—compel the disclosure of confidential commercial information where there exists an overriding public interest.⁷³ Efforts to refine and limit trade secrecy laws through the countervailing safeguards for access to medicines that we describe, are, we believe, fully consistent with the flexible international protections for undisclosed information.

Advocates for broad trade secret protections contend that trade secrecy law encourages innovation and so serves the public good. Under this reasoning, trade secret protections ensure profits for innovators by discouraging “free riding.”⁷⁴ They also reduce the need for companies to invest in inefficient security measures.⁷⁵ Others see trade

secrecy protection as an important supplement to patent law because it does not require registration, application, or publication and is low cost and long lasting.⁷⁶

It is important to recognize, however, that overly broad trade secrecy law can impede innovation in a multitude of ways. Trade secrecy and other intellectual property protections can create dynamic inefficiencies by increasing the cost of inputs—especially in the research context—thereby frustrating innovation.⁷⁷ Restrictions on the exchange of information—for example, by discouraging the movement of employees to new employers—can also reduce spillovers of information to other firms. The unlimited duration of trade secret law is also problematic from an innovation perspective, because companies can prevent public access forever, avoiding the “quid pro quo” disclosures of patent law. Indefinite protection is also economically unnecessary under conventional assumptions that companies “discount” the present-day value of protection that exists many years in the future.

Moreover, in general, exclusive rights to information create inefficiencies because information has a marginal cost of zero: it is costless to allow others to enjoy knowledge once it is created, and so from a static perspective should be priced at zero. Limiting access to knowledge may be desirable if it is needed to prevent free-riding problems. But, even without trade secrecy protections, companies would still produce much of the information that trade secrecy laws cover today. For example, businesses create a great deal of secret information simply because it is required by their business, including data demanded by regulators, and prices. A lot of secret information is not expensive to create, meaning that it is not subject to real free-riding problems. In addition, as trade secrecy law has expanded, it has come to implicate public interests—including interests in access to information about products and corporate behavior—that are essential to democracy and the public good. Those who describe the incentive effects of trade secrets law rarely consider these broad public implications, the measures that may be needed to ensure that

trade secrets do not overprotect information that would be created anyway, or the law’s interference with important public interests.

Conclusion

Access to medicines is integral to the right to health. Today, commercial actors utilize trade secrecy to hide numerous types of health-related data, including clinical trial data, engineering and manufacturing data, data related to algorithms and machine learning, pricing data, and information on corporate wrongdoing. The consequences for access to medicines, and thus human rights, are significant, undermining patient-level health, the development of affordable treatments, and the effectiveness of health systems as a whole. This paper has proposed several measures that states could adopt to protect against overly expansive trade secrets regimes. By guarding against the entrenchment of trade secret law as creating “rights” protected under international and domestic law, by protecting the public interest in confidential commercial information by allowing or mandating data sharing, and by strengthening whistleblower protections, countries can protect the pressing public need for collaboration and transparency. In so doing, countries can expand access to medicines and promote the right to health.

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PERSPECTIVE

Should COVID-19 Vaccines Authorized for Emergency Use Be Considered “Essential” Medicines?

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Abstract

A critical debate in the race to develop, market, and distribute COVID-19 vaccines could define the future of this pandemic: How much evidence demonstrating a vaccine’s safety and efficacy should be required before it is considered “essential”? If a COVID-19 vaccine were to be designated an essential medicine by the World Health Organization, this would invoke special “core” human rights duties for governments to provide the vaccine as a matter of priority irrespective of resource constraints. States would also have duties to make the vaccine available in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at an affordable price. This question is especially critical and unique given that COVID-19 vaccines have in many cases been authorized for use via national emergency use authorization processes—mechanisms that enable the public to gain access to promising medical products before they have received full regulatory approval and licensure. In this paper, we examine whether unlicensed COVID-19 vaccines authorized for emergency use should ever be considered essential medicines, thereby placing prioritized obligations on countries regarding their accessibility and affordability.

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Introduction

A critical debate in the race to develop, market, and distribute COVID-19 vaccines could define the future of this pandemic: How much evidence demonstrating a vaccine's safety and efficacy should be required before it is considered "essential"? The World Health Organization's (WHO) concept of "essential medicines" suggests that COVID-19 vaccines that satisfy priority health care needs and have public health relevance, evidence on efficacy and safety, and comparative cost-effectiveness should be considered strong candidates for being listed as "essential medicines."¹ This is important because if a COVID-19 vaccine were to be designated an essential medicine by WHO, this would invoke special "core" human rights duties for governments to provide the vaccine as a matter of priority irrespective of resource constraints.² States would also have duties to make the vaccine available in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at an affordable price.³

This question is especially critical and unique given that COVID-19 vaccines have in many cases been authorized for use via national emergency use authorization (EUA) processes—mechanisms that enable the public to gain access to promising medical products before they have received regulatory approval and licensure.⁴ With some countries poised to vaccinate their entire populations under emergency use authorizations, in addition to many other COVID-19 vaccines in the pipeline and the potential need for new vaccines to address variants of concern, vaccination under EUAs could continue to be the norm for COVID-19 vaccination programs.

Might it be possible for COVID-19 vaccines to meet WHO's standards to be considered an essential medicine? Undoubtedly, any COVID-19 vaccine would satisfy the condition of disease prevalence and public health relevance. Whether a COVID-19 vaccine is comparatively cost-effective will depend on the product, its price, and its alternatives. Vaccine pricing may invoke legal and political challenges regarding intellectual property rights well-traversed in relation to other essential

and non-essential pharmaceuticals over the past decades.⁵ The critical gray area we focus on in this paper—and therefore the crux of essentiality in this case—is determining the evidentiary standard of clinical efficacy and safety that must be met in the context of a public health emergency in order for a COVID-19 vaccine to be deemed an essential medicine. In this paper, we focus specifically on whether unlicensed COVID-19 vaccines authorized for emergency use should ever be considered essential medicines, thereby placing prioritized obligations on countries regarding their accessibility and affordability. We first outline the implications of right to health standards for essential medicines, then consider whether EUA COVID-19 vaccines should ever be considered as candidates for essential medicines status, and conclude by evaluating WHO's Emergency Use Listing procedure as a potential mechanism for categorizing emergency use vaccines for the purposes of being considered for essential medicines status.

Essential medicines and the right to health

Essential medicines, which include vaccines, hold considerable importance in the interpretive frameworks of the right to health, as they are critical to individual and population health. According to article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), states have obligations to prevent and control epidemics.⁶ In General Comment 14, the Committee on Economic, Social and Cultural Rights notes that the provision of vaccines is critical to fulfilling this objective.⁷ The committee has also firmly positioned the provision of essential medicines defined by WHO as a "core obligation" under the right to health. Such obligations are defined in General Comment 3 as the minimum standards that must be met by states in order to give meaning to the enjoyment of covenant rights.⁸ Core obligations to provide essential medicines under the right to health do not necessarily constitute a strictly binding (rather than authoritative) legal standard, even for the 171 states that have ratified the ICESCR.⁹ However, national governments have enshrined the state duty to guarantee

access to essential or needed medicines for all in various domestic legal frameworks, from binding constitutional law and universal health coverage laws to national medicines policies guiding the pharmaceutical sector.¹⁰ For instance, at the height of the AIDS crisis, state provision of “essential” antiretrovirals as part of the fulfilment of the right to health recognized in domestic constitutions and international treaties was enforced through domestic courts.¹¹ This evidence suggests that core obligations hold a customary legal status.

There is increasing consensus in the international community of an emerging custom that essential medicines should be part of the human right to health. For instance, the international community has used the human rights language of access to medicines to create new global health institutions such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, which provides free access for developing countries that cannot provide relevant medicines for their citizens. This seems to imply a wider recognition that access to medicines should be part of a broader realization of the right to health.¹²

Irrespective of the precise legal status of core obligations to provide essential medicines, in a global pandemic such as COVID-19, a vaccine’s designation as an essential medicine by WHO would clearly invoke strong and urgent human rights and public health responsibilities of states articulated in international norms and domestic law, and raise fundamental questions about whether states should make such products widely available at an affordable price.

National emergency use authorizations of unlicensed COVID-19 vaccines

The urgent need to alleviate the global crisis caused by COVID-19 perhaps necessitates a departure from traditional vaccine regulatory pathways, but not at the expense of vaccine safety, efficacy, and quality.¹³ Emergency use authorization processes (or similar regulatory mechanisms) allow national regulatory authorities to authorize the use of

unapproved medical products in a public health emergency in order to diagnose, treat, or prevent serious or life-threatening diseases or conditions when there are no adequate, approved, and available alternatives, but prior to there being sufficient evidence to meet the standards required for regulatory approval.¹⁴ For example, at the time of writing, the US Food and Drug Administration (FDA) had issued EUAs for three COVID-19 vaccines, 10 drug and biological therapeutic products, and 346 *in vitro* diagnostic products.¹⁵ Also of note is that the FDA issued EUAs for chloroquine and hydroxychloroquine, which were later revoked following the removal of hydroxychloroquine as a COVID-19 treatment in WHO’s Solidarity Trial.¹⁶

Given these national-level authorizations, a pertinent question is whether unlicensed medical products authorized for emergency use, including vaccines, should ever be considered essential medicines, thereby placing prioritized obligations on countries regarding their accessibility and affordability. On the one hand, this is an attractive idea. For example, COVID-19 vaccines that have promising safety and efficacy profiles and are issued EUAs could be critical to combatting the pandemic in a timely manner. Yet, if such vaccines are neither accessible nor affordable, then the least advantaged will be disproportionately harmed. If listing COVID-19 vaccines that have received EUAs as essential medicines would trigger responsibilities to make these products available and accessible at an affordable price, this could have the potential to address the problem of accessibility.¹⁷ However, it is important to note that human rights obligations with respect to essential medicines are not absolute and are subject to gradual fulfillment, and so being listed as an essential medicine would of course not guarantee accessibility. Listing COVID-19 vaccines as essential medicines only once they receive market licensure—that is, long after they are likely to have received EUAs in many countries—means that many months may pass in which many people, including the least advantaged, are less able to benefit from these vaccines. Proposals exist for the fair allocation of unlicensed medical products autho-

alized for emergency use, but they do not establish obligations in the same way that being listed as an essential medicine does.¹⁸

While listing an EUA vaccine as “essential” would have important advantages, it may seem counterintuitive to consider a medical product “essential” when evidence for that product has not met traditional standards of safety and efficacy. There are several reasons that militate against considering unlicensed medical products to be essential medicines even if there are countries that have authorized them for emergency use. First, as the US FDA’s issuance and later revocation of EUAs of chloroquine and hydroxychloroquine for COVID-19 highlights, evidence may quickly emerge that a medical product’s safety or efficacy profile no longer supports its emergency use. Given the attenuated evidentiary standards that exist for EUAs compared with market licensure, it may be too hasty to consider such medicines “essential.” Second, as the global race for a COVID-19 vaccine demonstrates, political factors, including vaccine nationalism, can have a perverse influence on the issuance of EUAs. In other words, vaccine nationalism could inappropriately incentivize governments to issue EUAs. Given that countries have been criticized for hurried approvals of vaccine candidates because of concerns over a lack of safety and efficacy data, it is hard to imagine how such products could at the same time be considered “essential.”¹⁹ That the US FDA has resisted political pressure to abruptly issue EUAs for COVID-19 vaccines emphasizes the paramount need to ensure a high degree of safety and efficacy prior to the procurement and widespread dissemination of a potentially dangerous vaccine by a government to its population.²⁰

There are also several potentially negative implications of listing EUA COVID-19 vaccines as essential medicines. Namely, labeling such products “essential” could create the impression that the safety and efficacy of such products is more certain than it actually is. One can only imagine the consequences had chloroquine or hydroxychloroquine been deemed “essential medicines” for COVID-19

when they received EUAs in the United States. In addition, considering such medical products as essential medicines candidates could have profound and far-reaching effects on the perceived value of investigational medical products more generally, such as by emboldening “right to try” movements for medical products whose clinical value and safety is unknown.²¹ Finally, recognizing an EUA product as “essential” would trigger the obligation on states to provide it affordably to all. Consider in this scenario the potential for states to pour significant investments into “essential” EUA products of questionable added value for diagnosing, preventing, or treating COVID-19. Worse yet would be the opportunity costs if those investments precluded a state’s future purchase of other COVID-19 products that are proven resolutely safe and effective. For example, because of the FDA’s issuance and subsequent revocation of an EUA for hydroxychloroquine, the US federal government was left with a stockpile of 63 million doses of a drug that is ineffective in treating COVID-19 and whose cost could have been spent elsewhere.²²

These arguments suggest that the mere fact that a COVID-19 vaccine has received emergency authorization should not automatically render it a candidate for essential medicine status. Conversely, in a public health crisis, it may seem imprudent to require that COVID-19 vaccines receive licensure before they can be considered essential medicines, particularly if vaccination programs are likely to continue under EUAs for some time. Given the dire need for COVID-19 vaccines and the real prospect that the least advantaged will not have the opportunity to access or afford them if and when they are authorized for emergency use, a middle ground is needed.

WHO’s Emergency Use Listing procedure

A potential middle ground would be to leverage the WHO Emergency Use Listing procedure, a risk-based procedure for assessing and expediting the listing of unlicensed diagnostics, therapeutics, and vaccines for use during public health emergencies.²³

At the time of writing, three COVID-19 vaccines had been issued emergency use validation through this process.²⁴

Utilizing this procedure would have the benefit of considering (but not guaranteeing) essential medicine status only among those medical products that have undergone a global, systematic, consistent, transparent, and coordinated process for assessing and listing medical products for emergency use. Relying on a global process with harmonized standards could help identify vaccines that should be considered for essential medicine status without the risks associated with national EUAs. COVID-19 vaccines that have been listed via WHO's Emergency Use Listing procedure could therefore serve as the authoritative roster of medicines authorized for emergency use that WHO may further independently consider for the purposes of being listed as essential medicines.

Conclusion

Given the lower evidentiary standards for EUAs relative to market licensure, political factors that can influence the issuance of EUAs, and the possibility that labeling such products "essential" could create the impression that the safety and efficacy of such products is more certain than it actually is, COVID-19 vaccines authorized for emergency use should not automatically be considered as candidates for essential medicine status. Yet, in the context of a pandemic and large-scale vaccination programs rolled out under EUAs (or similar regulatory mechanisms), it may be imprudent to require that COVID-19 vaccines wait to receive licensure before they can be considered as essential medicines. We therefore argue that COVID-19 vaccines authorized for emergency use should not necessarily be precluded from being considered as essential medicines candidates, but rather be considered for essential medicine status only if they have undergone a systematic, consistent, transparent, and coordinated process for being assessed and listed for emergency use. WHO's Emergency Use Listing procedure comprises harmonized standards and can serve as an authoritative roster of vaccines that

may be further independently considered for essential medicines status.

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Supreme Court v. Necropolitics: The Chaotic Judicialization of COVID-19 in Brazil

JOÃO BIEHL, LUCAS E. A. PRATES, AND JOSEPH J. AMON

Abstract

Worldwide, governments have reacted to the COVID-19 pandemic with emergency orders and policies restricting rights to movement, assembly, and education that have impacted daily lives and livelihoods in profound ways. But some leaders, such as President Jair Bolsonaro in Brazil, have resisted taking such steps, denying the seriousness of the pandemic and sabotaging local control measures, thereby compromising population health. Facing one of the world's highest rates of COVID-19 infections and deaths, multiple political actors in Brazil have resorted to judicialization to advance the right to health and other protections in the country. Responding to this litigation has provided the country's Supreme Court an opportunity to assertively confront and counter the executive's necropolitics. In this article, we probe the malleable form and the constitutional basis of the Supreme Court's decisions, assessing their impact on the separation of powers, on the protection of human rights (for example, on those of prisoners, indigenous peoples, and essential workers), and relative to the implementation of evidence-based interventions (for example, lockdowns and vaccination). While the court's actions open up a distinct legal-political field (sometimes called "supremocracy")—oscillating between progressive imperatives, neoliberal valuations, and conservative decisions—the capacity of the judiciary to significantly address systemic violence and to robustly advance human rights remains to be seen.

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Introduction

In the first week of March 2021, Brazil reported more than 468,000 cases of COVID-19, the highest number of cases in any country in the world, and the most yet recorded in Brazil.¹ Since the start of the pandemic through May 1, 2021, the country has reported more than 14 million cases and 400,000 deaths—and this despite high rates of underreporting.² The country’s universal public health system (Sistema Único de Saúde), once heralded as a pioneering means of social protection, is collapsing. As the pandemic assails the country, regional disparities are tragically exposed.³ In the Amazon, for example, where three-quarters of the population in cities such as Manaus are estimated to have been infected, there are no oxygen cylinders available, and researchers describe hospitals as “suffocation chambers” where patients are unable to breathe and need to be manually ventilated.⁴ Meanwhile, there is increasing concern that the immune protection conferred from previous infection may be waning or may not effectively prevent infection of new variants.⁵ All this at a time when vaccination efforts are highly politicized and without clear operational plans.⁶

Critical voices around the world note that the responsibility for this calamity lies with President Jair Bolsonaro, as he downplayed COVID-19 and systematically sabotaged control measures (promoting herd immunity by contagion).⁷ While this “necropolitical” scenario unfolded (subjugating “life to the power of death” and seriously comprising population health and human rights), new power dynamics crystallized.⁸ Amidst Brazil’s unprecedented political and public health crises, and under intense social pressure, other state actors have been seeking to articulate effective responses, assert their authority, and save the day.

No other institution has been more directly involved in countering the Brazilian executive’s catastrophic handling of the pandemic than the country’s highly scrutinized Supreme Court, the Supremo Tribunal Federal (STF). Following approval of Federal Law 13,979 by the Congress in February 2020, the court has been playing an increasingly active, central political role.⁹ The legislature acted

swiftly early in the pandemic, declaring a “state of public calamity” and creating the legal framework for subsequent political action.¹⁰ Law 13,979 specifically stipulated that the responsibility to respond to the emergency was distributed throughout the federation—that is, it was not only in the hands of the central government but also in the hands of federal district and state and municipal authorities. According to the Brazilian Constitution (art. 24, XII), it is the concurrent competency of all spheres of government (federal and state governments, as well as municipalities) to legislate on health issues.¹¹ Since March 2020, the court has thus been adjudicating disputes between the central and regional governments over their concurrent competence to act on the right to health and issue normative measures (as in the case of lockdowns) and, at the same time, resetting the very terms of their interaction.

While doing so, the STF has often exercised discretionary, if controversial, decision-making powers (such as issuing monocratic decisions, which are verdicts handled by a single justice), thus fashioning new ways of positioning itself in relation to the other branches of government and the broader public.¹² The STF has also strategically retrieved and ruled on difficult lawsuits that had rested idle, and has anticipated disputes (as in the case of vaccination), thereby reshaping the political field and consolidating its policymaking-like power.¹³

Critics have called such an active pursuit of power by the Supreme Court an expression of “supremocracy.” For legal scholar Oscar Vilhena Vieira, the term speaks to the efforts of the court to consolidate “its authority in relation to other levels of the Brazilian judiciary” and to expand “its authority to the detriment of the legislative and executive powers.”¹⁴ However, the label of supremocracy can be contested by those who see the actions of the Supreme Court as an appropriate response to an unprecedented crisis. Regardless of perspective, the pandemic has put the STF at the center of the political stage, having the final word on decisions taken by the executive and legislative powers in relation to a broad range of political, economic, moral, and social issues.¹⁵

In what follows, we probe the form and reach

of judicial power in a time of public health crisis and necropolitical authoritarianism. We highlight the biopolitical role of the Brazilian judiciary during the pandemic and probe the effect that COVID-19 judicialization is having on the separation of powers and on human rights, accountability, and democratic governance writ large. Specifically, we examine the court's responses to the vulnerability of marginalized groups (including prisoners, indigenous peoples, and essential workers) and the steps needed for their protection—including the protection of civil, political, and socioeconomic rights—as well as the emerging role of the court in shaping vaccination policy and access. In other words, in the context of a federal executive government that has done little to advance human rights protections, we examine how an emboldened Supreme Court, in a moment of unprecedented public health crisis, can counter and advance rights protections and the implementation of evidence-based interventions—and what negative impacts may also arise.

Context and methods

The Brazilian legal system derives from the civil law system in place in European countries (for example, Portugal, France, and Germany) and is based mainly on statutes (elevating the importance of codified law over judicial precedent).¹⁶ Given the broad range of citizen rights and state duties specified by the country's democratic Constitution of 1988, the Supreme Court analyzes a wide range of cases, without setting precedents.¹⁷ Addressing myriad plaintiffs and with over 73,000 new cases under review in 2020 alone, the STF is the last instance for legal appeals.¹⁸

The pandemic lockdown and the challenges of online legal access has not limited the general functioning of the Brazilian judiciary, which reviewed more than 1 billion procedural acts and issued more than 22 million rulings between March and December 2020.¹⁹ Since the beginning of the outbreak, courts throughout the country have been inundated with COVID-19-related cases. Cases have included demands for access to intensive care units, unapproved and unlicensed treatments,

economic aid relief, the temporary release of prisoners, and the adjudication of disputes over the public health duties of the various branches of government and of the private health insurance sector. The Supreme Court alone received over 7,000 COVID-19-related cases in 2020.²⁰ All of this occurred in a context where the judicialization of health (and especially medicines) has been growing exponentially throughout the country.²¹ Data from the National Justice Council show that in 2017 there were nearly 1.8 million judicial cases concerning the right to health under review in Brazil.²²

To grasp the scale and impact of the judicialization of the COVID-19 pandemic, we are in the process of conducting a multimethod exploratory study that includes (1) tracking COVID-19-related legislation, judicial rulings, and executive orders and their enforcement (using mainly the *Boletim Direitos na Pandemia, Conectas/CEPEDISA-USP*); (2) monitoring press coverage of the pandemic and tracking social media reactions from government authorities and civil society; (3) analyzing representative legal cases available in the *Observatório Nacional do Conselho Nacional de Justiça*, the *Painel de Ações COVID-19*, the *COVID-19 Processos Judiciais* platform, the *Dados Auxílio Emergencial* platform, and official databases from federal and state courts; and (4) conducting online interviews with key scholars and judicial and policy actors and attending COVID-19-related conferences organized by the *Observatório Nacional do Conselho Nacional de Justiça* (National Justice Council) and the Brazilian Bar Association. As this work continues, we present here an initial descriptive analysis of representative, and high-profile, cases that illustrate the tensions between federal and state/municipal executive authority and the ways in which the STF has intervened in response to COVID-19.

While in earlier work we sought to understand individual and community-level drivers of judicialization, here we are interested in its institutional drivers, particularly in the extent to which judicialization consolidates the authority of the judiciary vis-à-vis the other branches of the Brazilian government.²³ This tension between the

executive, legislature, and courts—at state and federal levels—is of particular interest in relation to government actions and policies that infringe upon rights, where the judiciary has a distinct role in evaluating whether such actions meet standards of legality, evidence-based necessity, proportionality, nondiscrimination, and gradualism.²⁴ More broadly, analyzing the judiciary’s response to executive branch actions further informs our understanding of the justiciability of health rights generally and during public health emergencies in particular.

The judiciary as a key site of politics during the COVID-19 pandemic

Reflecting the pervasive impact of the COVID-19 pandemic in Brazil, our analysis found great diversity in all of the key domains examined. First, we identified a diversity of litigants, ranging from individual patients and at-risk subjects to municipalities and states and public and private institutions (from the health and non-health sector alike)—represented by both public and private attorneys. Second, we found a diversity of issues deemed an “emergency,” such as the lack of hospital beds and ventilators, labor rights and access to financial assistance, lockdowns and quarantine enforcements, commercial operations, and taxation exemptions. Third, unlike the more individualized phenomenon of the right to medicines, we found that COVID-19 cases tended to speak to larger structural issues affecting entire populations, with the rulings more directly impacting governance and the public-private sector interface.

During the pandemic, the country has been witnessing clashes between the Supreme Court and the federal executive branch in a frequency and scale never seen after the redemocratization period. Some of the main conflicts have revolved around the autonomy of states, municipalities, and the federal district; the protection of vulnerable populations; and issues related to infrastructure and technoscience. A close look at specific cases reveals significant legal and ideological contradictions and social biases at play in the work of the judiciary,

determining progressive advances as well as conservative impediments.

Supremocracy v. necropolitics

Three cases vividly illustrate how the Supreme Court has opposed the Bolsonaro administration and strengthened the decision-making power of other spheres of government. Early on in the pandemic, the left-wing political party Rede Sustentabilidade filed a direct action of unconstitutionality (ADI 6.343) against the federal government. The plaintiff asked the STF to suspend a provisional presidential decree that centralized authority in the federal government of all actions related to the transportation of people and cargo, thus precluding the implementation of local prevention measures. The court agreed with the plaintiff’s request and emphasized the authority of states and municipalities to implement measures to control the pandemic, also mandating that future measures be scientifically based.²⁵

In April 2020, the Brazilian Bar Association followed suit, filing a claim of non-compliance (ADPF n. 672) against the federal government, demanding that the Supreme Court oblige the president to uphold COVID-19 control measures implemented by states, municipalities, and the federal district. The Bar Association also asked the court to require that the president implement emergency economic measures to aid the population. The STF partially accepted the Bar Association’s arguments, determining that the federal government could not override the policies that states, municipalities, and the federal district levied against COVID-19.²⁶ Yet the STF passed on the opportunity to force the Bolsonaro administration to change its course of denying the seriousness of the pandemic in the name of putting the ‘economy first.’ In the words of Minister Alexandre de Moraes, it was constitutionally “unacceptable” for the court to mandate the president on policymaking.²⁷

That same month, the northeastern state of Maranhão, then an epicenter of the country’s pandemic and governed by the leftist Partido Comunista do Brasil, petitioned the STF to halt the

Bolsonaro administration's efforts to confiscate and redistribute dozens of ICU ventilators purchased by the state. The federal government's move revealed the precariousness of the country's public health infrastructure and was widely seen by the Brazilian public as a partisan and retaliatory attack on a state that provided Bolsonaro little political support. The court ended up ruling in favor of the state of Maranhão, preventing the seizure of the ventilators.²⁸

These three cases evince the large assortment of political actors and entities resorting to judicialization in their efforts to tackle the direct impact that the judiciary has had on governance in the midst of the pandemic. By exposing and opposing the Bolsonaro administration's refusal to implement adequate control measures and stopping its predatory rule (as in the attempt to confiscate equipment), the STF tactically acted in tandem with the legislature, seeking to both rectify the federal government's fatalistic public health policymaking (downplaying prevention to keep the economy open) and limit its authority. In doing so, "the judiciary has given power to the states," as one interlocutor poignantly told us.²⁹ Given the dire fiscal situation of most states and their dependence on federal funds, in practice this power has had limited effect. The fact is that the Bolsonaro administration has required local governments to support the president's denialism in order to receive emergency funds critical to keep the economy going.

Meanwhile, these three rulings were widely disseminated by the press and in social media platforms, generating a heated public debate about the lack of a federal plan of action to fight the pandemic and about the political authority of the country's highest court. A rhetorical turf war between President Bolsonaro and the country's governors and mayors over leadership, constitutionality, effectiveness, and accountability has also crystallized in the process. At this early point in the pandemic, the Supreme Court, using its malleable form of authority, consolidated its problem-solving image. And in doing so, the STF helped instantiate an informal, parallel form of political power that operates against and in tandem with Bolsonaro's necropolitical authoritarianism, challenging his

authority but not directly forcing him to effect a biopolitics appropriate to the situation.

Selective justice

The numerous interventions of the Brazilian Supreme Court during the pandemic have also been marked by contradictions and internal fissures, especially when it comes to the guarantee of constitutionally mandated human rights. While quick to assert its authority to advance the ability of states, municipalities, and the federal district to implement COVID-19 measures, the STF was mixed in its response to the impact of the pandemic on racial minorities resulting from the country's historical and pervasive contemporary systemic racism.³⁰

For example, two-thirds of Brazil's inmate population are Black, and the great majority are poor.³¹ The country's infamous correctional system is crumbling and overcrowded, indisputably putting detainees at high risk of infection.³² Over 75% of all COVID-19-related cases submitted to the STF between March and May 2020 were *habeas corpus* (mostly filed by public defenders), requesting the release of older prisoners and those with underlying health conditions that put them at risk of severe illness and death. Yet the STF rejected over 90% of these requests, finding decisively against the right to health for this population.³³

Among the collective claims, ADPF 347 stands out. Introduced by the Socialismo e Liberdade political party, the lawsuit asked the court to deem the country's "hellish" and "negligent" penal system "unconstitutional" and therefore requested the court to act immediately, either by commuting or by reducing sentences.³⁴ In March 2020, given the pandemic's rapid encroachment among vulnerable populations, Justice Marco Aurélio issued a temporary injunction (valid for all inmates in the country) asking criminal court judges to assess the situation of prisoners at risk of COVID-19 in their jurisdictions.³⁵ Nonetheless, a majority of justices swiftly overturned Justice Aurélio's injunction.

The judiciary's punitive tendency, as reflected in this action, has also been clearly manifested in public statements. On several occasions, the current chief justice, Luiz Fux, claimed that it was

not possible to release prisoners in the context of the pandemic because of the risk of such individuals committing more crimes.³⁶ Such conservative discourse is aligned with one of the key mottos of *bolsonarism*—“a good bandit is a dead bandit”—and appeals to the president’s constituency that supports the idea that “the culture of human rights is over and now it is the turn of the good humans.”³⁷

In its actions in response to the COVID-19 pandemic, the STF can be seen as marshalling public support by choosing which causes to sponsor and which battles to fight. Under coordinated attack from right-wing extremist groups, the court is clearly concerned with its autonomy and political relevance in a vacuum of effective governance and threatened by retaliation from Bolsonaro.³⁸ Thus, when it comes to ruling on unpopular causes, such as the rights of prisoners to health and life, the court is cautious. This is evident in the more recent decision by Justice Edson Fachin asking criminal judges to commute the sentences of only those prisoners who have committed “crimes with no violence.”³⁹

In contrast to its unwillingness to protect prisoners, the Supreme Court has been more proactive and decisive in the case of indigenous rights (also maligned in Bolsonaro’s predatory rhetoric and neo-extractivist policies).⁴⁰ The most significant example here is the court’s uptake of the claim ADPF 709, in which the Articulation of Indigenous Peoples of Brazil, an indigenous organization supported by six leftist political parties, asked the STF to order the Bolsonaro administration to implement a series of specific protective measures for indigenous peoples during the pandemic.⁴¹ In its August 2020 ruling, the STF acknowledged the validity of most of these requests and demanded that the government, among other things, introduce sanitary barriers to protect indigenous villages, convene an emergency task force involving all stakeholders, and present a comprehensive action plan.⁴²

This was a historic ruling. Never before had the judiciary acknowledged the legitimacy of an indigenous organization to present claims to the country’s highest court. As indigenous attorney and anthropologist Eloy Terena put it, “for the first

time, indigenous [peoples] come to the judiciary in their own name.”⁴³ By early 2021, the Bolsonaro administration had already submitted several versions of the required action plan: all of them were rejected by the STF because they were deemed inadequate and because the government kept “putting the lives and health of indigenous peoples at risk.”⁴⁴

In pragmatically advancing the indigenous cause (as duly mandated by the Constitution) during the pandemic, the court once again tactically assessed the political impact of its stance. It certainly did not escape the justices that claims of the vulnerable indigenous peoples were supported by a strong social and media mobilization and that President Bolsonaro was already being cast internationally as inciting genocide.⁴⁵ Newly emboldened, Amazonian indigenous leaders have since filed a new case against Bolsonaro before the International Criminal Court.⁴⁶

Neoliberal values and judicial populism

The court’s conservative slant toward prisoners is aligned with the neoliberal consequentialist reasoning embraced by most justices when adjudicating cases related to socioeconomic rights. During the pandemic, this was clearly visible when the majority sided with the Bolsonaro administration’s policies that allowed the reduction of wages and the suspension of contracts without the acquiescence of labor unions (ADI 6.342 and ADI 6.363).⁴⁷ According to Justice Luiz Fux, “In situations of serious crisis, the Supreme Court is required to act in a manner marked by the precepts of prudence, deference to technical judgments made by other powers and consequentialism, understood as an attempt to foresee the systemic consequences of a given decision before it is made.”⁴⁸

In her dissenting vote, Justice Carmen Lúcia laid bare the exclusionary neoliberal underpinnings of such a ruling:

We are not talking about the ideal here. We are talking about sticking to constitutional principles that allow us to interpret them in such a way as to ensure the value of labor and of workers. If you lose your job, it may have yet another consequence ...

*you may not be able to socially isolate as you will go out looking for a job. That's what life is, that's what guarantees the survival of each person, especially those most socially vulnerable.*⁴⁹

The acknowledgement of the relationship between economic position and vulnerability to infection (and severe illness) during public health emergencies has been absent not only in the majority view of Brazil's Supreme Court but also in many (if not most) countries, and has been granted insufficient attention in normative human rights standards.⁵⁰ As noted by Leonard Rubenstein and Matthew Decamp, the vulnerability of essential workers is inadequately considered under article 4 of the International Covenant on Economic, Social and Cultural Rights, in the Committee on Economic, Social and Cultural Rights' General Comment 14 on the right to the highest attainable standard of health, and in the Siracusa Principles—all of which fail to envision circumstances where exceptions to restrictions on rights (such as the right to movement) risk health rather than protect it.⁵¹ In these cases, individuals such as essential workers who are *not* subject to rights restrictions may need equal or greater support from the government than those under lockdowns or state-imposed quarantines.

Anticipating the war over vaccines

The Supreme Court's stance on COVID-19 vaccination is emblematic of its ability to both counteract the Bolsonaro administration's (in)actions and shape the political game to come (albeit not substantially altering the lagging federal policy). In December 2020, the Supreme Court ruled by a vast majority (10 to 1) that compulsory vaccination is constitutional and that it can be carried out by any sphere of government. The court swept aside concerns about informed consent and bodily autonomy and rejected the reasoning of unconstitutionality presented by the center-right party Partido Trabalhista Brasileiro (a supporter of the Bolsonaro administration) in ADI 6.587. Instead, the STF agreed with the local governance and public good arguments presented by the left-leaning Partido Democrático Trabalhista in ADI 6.586.⁵² While consolidating the biopolitical authority of

states, municipalities, and the federal district (in line with the legislature's first pandemic decentralizing ruling), the court also reinforced its image of relying on scientific principles and exposing right-wing appropriation of human rights language. This said, the vaccination ruling basically reinforced the compulsory elements of the country's celebrated mass child-immunization campaigns of the past four decades.⁵³

The Supreme Court's techno-juridical authority has certainly been strengthened through the political war over immunization. Since December 2020, the STF has been flooded with vaccination-related lawsuits and has ruled, for example, that states and municipalities could purchase vaccines even if these had not been authorized by ANVISA (Brazil's National Health Surveillance Agency).⁵⁴ Given the president's and his allies' campaign to discredit vaccines, the rulings on these lawsuits sharpened the antagonism between the judiciary and *bolsonarism* at large.

Interestingly, the court anticipated—and, to a certain extent, choreographed—this clash. As early as October 2020, the STF began to signal that it would be acting on the COVID-19 vaccination question. Attuned to a growing societal polarization over the value or danger of immunization (as fomented by President Bolsonaro and his cronies), Chief Justice Luiz Fux then told journalists: “Mark my words: there will be a judicialization of vaccination, and I think that this is a necessary thing.”⁵⁵ According to Fux, the issue should be settled by the STF because the court is the most important institution for guaranteeing the country's *segurança jurídica* (i.e., legal transparency, stability and predictability). The court's move therefore sought to both impede the authoritarian erosion of the rule of law and engender new rules for the political field (at a time when the vaccines themselves had not yet materialized). This anticipatory *modus operandi* created the conditions for new confrontations and political repositioning. In the wake of the government's disastrous handling of vaccination planning and vaccine production and distribution, there has been a significant drop in the government's approval rating and there are growing calls

for the president's impeachment. This said, the effectiveness of this anticipatory action by the Supreme Court (seen by many as rushed) is also quite limited, since an effective vaccination plan needs a centralized purchase and distribution process to gain scale.

Conclusion

Worldwide, governments have reacted to the COVID-19 pandemic with emergency orders and policies restricting the rights to movement, assembly, and education that have impacted people's daily lives and livelihoods in profound ways. These include lockdowns, stay-at-home orders, and restrictions on public gatherings, schools, restaurants, and other business. These orders sometimes include harsh criminal sanctions and police or military enforcement. Some of them have been arbitrary or opportunistic, such as by lifting or loosening environmental regulations or restricting access to sexual and reproductive health and rights (including access to abortion and contraception).⁵⁶ Only some of the myriad impacts on physical and mental health from these actions have been documented; the full consequences will undoubtedly be significant and concentrated in already vulnerable and marginalized communities.

Recognizing the potential for harm from restrictions on human rights in times of emergency, international law requires that such restrictions be considered in relation to key standards, as codified in the Siracusa Principles. However, this task requires an ability to foresee specific harms that may be hard to assess or inconvenient to political expediencies. Courts therefore serve an important role in checking the potential for abuses during such emergencies, when fear of a serious and poorly understood emerging infectious disease may cause overreaction and a discriminatory or indiscriminate trampling of rights. Complementing this role of checking abuses resulting from emergency responses that restrict rights is the responsibility of courts to uphold the right to health and the state's obligation to implement evidence-based prevention and treatment and to ensure that vulnerable popu-

lations are protected.

During the COVID-19 crisis in Brazil, most of the Supreme Court's actions have been in tension with the executive (both confronting some of its omissions and decentralizing its authority). The STF has acted to support states and municipalities in their desire to implement prevention measures and has blocked the Bolsonaro administration from interfering with such efforts. These legal actions can be seen as a necessary (but insufficient) corrective to ongoing necropolitics and also as a minimal counterpoint to the president's efforts to undermine democratic processes. Importantly, the court has not been consistent in its interventions in support of the right to health, for it has upheld the rights of indigenous people while simultaneously choosing not to act on behalf of prisoners or essential workers. In these instances, the Supreme Court can be seen as less concerned with the rights guaranteed in the Constitution and international treaties and more mobilized by a political project of its own, which includes its self-preservation in the face of constant attacks by the executive and by right-wing forces associated with it.

In sum, the widespread judicialization of COVID-19 has provided the Supreme Court an opportunity to strengthen its capacity to confront and rectify the executive's governing failure, while also supporting its own efforts to concentrate greater power. In the lawsuits analyzed in this initial study, the STF acted assertively to prohibit the federal executive from superseding state and local authority—whether related to the implementation of public health control measures (lockdowns), control of vital means for treatment (ventilators), or vaccination policy. Further, the court ruled on which populations at high risk of COVID-19 got relief and which did not, thus reinforcing the STF's authority as a kind of commander-in-chief on various fronts. Most of the actions of the court have, in fact, been to the detriment of the executive, both confronting its omission and directly shaping the agenda of governance during the pandemic (*realpolitik* with the legislature and at times exacerbating the overall policymaking chaos).⁵⁷ In this way, the STF has expanded its role as a check

on federal executive power. This growing authority of the Supreme Court has been recognized and supported by various social, political, and economic actors (from marginalized groups to political parties and corporations). In other words, the justices seem well aware that politics today depends on judicialization and, ultimately, on the STF.

As Brazil faces the perfect storm involving an intersection of public health, economic, and political crises, the STF is forging ahead in a forceful and cunning fashion (oscillating between progressive imperatives, neoliberal valuations, and conservative decisions), orchestrating the political field, and probing the plasticity of the separation of powers and the limits of constitutionality. The court is thus extending the exercise of its core functions to actual governance, with wide-ranging political impact and uneven sociomedical outcomes (as the court only tangentially and strategically addresses unpopular causes that speak to the country's historical inequalities).

The Supreme Court has indeed become a decisive political locus: not only for the deliberations and decisions of other justices or other powers but for any biopolitical impasse during the unfolding calamity. Amidst cries of "supremocracy" and increasing judicialization, the right course of action to check Bolsonaro's necropolitics remains undetermined. While the court opens up a distinct legal-political maneuvering vis-à-vis authoritarianism during the pandemic, the capacity of the judiciary to significantly address Brazil's precarious infrastructures of care, and to robustly advance human rights protections, remains to be seen.

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Is Mandatory Vaccination for COVID-19 Constitutional under Brazilian Law?

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Abstract

Mandatory vaccination for COVID-19 has been the object of heated debate in Brazil. This article discusses the legality and constitutionality of such a policy. First, it analyzes the laws, regulations, and Supreme Court decisions that provide for the possibility of mandatory COVID-19 vaccination. Subsequently, it analyzes the constitutionality of a mandatory vaccination policy through the proportionality method to address the conflict between, on one side, the right to individual autonomy, which includes the right to refuse a medical intervention, and, on the other, health policies that interfere with individual autonomy to protect the rights to life and health. The application of this method allows for the identification of key questions that need to be answered to determine the constitutionality of a mandatory vaccination program. These questions cannot be answered *a priori* and in the abstract because they depend on the concrete circumstances of the pandemic, on the characteristics of the vaccine(s) against COVID-19, and on how a mandatory vaccination policy might be designed and implemented by authorities.

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Introduction

The devastating effects of COVID-19 on public health are well known, especially when the necessary social distancing measures are not taken to avoid contagion. It is also clear that strict social distancing measures have significant impacts on the economy, people's freedom, the education of children and adolescents, and the physical and mental health of the population.

The development of effective vaccines for COVID-19 offers the main route out of the present tragic bind. Effective vaccines can help reduce COVID-19-related mortality and hospitalization. It is also hoped that mass vaccination will help achieve herd immunity (also called "community protection" or "population immunity"), which is defined as the immunization of a sufficiently large portion of the population, either by infection or vaccination, to control the epidemic in a given location to the point of preventing major outbreaks.¹

Vaccines pose dilemmas and difficult choices of their own. The first is related to the distribution of vaccines at the global level. Production capacity is still insufficient to meet global demand and—because the existing vaccines are mainly distributed through market mechanisms—access has been mostly restricted to the countries with the greatest purchasing power. This economic disparity can be mitigated by global aid and initiatives such as COVAX, led by the World Health Organization, which brings together most of the world's countries to facilitate the development of vaccines and their equitable distribution among participants.²

The challenges of global justice are followed by others at the national level in terms of whom to prioritize for vaccination: health professionals, other essential workers, people in high-risk groups, or those living in areas with high degrees of contagion?³ Prioritization guidelines have already been proposed to address scenarios of scarcity.⁴

If the issues of access and distribution are solved, the next debate may well concern vaccine mandates. Mandatory COVID-19 vaccination has been discussed in the specialist literature and is being considered for specific groups, such as

workers in older adult care homes in England, and determined for others, such as health care workers in Italy.⁵ To our knowledge, mandatory COVID-19 vaccination for the general population has not been implemented anywhere. Yet, in Brazil, compulsory COVID-19 vaccination for the general population is expressly authorized by the federal legislation that entered into force in March 2020, which was upheld by the Supreme Court in December 2020.

Brazil has a history of successful immunization policies, having served as a benchmark for other countries during many years. The universal access to vaccines from the 1970s onwards led to the eradication of polio and to the reduction in cases of measles, whooping cough, tetanus, and tuberculosis.⁶ However, the drop in vaccine coverage in recent years, coupled with declarations by President Bolsonaro that promote vaccine hesitancy, have raised concerns that voluntary vaccine uptake for COVID-19 may be low.⁷ It is against this backdrop that debates about mandatory COVID-19 vaccination gained momentum in October 2020, when the governor of São Paulo, João Dória, declared that vaccination would be mandatory in his state and President Jair Bolsonaro immediately took a contrary stance to it.⁸ Mandatory vaccination is by no means a new debate in Brazil, and it is worth recalling the historical and symbolic importance of the Brazilian "vaccine riots" (*revolta da vacina*) that broke out in response to mandatory smallpox vaccine legislation at the beginning of the 20th century.⁹

Compulsory vaccination raises difficult issues due to the direct clash between, on one side, the autonomy of individuals to decide about their own bodies, which includes the right to refuse medical interventions, and, on the other, the imperative to protect public health, which may require restricting individual liberties to avoid disease and protect life in the population. There is a vast literature on this topic, but, for reasons of scope, this paper will not engage with it in depth. We will simply start from the proposition that freedom cannot be absolute when an individual's choices make him or her a potential vector of illness and death to others, and

that any restriction on individual freedom needs to be justified and proportional to the desired public health gains.¹⁰

The tension between individual freedom and public health has been recognized in international human rights law documents—for example, the European Convention on Human Rights, the American Convention on Human Rights, and the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights—that accept restrictions on some civil rights if necessary to protect health. This tension has certainly been accentuated by the COVID-19 pandemic and the public measures to contain it.

This article offers a legal analysis of the possibility of the state making vaccination against COVID-19 mandatory. Although no legal analysis can ever be completely dissociated from ethical and political considerations, legal norms and problem-solving methods should be known and analyzed since, ultimately, they will determine whether vaccination against COVID-19 can be mandated. Rather than proposing a definitive position on the topic, this article argues that it is impossible to give an *a priori* and abstract legal response to the conflict between the claims of individual autonomy and public health. An adequate response will depend on the concrete circumstances of the pandemic, the characteristics of the COVID-19 vaccine(s), and how any mandatory vaccination policy might be designed and implemented by authorities. Although the paper focuses on the case of Brazil, our analysis should contribute to debates in other jurisdictions where mandatory vaccination is being or will be considered to tackle the COVID-19 pandemic.

Mandatory vaccination under Brazilian law

In this paper, mandatory vaccination is understood as the legal obligation to receive a vaccine or to take minors under one's care to receive a vaccine. There may be legal sanctions for non-compliers, but, as will be discussed below, *mandatory* vaccination

does not necessarily imply that people will be forced to vaccinate. By way of comparison, mandatory voting does not allow the state to drag people to a ballot box.

Mandatory vaccination exists in several countries, although it varies widely in terms of scope (in other words, which vaccines are mandated), reach (it may be general or targeted at children, risk groups, or health professionals), the types and intensity of sanctions (including fines, the loss of social benefits, and criminal sanctions), and the possibility of opting out (whether for religious, philosophical, or medical reasons).¹¹

Mandatory vaccination has been provided for in Brazilian law. The first instance was Federal Law 1.261/1904, which made the smallpox immunization mandatory at the beginning of the 20th century and led to the famous vaccine riots. Regarding the legislation currently in force, an important part of it dates from the 1970s, when the National Immunization Program was created. Federal Law 6.259/1975 establishes the following:

Art. 3. The Ministry of Health is responsible for creating the National Immunization Program, which will define vaccinations, including mandatory ones.

Sole paragraph. Mandatory vaccinations will be provided systematically and free of charge by public bodies and entities, as well as by private entities subsidized by the Federal, State and Municipal Governments, throughout the national territory ...

Art. 6. The state governments, subsequent to consultation with the Ministry of Health, may propose complementary legislative measures aiming at the provision of compulsory vaccinations to parts of the population, within the scope of their territories.

Federal Decree 78.231/1976, which regulates Federal Law 6.259/1975, sets forth the obligation of the Ministry of Health to draw up the National Immunization Program listing mandatory vaccines; allocates responsibilities for the execution of the vaccination program; and affirms the “duty

of every citizen to submit himself and the minors under his custody or responsibility for mandatory vaccination.” The decree provides for cases in which there is an explicit medical contraindication proven by a medical certificate as the only allowed exemption from the vaccine mandate. Federal Law 6.347/1977 lists as a sanitary infraction “hindering or opposing the execution of sanitary measures aimed at the prevention of contagious diseases and their dissemination, and at the preservation and maintenance of [public] health.”

The list of vaccines that make up the National Immunization Program is updated periodically through ordinances issued by the Ministry of Health. The first list was established by Ministry of Health Ordinance 452/1977, mandating immunization against tuberculosis, polio, measles, diphtheria, tetanus, and whooping cough for infants under one year of age.

In 2004, Ordinance 597/2004 determined that all vaccines listed in the National Immunization Program were mandatory. In terms of enforcement, the presentation of a certificate proving that a person received all the vaccines became mandatory for receiving social benefits; for nursery, school, and university enrollment; for military conscription (military service is compulsory for 18-year-old men); and for signing work contracts in the public or private sector. These provisions were revoked by Ordinance 1.602/2006, which updated the list of vaccines but excluded any explicit mention of mandatory vaccination. Subsequent ordinances have not made vaccination mandatory for the general population either.

Vaccination is currently mandatory in Brazil for specific groups only. Ministry of Defense Ordinance 94/2020, which creates a specific list of vaccines for military personnel, determines that immunization is mandatory for this group. The obligation to vaccinate children was established by Federal Law 8.069/1990, which, in article 14(1), states that “vaccination of children is mandatory in the cases recommended by the health authorities.” Federal Law 8.069 of 1990 defines children as those under the age of 12, and establishes that the

vaccines recommended for children would be defined by Ministry of Health ordinances. Mandatory vaccination with respect to minors also appears in other laws that create mechanisms to enforce it. For example, Federal Law 10.836/2004, which created the “Bolsa Família” Program (a cash transfer program for low-income families), established “health monitoring” as a condition for receiving this social benefit. According to Federal Decree 5.209/2004, this includes vaccination. São Paulo State Law 17.252/2020 makes it compulsory to present an up-to-date vaccination certificate for all students aged up to 18 years upon enrollment at any of the schools in the state. Other municipalities and states across the country also provide for this obligation.

Finally, and more specifically related to COVID-19, Federal Law 13.979/2020 establishes:

Art. 3. To respond to the public health emergency of international importance referred to in this Law, the authorities may adopt, within the scope of their competencies, among others, the following measures: ...

III - determination of the compulsory undertaking of: ...

d) vaccination and other prophylactic measures; ...
s. 1. The measures provided for in this article can only be determined on the basis of scientific evidence and the analysis of strategic health information and must be limited in time and space to the minimum necessary for the promotion and preservation of public health.

Therefore, there are legal provisions in force, including primary legislation, allowing mandatory vaccination in Brazil, but this has mostly been implemented for specific groups only. In the case of COVID-19, although further regulation may establish more strict conditions, the current law gives the state quite broad powers to compel the population to vaccinate while the pandemic lasts by not specifying any specific target groups.

However, the mere legal provision for a vaccine mandate does not completely resolve the legal issue. Clarification is needed as to whether a mandatory vaccination program for COVID-19 is constitutional—in other words, whether it is compatible with

the Brazilian Federal Constitution, the highest law in Brazil.

Mandatory vaccination according to Supreme Court case law

The nonconsensual administration of medical treatment raises difficult legal issues, as it is a serious interference with human rights such as the right to bodily autonomy. When, or if, it is legally permissible will normally depend on the group for which it is proposed.

Under Brazilian law, children under the age of 12 are not considered to be fully competent to make autonomous decisions, although their wishes and preferences should be considered. Decisions may therefore be imposed on them when in their best interests, even if a decision is contrary to the manifest wishes of the person herself or of her parents or guardians. There may be disputes as to what is best for the child, but, with regard to vaccination, the choice has already been made by the law insofar as vaccination is mandated.

There are instances of legal proceedings against parents who refuse to vaccinate their children, and one of them reached the Supreme Court (Supremo Tribunal Federal, or STF), the highest court in Brazil, through Extraordinary Appeal 1267879. This case involved parents who claimed the right not to vaccinate their children on the basis of their philosophical convictions and the alleged risks involved in vaccination. The STF issued a ruling in December 2020 concluding that mandatory immunization for children is constitutional if (i) it is prescribed by law, (ii) the vaccine has been approved by the national drug regulatory agency, and (iii) the vaccine is listed in the National Immunization Program or local-level immunization programs. According to the STF, if these conditions are met, then mandatory vaccination for children will not breach the freedom of thought and conscience of parents or those with parental responsibility.

The STF ratified what the law establishes in relation to children, whose best interests prevail over contrary wishes (even if expressed by parents or guardians). The court's judgment is also in line

with precedents of the Brazilian judiciary, which tends to reject the idea that parents' philosophical or religious convictions can justify health care-related decisions that can harm their children, as shown by judgments authorizing the administration of treatments involving blood transfusions for children despite opposition from their Jehovah's Witness parents.

However, the question of the constitutionality of mandatory vaccination for the general population, which includes adults with the capacity to consent, is more difficult because there is a direct clash with the individual autonomy of those who refuse to be vaccinated. Legislation and the Brazilian Federal Medical Council's Code of Ethics recognize, with few exceptions (such as when the person lacks the capacity to decide for herself), that medical treatment can be given only if the person consents to it.¹²

Not acquiescing to an individual's choice in order to protect her from harm raises concerns about paternalism. This is not the focus of this article because even though vaccination protects the individual, the dilemma that arises goes beyond the individual. Vaccination offers a benefit not only to the person who is immunized but also to the community. There is evidence that an immunized person is much less likely to spread COVID-19.¹³ In this sense, making a vaccination mandatory is a way of increasing its coverage and protecting those who for some reason cannot be immunized.¹⁴ The focus of this article is thus exclusively on the conflict between the individual autonomy to refuse a COVID-19 vaccine and the moral and legal imperative of protecting the most people possible from a highly contagious disease.

The constitutionality of provisions that allow mandatory vaccination for the general population had never been decided by the STF before December 2020. There is a decision—Habeas Corpus 71373-4, issued in 1994—in which several STF justices cited mandatory vaccination as an example of a situation in which the public interest may prevail over that of the individual. However, these comments were only *obiter dicta*, as mandatory vaccination was not the central issue in the case and was mentioned for

mere illustrative purposes.

In 2020, this issue reached the STF through legal challenges against Law 13.979/20, which, as mentioned above, allows authorities to require immunization for COVID-19. In December 2020, the STF ruled on cases ADI 6586 and ADI 6587 and concluded that the provisions in Law 13.979 are constitutional in principle. The court accepted that individual autonomy cannot be used as a trump against public health measures that promote the constitutionally protected right to health. The court also confirmed that local authorities at the state and municipal level can require COVID-19 if the federal government refuses to do so.

However, the STF clarified that a concrete policy mandating COVID-19 immunization needs to satisfy certain requirements. Non-compliers may be sanctioned, but in no circumstance may they be forcefully vaccinated, as this would breach their individual autonomy, bodily integrity, and human dignity; the decision to make vaccination mandatory must be informed by scientific evidence regarding the vaccines' safety and efficacy and by strategic health information (such as epidemiological data and the existing policies to control the disease); there must be free and universal access to the COVID-19 vaccines; and the policy must respect human rights and satisfy the reasonableness and proportionality tests.

In sum, mandatory vaccination for COVID-19 is constitutional in principle, but the issue is far from settled since an actual mandate may still be unconstitutional depending on the concrete elements of such a policy. It is therefore necessary to further analyze the elements that should be considered when determining the constitutionality of a mandatory COVID-19 vaccine policy.

Mandatory vaccination and the proportionality test

The proportionality test is a commonly used method in law to resolve conflicts in which a fundamental right (such as the individual right to make decisions in relation to one's own body) must be restricted in order to protect another (such as the

right to life and health of others). This test aims to guarantee the greatest protection of a right with the least restriction on another.

The proportionality test was required by the aforementioned STF judgment. The STF also mentioned the reasonableness test, but, putting aside the details of the distinction between the reasonableness and the proportionality tests, it is generally agreed that the latter is more intensive in scrutinizing the merits of a policy than the former.¹⁵ Therefore, a policy that is proportionate is almost certain to be reasonable, but the opposite is not necessarily true. As shown below, the structure of the proportionality test also allows the analysis of the other requirements mentioned by the STF. Moreover, because the proportionality test is widely used by constitutional and international courts, focusing on this method will allow this paper to offer a direct contribution to debates in other jurisdictions where mandatory vaccination for COVID-19 may be considered.¹⁶

There are variations in the application of the proportionality test, but the structure and rationale are recognizable across different jurisdictions. This paper adopts the original and one of the most widespread versions of this method (which is also the one adopted by Brazilian courts), which consists of three subtests: suitability, necessity, and proportionality in the strict sense.¹⁷ A measure can be proportional and, consequently, constitutional, only if it satisfies all three subtests.

Suitability

The suitability test requires that a measure that restricts a fundamental right contribute to promoting another right—in other words, it requires that there be a rational connection between means and ends. In the case under analysis, is mandatory vaccination (which is a direct restriction on the autonomy of individuals to refuse a medical intervention) suitable to promote health protection (which promotes mainly the rights to health and life)? The answer for the suitability test here is apparently easy given that vaccination is an effective measure for containing the pandemic and there is solid evidence that mandates may increase vaccine uptake.¹⁸

However, the specific case of vaccination against COVID-19 presents peculiarities that make the analysis more complex when compared to immunization with vaccines that have been long used for diseases that are better understood. There is, of course, a great deal of haste to develop a vaccine, and the international scientific community has already expressed concern about the risk of losing scientific rigor due to the premature administration of vaccines.¹⁹ In Russia, for example, vaccines began to be applied before phase III clinical trials were concluded.²⁰ The results of phase III trials, in which the vaccine is tested on a large number of volunteers, are normally required to obtain registration before health authorities. Other countries have started their campaigns with vaccines that have gone through phase III trials but that were approved for emergency use only—that is, before full marketing approval.

There are good reasons for allowing and encouraging people to voluntarily receive vaccines for which there is still some uncertainty about efficacy and safety. However, without robust evidence that a vaccine is effective and safe, the argument for restricting individual autonomy by making vaccination mandatory is weaker. The data for the COVID-19 vaccines currently in use in high-income countries are very encouraging, despite concerns about rare adverse events. However, many of the vaccines that are being or will be administered in middle- and low-income countries have not yet been approved by “stringent regulatory authorities,” as defined by the World Health Organization.²¹

One must also consider whether conditions exist for universal vaccination coverage.²² Mandatory vaccination without enough doses or infrastructure to reach the entirety of the population can generate distrust and controversy and can distort the priorities for the vaccine’s distribution. If universal coverage is not feasible, it makes more sense to prioritize based on clear and transparent criteria rather than to impose mandatory vaccination.

Finally, one must consider the risk that the mandate will end up fomenting resistance to the vaccine. Empirically, there is little evidence that

this has occurred where mandatory vaccination has been implemented.²³ On the contrary, as discussed, vaccination coverage tends to increase with mandates. Since the vaccine riots, Brazil has had no record of popular resistance to vaccination.²⁴ In any case, this is a risk that needs to be considered.

Necessity

If mandatory vaccination passes the suitability test—that is, if there is evidence that it promotes the protection of public health—the next test is that of necessity. A measure is necessary when it is not possible to promote the same aim, to the same degree, by another less right-restrictive means. In other words, is it possible to achieve the public health result that is sought with mandatory vaccination, with the same intensity, through a means that is less restrictive of individual autonomy? The answer will depend fundamentally on the stage of the disease, the willingness of the population to be vaccinated voluntarily, and the alternatives to vaccination for preventing contagion.

Vaccine hesitancy is a serious challenge that may hamper COVID-19 vaccine uptake. There is huge variation in COVID-19 vaccine hesitancy across the world; in Brazil, the percentage of people who do not intend to get vaccinated is low when compared to other countries.²⁵ This probably reflects the “culture of immunization” in Brazil, in which society accepts the need for and the importance of vaccination.²⁶

To determine whether voluntary vaccination is sufficient (thus making mandatory vaccination unnecessary), it is important to consider the emerging evidence demonstrating that those who have already recovered from COVID-19 infection will acquire some form of durable immunity.²⁷ If this is confirmed by further studies, then it is possible that the two groups combined—those who have already been infected and recovered and those who are willing to vaccinate voluntarily—will allow for the achievement of a sufficient level of community protection. This, of course, would depend on the analysis of other factors such as the rate of contagion of the disease and the effectiveness of the vaccine. The rate of contagion is affected by

factors such as the profile of the population (age, co-morbidities, etc.) and their habits and their living conditions (housing, hygiene, etc.).²⁸ Although the data suggest high or very high efficacy for many of the vaccines that have been tested, their efficacy will certainly not be 100%, and, therefore, not all those vaccinated will acquire immunity. As a rule, the higher the rate of contagion and the less effective the vaccine, the more people need to be vaccinated for herd immunity to be achieved. However, the lower the effectiveness, the lower the incentives for individuals to vaccinate voluntarily. This creates a problem of collective action that can make a vaccine mandate necessary.

It is also necessary to consider alternatives to vaccine mandates. For example, information campaigns, awareness-raising, and the removal of barriers to access (such as cost, location, and opening hours of vaccination sites) could avoid the three main obstacles to people getting vaccinated: distrust of the vaccine and of the purposes of the vaccination campaign; complacency regarding the risks of non-vaccination; and difficulty in accessing vaccination services.²⁹

Nudge mechanisms should also be considered in order to change the choice architecture and increase the likelihood that people will choose to be vaccinated.³⁰ Examples may include “immunization passports” so that others can identify people who have already been immunized, the creation of a mechanism that sends periodic alerts to individuals who have not yet been vaccinated, and cash prizes or other incentives for those who get vaccinated.³¹ These measures do not necessarily have to be alternatives to mandatory vaccination—they may coexist with it. The question, however, is whether it is possible to show with any degree of plausibility that a vaccine mandate will still be necessary if some or all of these measures are implemented.

Even if we come to the conclusion that a mandate is necessary, we must consider whether targeting certain groups (for example, those at high risk of contagion, of infecting others, or of dying in the case of contagion) could be an alternative to a general mandate. This is an option to be assessed in light of the concrete circumstances of the epidemic

and of the characteristics of the vaccine(s) when (or if) the time comes to make such a policy.

Finally, it will be necessary to assess whether it is possible to achieve the aim of containing the pandemic through alternative measures to vaccination, such as mass tests, contact tracing, quarantine measures, social distancing, and so on. Even if this set of measures is equally capable of promoting this aim, we must consider whether such measures would be more or less restrictive of rights than mandatory vaccination. This leads us to the third test, discussed below.

Proportionality in the strict sense

Even where a mandate is suitable and necessary, it must also be proportional in the strict sense, which is to say that there must be a balance between the intensity of the restriction of a right and the gains made for the other right(s) with which it collides. Therefore, mandatory COVID-19 vaccination will be proportional in the strict sense only if the interference with the individual autonomy to refuse treatment is justified by the gains in the protection of the rights to health and life.

We must then consider what is lost in individual autonomy due to the obligation to be vaccinated against what is lost due to the pandemic or social distancing measures when these are imposed. The pandemic causes enormous losses in terms of mortality and morbidity, in addition to the massive financial and opportunity costs to the health system. This diverts financial and human resources that could be used to care for other diseases and patients.³² In other words, the absence (or insufficiency) of state intervention to promote public health and thus reduce the risk of harm to individuals also interferes with rights.³³

The pandemic can be, to a certain extent, controlled through social distancing measures. However, such measures on their intensity and duration, may be even more limiting to a series of individual rights (such as the freedom of movement, freedom of association, and economic freedom) than the obligation to get a vaccine. In addition, social distancing measures have serious deleterious effects, such as on people’s physical and

mental health, the right to education of children and young people, and the economy.³⁴

Let us consider three scenarios. In the first, there is mandatory vaccination, which restricts the individual autonomy to refuse treatment, but which controls the pandemic and makes harsh social distancing measures unnecessary. In the second, there is no mandatory vaccination, but the pandemic is contained by strict social distancing measures (such as long lockdowns), which protects the rights to health and life but imposes severe limits on individual liberties. In the third, there is neither mandatory vaccination nor social distancing measures, which needlessly aggravates the COVID-19 health crisis, causing excess morbidity and mortality. A careful analysis of the three scenarios, considering the concrete facts and the nature and intensity of the interference with the different rights involved, may lead to the conclusion that, overall, the first scenario is the one with the least restriction of fundamental rights.

If this is indeed the case, then mandatory vaccination will be proportional in the strict sense. What is lost by this restriction on individual autonomy to refuse treatment is offset by what is gained in rights terms when pandemic control is achieved without the need for harsh social distancing measures.³⁵

Sanctions and exceptions

The result of the proportionality test will depend on the scope and severity of a given policy. Therefore, when applying the three subtests to a concrete COVID-19 vaccine mandate, one must pay attention to the sanctions that are provided for in cases of noncompliance and the provision (or lack thereof) of exceptions to the vaccine mandate.

Mandatory vaccination means that a person can be subject to sanctions if she does not fulfill this duty. Sanctions can vary widely in their type and intensity. Examples include warnings, fines (as applied in some Brazilian cities to people who do not use face masks in public spaces), the loss of benefits (for example, a government benefit such as the “Bolsa Família” program), restrictions on freedom of movement or association (for example, an

obligation to be monitored or restricted access to places), and even criminal sanctions. It is possible that, in certain contexts, the mandatory vaccination itself is constitutional, but, in light of the proportionality method, some of the sanctions are not. The Brazilian Supreme Court has already ruled that non-compliers cannot be forcefully vaccinated and, in the same judgment, some justices mentioned *in obiter* that criminal sanctions are likely to be disproportionate.

Another question to be considered is whether the law should tolerate exceptions and allow some people to opt out of the vaccine mandate. Exceptions could be for medical reasons for those to whom the risk of side effects (for example, due to allergy) is much greater than for the rest of the population. This exception is already provided for in article 29 of Federal Decree 78.231/1976: “Only persons who present a medical certificate explicitly informing a contraindication to the vaccine will be exempted from mandatory vaccination.” For these people, measures that promote herd immunity are highly protective of their lives and their freedom. On the other hand, forcing them to get vaccinated is probably disproportionate given the risk it presents to them.

Exceptions for nonmedical reasons are more controversial. Exceptions to the mandatory vaccination of children due to philosophical or religious views held by their parents are contemplated in places as Canada, Indonesia, Australia, and several US states.³⁶ In Brazil, as previously mentioned, the STF has held that parents who are philosophically opposed to vaccines are still obliged to have their children vaccinated. The question of whether an adult can reject treatment for religious reasons was also referred to the STF in two cases dealing with blood transfusions refused by Jehovah’s Witnesses, but these cases have not been decided yet.³⁷ These cases, however, are distinct from the question of vaccination because the balance therein is between the individual’s autonomy to refuse treatment and his or her right to life. In the case of vaccination, the conflict is between the individual’s autonomy and the rights of others.

For some people, a vaccine mandate may be

an intense restriction on their freedom, including their freedom of religion and thought. However, following the logic of the proportionality method, the constitutionality of a vaccine mandate with very limited or no nonmedical exemptions will depend on the concrete circumstances, particularly the impact on the rights of others that may result from these exemptions.

It is important to note that there is evidence that people who oppose vaccination for religious or personal reasons tend to be concentrated in certain locations, meaning that such exceptions can generate localized epidemic outbreaks.³⁸ In the case of diseases as contagious as COVID-19, this could have serious widespread implications. If this phenomenon is observed or expected, there is even greater justification for limiting or excluding non-medical exceptions.

Conclusion

Whether a mandatory vaccination policy is constitutional will depend on the answers to some key questions in the application of the proportionality method (see Table 1). These questions can guide constitutionality reviews undertaken by the judiciary and help the executive and legislative branches

formulate policies in a more transparent, informed, and balanced way, giving due weight to fundamental rights. The analysis in this text reinforces the view that the constitutionality of mandatory vaccination cannot be answered *a priori* and in the abstract. Any answer depends on the assessment of the actual facts when (and if) such a decision is made. This means that constitutionality can vary over time. An unconstitutional policy can become constitutional and return to being unconstitutional in light of new information or a change in context.

This paper has focused mainly on substantive issues related to the constitutionality of mandatory vaccination. Yet there are also institutional questions that are key to a court decision on this topic. Should the judiciary, in reviewing a mandatory requirement, have a more activist role in scrutinizing facts and policy considerations to impose what it considers the correct answer to these key questions, or, alternatively, should it grant the executive or the legislative branches a wider margin of discretion on these issues? An in-depth analysis of this question is beyond the scope of this article, but courts will have to engage with concerns about the limits of their institutional capacity to decide on issues that require the assessment of complex social facts and scientific information. This is all the more import-

TABLE 1. Key questions for assessing the proportionality of mandatory vaccination

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| <p>Suitability</p> <ul style="list-style-type: none"> • Is there evidence that the vaccine is safe and effective? • Is vaccination coverage for the entire population feasible? • Is there a risk that a mandate could increase people's resistance to the vaccine? <p>Necessity</p> <ul style="list-style-type: none"> • Is it possible to achieve a satisfactory degree of vaccination coverage through voluntary vaccination? • Is it possible to achieve a satisfactory degree of vaccination coverage exclusively through noncoercive strategies to promote vaccine uptake? • Is it possible to achieve a satisfactory degree of vaccination coverage if vaccination is mandatory only for certain target groups? • Is it possible to control the pandemic through other measures apart from vaccination? <p>Proportionality in the strict sense</p> <ul style="list-style-type: none"> • Is mandatory vaccination less restrictive of rights than other measures to contain the pandemic that could prevent or reduce its spread? • Is mandatory vaccination less restrictive of rights than the effects of the pandemic that it could have prevented or reduced? <p>Sanctions and exceptions</p> <ul style="list-style-type: none"> • What type of sanctions are there for noncompliance with the obligation to be vaccinated? • What exceptions are contemplated for mandatory vaccination? |
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ant considering that there will likely be reasonable disagreements over the answer to many of the key questions and that the evidence needed to decide on some matters may be inconclusive.

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Accountability for the Rights of People with Psychosocial Disabilities: An Assessment of Country Reports for the Convention on the Rights of Persons with Disabilities

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Abstract

The Convention on the Rights of Persons with Disabilities (CRPD) has been identified as a milestone in human rights protection, offering people with psychosocial disabilities the opportunity to hold their governments accountable for the realization of their rights. To facilitate such accountability, the country reports produced under the CRPD reporting process should adequately reflect these persons' experiences and relevant positive or negative developments in the country. Our study used content analysis to review the extent and quality of reporting related to mental health and psychosocial disabilities in 19 country

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reports. The criteria used were based on provisions of the CRPD and on priorities identified by a steering committee of people with psychosocial disabilities. We found a wide variation in the quantity and quality of states' reporting, with an indication that this variation relates to countries' economic development. Increasing the participation of representative organizations of people with psychosocial disabilities is needed for state parties to fulfill their reporting obligations. While there has been progress in improving organizations of persons with disabilities capacity to be heard at the global level, our findings suggest low levels of participation in CRPD processes at the national level in many countries. State parties must actively include these groups to ensure implementation of the CRPD principles.

Introduction

Around the world, people with mental conditions and associated psychosocial disabilities are among the most marginalized groups in society.¹ Psychosocial disabilities are those disabilities that arise from barriers to social participation experienced by people who have or who are perceived to have mental conditions or problems, and the term is now widely used within the disability movement.² While the form and extent of exclusion and abuse may differ from culture to culture, the problem is “near universal.”³ Since coming into force in 2008, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) has been heralded as marking a paradigm shift in the way that disability is understood and responded to.⁴ It moves away from the traditional perspective of persons with disabilities as “objects” of charity in need of “cure,” to a human rights perspective that addresses the barriers experienced by people with psychosocial disabilities across all life domains.⁵ This is the realization that people with disabilities are rights holders, who must be afforded agency to make their own decisions and to participate, on an equal basis with others, as active members of society.⁶ In addition, a systematic review in 2016 found that consultations with mental health service users in policy formulation processes increased the likelihood of improved mental health services and

outcomes.⁷ The CRPD provides a clear articulation of the human rights of people with psychosocial disabilities in line with other impairment groups, and was drafted with the involvement of their representative organizations.⁸

The accountability mechanisms for monitoring and reviewing states' implementation of the CRPD are detailed in the UN Disability Inclusion Strategy.⁹ The Optional Protocol to the CRPD includes further mechanisms for remedies and redress.¹⁰ The Committee on the Rights of Persons with Disabilities (CRPD Committee), an independent “committee of experts”—also known as a human rights treaty body—conducts a constructive dialogue with countries that have ratified the treaty (state parties). Initially, countries must submit a report two years after formal ratification of the treaty, and then periodically every four years, outlining their progress in the realization of disability rights in domestic law, policy, and practice. Persons with disabilities are expected to be full participants in this process—based on clear recommendations in the CRPD Committee's General Comment 7, which includes a discussion of articles 4(3) and 33(3) concerning the meaningful participation of people with disabilities in decision-making and in providing input into national reporting by state parties.¹¹ Civil society organizations and national human rights institutions are encouraged to sub-

mit parallel, or “shadow,” reports during the state’s drafting process. Other aspects of this process also encourage meaningful participation—for example, the review of the country report by national human rights institutions must include the expectation of participation and must be attuned to the priorities of people with psychosocial disabilities as identified by their representative organizations.¹²

A member of the CRPD Committee volunteers to lead the report review and drafts a “list of issues” to be addressed by the country in its response. This “list of issues” is a list of themes or questions formulated by the treaty body on the basis of a state party’s report and other available information (for example, information supplied by UN specialized agencies, national human rights institutions, civil society organizations, and other contributors), which is transmitted to the country government in advance of the session at which the treaty body will consider the country report. The list of issues provides the framework for a constructive dialogue with the government delegation. A good general understanding among actors in the process is essential if these issues are to be properly addressed in the “constructive dialogue” on the report at the CRPD Committee meeting.

Civil society organizations can access the committee’s concluding observations or recommendations issued to a government after the constructive dialogue. The concluding observations or recommendations provide civil society with another mechanism to hold state parties accountable. In this way, civil society organizations can contact the Secretariat of the CRPD Committee and draw the committee’s attention to inaction on the part of state parties. The CRPD Committee also has its own follow-up procedure whereby a dedicated member of the committee tracks the actions that state parties are undertaking or failing to undertake.¹³

Despite these formal procedures, throughout the world, it is unclear whether people with psychosocial disabilities are fully benefiting from the potential of the CRPD accountability mechanisms when it comes to the realization of their rights. There are a number of reasons why this may be the

case. First, while at the global level national organizations of persons with psychosocial disabilities have been very influential, not least in the CRPD development process, these organizations may be newly formed or emerging, financially vulnerable, or nonexistent at the national level in many countries, particularly in lower-income countries.¹⁴ Second, where such organizations do exist at the national level, there are barriers to their participation in the preparation of country reports, given that based on prejudice and exclusion, there is often no formal role for them to contribute to decision-making processes such as policy development. Such exclusion can also come from within the disability community itself, meaning that persons with psychosocial disabilities may be underrepresented in national disability federations. This exclusion undoubtedly results in members of organizations lacking the opportunity to advocate effectively as part of the reporting process.¹⁵

The aim of this research is to empirically assess these assumed limitations by measuring how psychosocial disabilities have been included in the reports submitted by state parties to date. By better understanding the content of these reports, it will be possible to gain insight into the inclusion of people with psychosocial disabilities in national policies and programs, as well as the success of their representative organizations in using the CRPD Committee as a mechanism to hold duty-bearers, including governments and the private sector, to account. We hope that these insights into the country reporting process will elucidate disparities in participation in the CRPD accountability process at the national level and inform the strengthening of this process going forward.

Methods

We reviewed 19 states parties’ official reports submitted to the CRPD Committee to ascertain the quantity and quality of content related to psychosocial disabilities. These reports were purposively selected for representation across global regions and income levels (low-, lower-middle-, upper-mid-

dle-, and high-income countries using World Bank criteria) to ensure that a diverse range of national experiences were captured.

Overall, the review included three countries classified as low income, five of each other classification, and one unclassified (Figure 1). The East Asia and the Pacific region, the Latin America and the Caribbean region, and the Sub-Saharan Africa region were the most represented, at four countries each. Myanmar was the only country included that is classified under “fragile and conflict-affected situations” by the World Bank. Table 1 includes a list of the countries reviewed and their detailed classifications.

A review of the relevant literature did not identify an appropriate tool for analyzing the content of such reports. We therefore developed a framework for assessing the variables considered to be particularly pertinent to reporting on the realization of rights of persons with psychosocial disabilities and used content analysis of the reports’ text to review them.¹⁶

At the start of the research, we established a

steering committee to inform the process and guide decisions at various stages. This committee was made up of people who have personal experience living with psychosocial disabilities and working in this field, some of whom had participated in CRPD reporting processes, and who come from a range of countries, including those in our study.

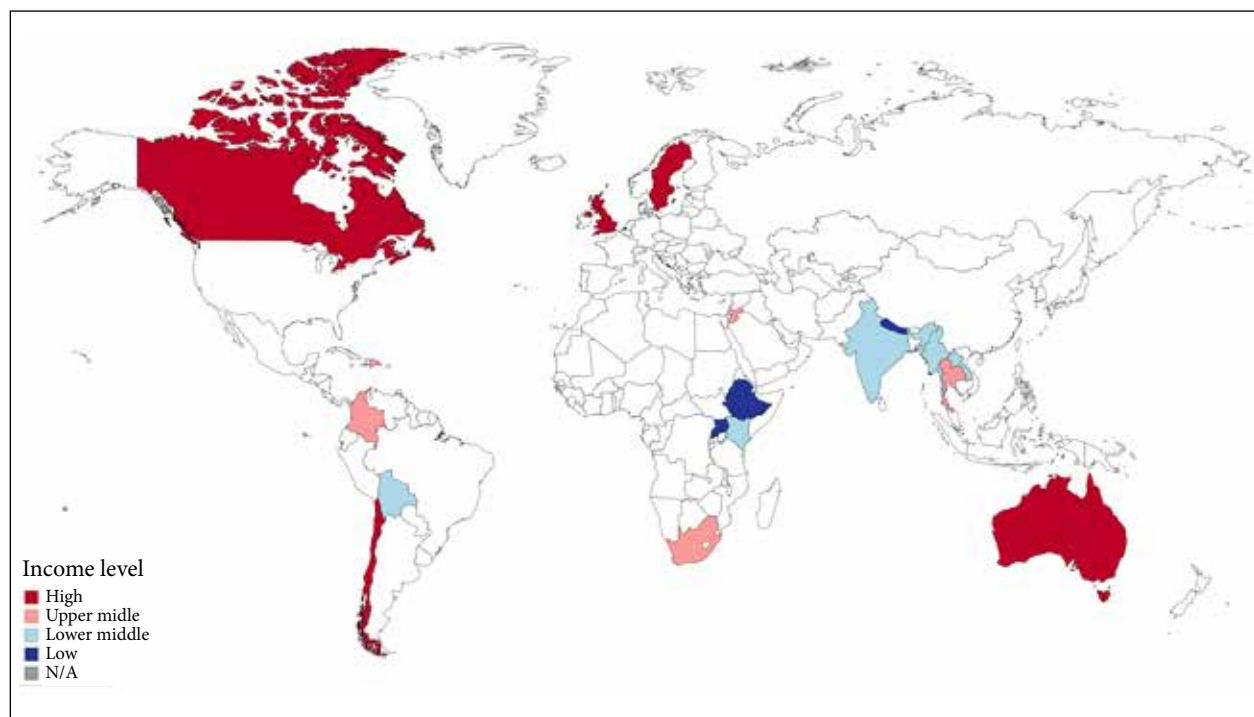
The steering committee (which included all of this paper’s authors) developed, by consensus, five variables for judging the strengths of the country reports with respect to psychosocial disabilities. These variables were based on CRPD principles, common errors in understanding psychosocial disabilities, and priorities identified by organizations of people with psychosocial disabilities in the literature.

Variable 1: *The extent of discussion in the report regarding psychosocial disability*

Variable 2: *Theoretical approaches informing the report’s discussion of psychosocial disability*

Variable 3: *The extent to which the report distin-*

FIGURE 1. World map showing countries included in the review and their classification by World Bank-defined income level (FY17 classifications)



guishes psychosocial disability from intellectual disability

Variable 4: *The extent to which the report addresses CRPD articles considered highly relevant to people with psychosocial disabilities*

Variable 5: *The extent to which the report’s discussion of accessibility initiatives (such as reasonable accommodation) addresses psychosocial disabilities compared to other disability types*

This framework was developed into a psychosocial disability rights content analysis tool (PDR-CAT), establishing a coding guide for each variable, which we used to analyze the country reports and assign scores for the reports against each variable. The tool and coding guidance are available on the Mental Health Innovation Network’s website. This process was repeated by a second independent reviewer using the same tool. We assessed inter-rater reliability using the Cohen’s Kappa method.¹⁷ Where there were discrepancies between the raters, reasons for this were discussed by the researchers and the steering committee to decide on clearer coding guidance to remove ambiguity, and with a view toward better reflecting the intended purpose of the variable. We

then recoded the relevant variables according to these decisions. In addition, there is much detail in the reports that cannot be captured in dichotomous variables, even where some intermediate scores were used. Thus, throughout the results, we have included notes that attempt to describe these nuances. More details for each variable, along with the reconciled coding and notes of these additional details, are presented below.

Results

Variable 1: The extent of discussion regarding psychosocial disability

Variable 1 measured the extent of each report’s discussion of psychosocial disability. We carried out a word search to identify paragraphs including “search terms” related to psychosocial disability (Table 3), which we identified through a literature review and review of a sample of country reports. We excluded paragraphs if they included the search terms but clearly did not refer to psychosocial disability. We then calculated the proportion of paragraphs in each report that included the search terms (see Figure 2).

TABLE 1. Countries included in the review

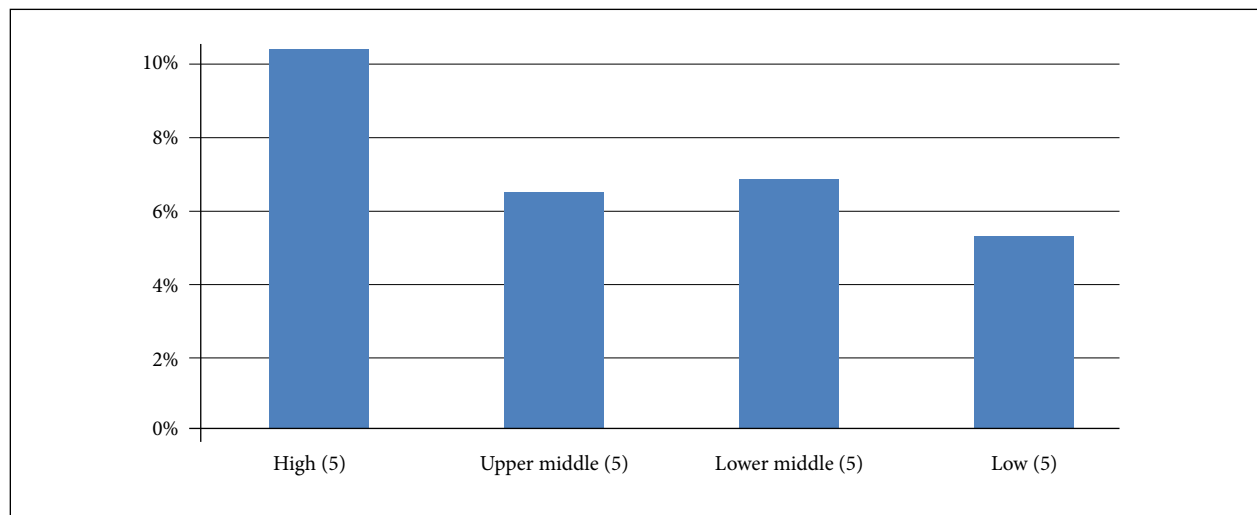
| Country | Income | Region | Fragile or conflict affected |
|--------------------|--------------|----------------------------|------------------------------|
| Australia | High | East Asia & Pacific | No |
| Bolivia | Lower middle | Latin America & Caribbean | No |
| Canada | High | North America | No |
| Chile | High | Latin America & Caribbean | No |
| Colombia | Upper middle | Latin America & Caribbean | No |
| Cook Islands | Unclassified | Western Pacific | No |
| Dominican Republic | Upper middle | Latin America & Caribbean | No |
| Ethiopia | Low | Sub-Saharan Africa | No |
| India | Lower middle | South Asia | No |
| Jordan | Upper middle | Middle East & North Africa | No |
| Kenya | Lower middle | Sub-Saharan Africa | No |
| Lao PDR | Lower middle | East Asia & Pacific | No |
| Myanmar | Lower middle | East Asia & Pacific | Yes |
| Nepal | Low | South Asia | No |
| South Africa | Upper middle | Sub-Saharan Africa | No |
| Sweden | High | Europe & Central Asia | No |
| Thailand | Upper middle | East Asia & Pacific | No |
| Uganda | Low | Sub-Saharan Africa | No |
| United Kingdom | High | Europe & Central Asia | No |

TABLE 2. Summary of results for variables 1–3

| | Variable 1: No. (%) of paragraphs containing search terms | Variable 1.2: Avg. rating among paragraphs mentioning search terms | Variable 1.2: No. (%) of paragraphs with high extent (3) of discussion of psychosocial disability | Variable 2: No. (%) of paragraphs using a human rights approach | Variable 3: No. (%) of times a term used clearly refers to psychosocial disability as distinct from intellectual disability |
|--------------------|--|---|--|--|--|
| Australia | 30 (14%) | 2.3 | 17 (8%) | 11 (37%) | 62 (93%) |
| Bolivia | 21 (6%) | 2.1 | 9 (2%) | 9 (43%) | 24 (71%) |
| Canada | 49 (13%) | 2.2 | 27 (7%) | 20 (41%) | 67 (71%) |
| Chile | 20 (8%) | 1.8 | 6 (2%) | 4 (57%) | 20 (65%) |
| Colombia | 13 (5%) | 2.2 | 7 (3%) | 5 (38%) | 12 (55%) |
| Cook Islands | 9 (4%) | 2.0 | 4 (27%) | 3 (33%) | 4 (44%) |
| Dominican Republic | 10 (6%) | 1.8 | 4 (3%) | 1 (10%) | 12 (52%) |
| Ethiopia | 5 (3%) | 1.6 | 1 (1%) | 1 (20%) | 1 (13%) |
| India | 40 (13%) | 1.9 | 15 (5%) | 17 (43%) | 44 (59%) |
| Jordan | 17 (6%) | 2.1 | 9 (3%) | 7 (41%) | 25 (51%) |
| Kenya | 15 (6%) | 1.8 | 5 (2%) | 7 (47%) | 2 (11%) |
| Laos | 4 (5%) | 1.0 | 0 (0%) | 1 (25%) | 3 (60%) |
| Myanmar | 5 (5%) | 1.8 | 2 (2%) | 4 (80%) | 4 (57%) |
| Nepal | 15 (5%) | 1.4 | 2 (1%) | 9 (60%) | 18 (64%) |
| South Africa | 52 (12%) | 2.4 | 34 (8%) | 28 (54%) | 51 (53%) |
| Sweden | 19 (6%) | 2.1 | 10 (3%) | 11 (58%) | 24 (62%) |
| Thailand | 7 (3%) | 1.6 | 2 (1%) | 4 (57%) | 6 (86%) |
| Uganda | 21 (8%) | 2.1 | 10 (4%) | 15 (71%) | 14 (42%) |
| United Kingdom | 37 (12%) | 2.5 | 24 (7%) | 14 (38%) | 46 (61%) |

Note: Full results are available on the Mental Health Innovation Network’s website.

FIGURE 2. Average percentage of paragraphs referring to psychosocial disability, by income level classifications



Note: Cook Islands unclassified

Of the 19 country reports assessed, the total report lengths ranged between 88 paragraphs (Laos) and 426 paragraphs (South Africa), with a median of 265 paragraphs (Uganda). The percentage of paragraphs discussing psychosocial disability ranged between 3.3% (Thailand) and 13.9% (Australia), with a median of 5.6% (Nepal) (Table 2). Following recoding for differences, Cohen’s Kappa for the inclusion/exclusion of paragraphs as discussing psychosocial disability was 0.91, “almost perfect” according to the guidelines proposed by J. Richard Landis and Charles Koch. While we cannot comment on the proportion of paragraphs deemed to be a good amount—as we would not expect to have specific impairment groups mentioned in some paragraphs—what is clear is that there is a wide variation among countries. In addition, the average proportion of paragraphs discussing psychosocial disabilities was twice as high in high-income countries compared to low-income ones (Figure 2).

The extent to which psychosocial disability is discussed in each paragraph

Variable 1.2 measured the extent to which psychosocial disability was discussed in each paragraph based on a set criteria and ordinal scale (1=low, 2=moderate, 3=high extent). The extent may be rated higher either because the search terms appeared in a large proportion of the paragraph’s sentences or because one or more sentences focused on issues relevant to psychosocial disability in particular (as

opposed to disability in general). These data inform several considerations:

- The total rating of all paragraphs mentioning the search terms, to give an overall summary of the amount of discussion of psychosocial disability in the report.
- The average rating among those paragraphs mentioning the search terms, to give a sense of the extent to which the discussion of psychosocial disability in the report focused specifically on psychosocial disability compared to including it in broader discussion.
- The average rating among all paragraphs, with paragraphs not mentioning the search terms rated as zero. This provides a composite between variables 1 and 1.2, providing an overall summary of the degree to which the report focused on psychosocial disability relative to other topics.

Key findings by country are given in Table 2. Of the 19 country reports assessed, the total scores for reports ranged between 4 (Laos) and 127 (South Africa), with a median of 36 (Chile). It should be noted that this is influenced in part by the overall length of the report (the South African report was long overall). The average score for paragraphs including search terms was 2.1, reflecting a range between 1.0 (Laos) and 2.5 (United Kingdom). The average score among all paragraphs was 0.16, reflecting a range

TABLE 3. Search terms for variable 1

| | |
|-----------------------------------|--|
| Mental | Include mentions of words that are direct derivatives of “mental” (e.g., “mentally”). Exclude mentions of words that signify separate concepts (e.g., “governmental” or “fundamental”). Also exclude mentions of words that signify intellectual impairment, namely “mental developmental disability” and “mental retardation.” |
| Psych* | Include mentions of words that are direct derivatives of “psych” (e.g., “psychosocial,” “psychiatric,” “psychological”). Exclude mentions of words that signify separate concepts. |
| Lunatic, lunacy, insane, insanity | These terms once held pseudo-scientific meanings but have been considered completely inappropriate and outside all formal classification systems for decades. Nonetheless, we considered it important to include these terms, as some reports may include them (for example, a number of countries still have “Lunacy Acts” in their legislation, even if outdated). |
| Unsound | This is intended to capture discussion of people with psychosocial disabilities as having “unsound” minds or “unsound” reasoning. Exclude mentions of the term “unsound” that clearly do not relate explicitly to people with psychosocial disabilities (e.g., exclude mentions of “unsound practices” if these do not refer explicitly to people with psychosocial disabilities). |
| Mind | Exclude mentions of the term “mind” that clearly do not relate explicitly to people with psychosocial disabilities. |
| Asylum | Exclude mentions of the term “asylum” that clearly do not relate explicitly to people with psychosocial disabilities (e.g., exclude mentions of asylum seekers, or asylums for children with physical disabilities). |

between 0.05 (Thailand, Laos, Ethiopia) and 0.32 (Australia). Notably, the report from Laos was the only report with no paragraphs with a high extent of discussion of psychosocial disability. Weighted Cohen's Kappa was 0.57, rated as "moderate" according to the guidelines proposed by Landis and Koch. The relatively low agreement is due to the multiple pathways by which scores are assigned and by a decision by the steering committee to clarify the criteria after coding had been done, at which point the first coder was not available to recode. (See "Strengths and weaknesses" below.)

Variable 2: Theoretical approaches informing the discussion of psychosocial disability

Variable 2 assessed the theoretical approaches informing each report's understanding of psychosocial disability, rating each paragraph that mentioned psychosocial disability according to one of four categories based on recognized models and ways of thinking about disability: (1) human rights approach; (2) medical/charity/welfare approach; (3) discriminatory denial of legal capacity; and (4) unable to determine. The percentage of paragraphs in a report that took each approach serves as an indicator of the report's theoretical approach, and not any underlying policies it describes. Thus, a paragraph that described a discriminatory policy, but criticized it, was rated "human rights approach." Cohen's Kappa was 0.61, rated as "substantial." Reduction in concordance was driven mostly by the tool stating that where a country report's frame was both "discriminatory denial of legal capacity" and "medical/charity/welfare approach," then the over-

arching approach subsumed the "discriminatory denial," causing some confusion. In general, this highlights that there was little disagreement as to whether the "human rights" approach was taken.

Findings for countries' use of the "human rights" approach are presented in Table 2. A summary of findings for variable 2 is presented in Table 4.

Variable 3: The extent to which psychosocial disability is distinguished from intellectual disability

The degree to which each country report made a clear distinction between intellectual and psychosocial disability might be judged to be a sign of depth of understanding among the report writers. Confusion between these two types of disabilities is fairly common, though it should be noted that the CRPD does not itself provide a definition. We assessed each individual mention of a search term and coded whether the term clearly referred to psychosocial disability or possibly included intellectual disability. A list of classifications is provided in the guidance, indicating whether a given term indicates one or the other; however, coders could classify terms based on their judgment as to whether the rest of the paragraph gave greater clarity.

Findings are shown in Table 2. Across all reports, 61% of all relevant terms used clearly distinguished psychosocial disability from intellectual disability. Australia had the highest percentage (93%), while Kenya had the lowest percentage (11%). Cohen's Kappa (following a reconciliation after a coding clarification) was 0.83, "almost perfect" under Landis and Koch's guidelines.

TABLE 4. Summary of results for variable 2

| Approach | Overall % | Highest % | Lowest % |
|---|-----------|-------------------------|---|
| Human rights | 46% | 80%, Myanmar* | 10%, Dominican Republic |
| Medical/charity/welfare | 9% | 50%, Laos | 0%, Bolivia, Colombia, Myanmar, Nepal, Uganda |
| Discriminatory denial of legal capacity | 20% | 38%, Colombia | 0%, Cook Islands, Laos, Myanmar, Thailand |
| Unable to determine | 25% | 60%, Dominican Republic | 16%, United Kingdom |

* Relatively high scores were achieved where few paragraphs discussed psychosocial disabilities at all, but where those that did so used a particular approach (as was the case for Myanmar).

Variable 4: The extent to which CRPD articles considered highly relevant to people with psychosocial disabilities are discussed

Certain articles in the CRPD (12, 14, 17, 19, and 29) are considered to be highly relevant to people with psychosocial disabilities (as determined by the steering committee and the priorities of people with psychosocial disabilities identified in the literature). Where specific content for one of these articles was identified in the country report, we scored the report “yes” (1.0) for that article. If the phrasing in regard to the article was not consistent with the priorities of people with psychosocial disabilities, then we gave a score of “no” (0). Reports were rated 1.0 only if they described the issue specifically for people with psychosocial disabilities, as

opposed to people with disabilities in general.

“Yes” ratings were rare for most topics. Following the initial round of coding, we modified this variable to allow for a score of 0.5 for articles with multiple criteria in which a report discussed some of those criteria but not all of them. We made this change to make the variable more sensitive, as initial ratings were extremely low. A summary of scores is presented in Table 5.

Out of a possible 10 points across all topics, South Africa had the highest total (5.5), while the Dominican Republic and Laos had the lowest (0.5). The median total score was 1.5—in other words, very low. Notably, no report discussed measures taken to protect all persons with disabilities from forced sterilization and girls and women from forced or coerced abortions or contraception. The

TABLE 5. Scores for each topic under variable 4

| Topic | Mean score | Countries scoring 1.0 (specific content identified) |
|---|------------|---|
| Article 12: Equal recognition before the law | | |
| Discusses whether legislation does or does not exist which restricts the full legal capacity on the basis of psychosocial disability, as well as actions being taken toward conformity with article 12 of the convention | 0.53 | Bolivia, Colombia, Kenya, Nepal, South Africa, Uganda |
| Support available to persons with disabilities to exercise their legal capacity and manage their financial affairs | 0.16 | Canada, Colombia, South Africa |
| The existence of safeguards against abuse of supported decision-making models | 0.05 | United Kingdom |
| Article 14: Liberty and security of person* | | |
| Measures taken by the state party to ensure that all persons with all forms of disabilities enjoy the right to liberty and security of person and that no person is deprived of their liberty on the basis of their disability | 0.05 | None |
| Actions being taken to abolish any legislation that permits the institutionalization or the deprivation of liberty of persons with any form of disability | 0.16 | Ethiopia, South Africa, Uganda |
| Legislative and other measures put in place to ensure that persons with disabilities who have been deprived of their liberty are provided with the required reasonable accommodation and benefit from the same procedural guarantees as all other persons to fully enjoy their human rights | 0.16 | None |
| Article 17: Protecting the integrity of the person | | |
| Measures taken to protect persons with disabilities from medical (or other) treatment given without the free and informed consent of the person | 0.11 | Nepal, South Africa |
| Measures taken to protect all persons with disabilities from forced sterilization, and girls and women from forced abortions | 0.0 | None |
| Article 19: Living independently and being included in the community | | |
| Measures taken to ensure the equal right of all persons with disabilities to live in the community (including access to support services) and to choose where they live | 0.18 | Canada |
| Article 29: Participation in political and public life | | |
| Legislation and measures to guarantee political rights for persons with disabilities (in particular persons with mental or intellectual disabilities), and, if it is the case, existing limitations and actions taken to overcome them | 0.53 | Colombia, South Africa, Sweden, Thailand, Uganda |

Note: Full results are available on the Mental Health Innovation Network's website.

* Under article 14, references to the deprivation of liberty exclude cases where people with psychosocial disabilities are subject to the same laws and due process as people without disability.

initial Cohen's Kappa for the entire data set (that is, analyzing all of the content pieces together) was 0.63, rated as "substantial" according to Landis and Koch's guidelines. After we recognized that all criteria for a "yes" were hard to meet, we introduced the 0.5 score and then recoded all reports using the new system.

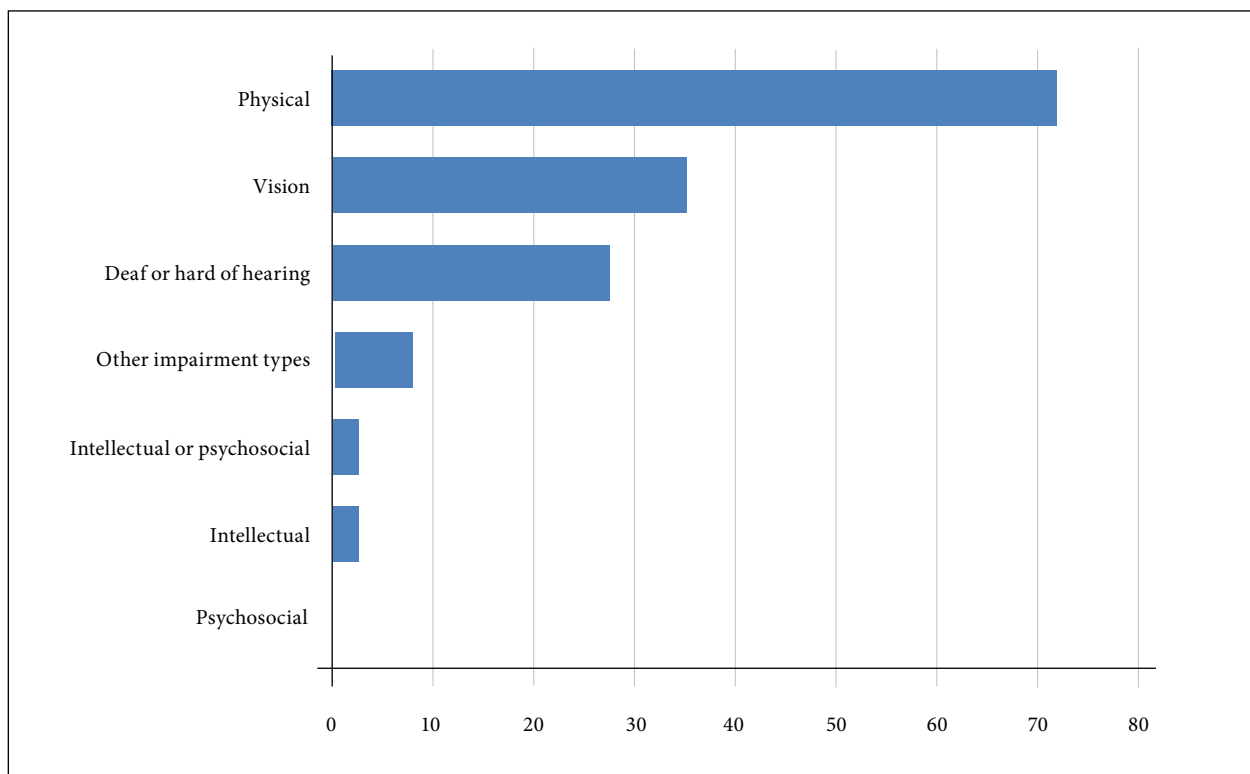
Variable 5: The extent to which the discussion of accessibility initiatives addresses psychosocial disabilities compared to other disability types

While issues related to accessibility and reasonable accommodations are generally well understood for people with physical and sensory disabilities, the means of addressing exclusion in psychosocial disabilities are often not well understood or even considered. We therefore examined discussion of article 9 in each country report to explore reported initiatives to address accessibility and reasonable accommodation in relation to psychosocial disabili-

ty compared to other disabilities. We used criteria to review this section of each report in full and identify any accessibility initiatives, coding each as "physical," "vision," "deaf or hard of hearing," "intellectual," "intellectual/psychosocial (unclear)," "psychosocial," "other impairments," or "unable to determine."

Our findings are shown in Figure 3. There was a dramatic lack of initiatives for psychosocial disabilities compared to every other group identified, except for intellectual disability. Across all reports, physical, vision, and deaf or hard of hearing had 71, 35, and 28 initiatives identified, respectively, compared to 0 for psychosocial disability and 2 for intellectual/psychosocial. The overall findings of the two coders were nearly identical. Due to the nature of coding this section, Cohen's Kappa could not be calculated on a pairwise comparison of specific initiatives and was instead calculated at the country level at 0.63, rated as "substantial" according to Landis and Koch's guidelines. This

FIGURE 3. Total initiatives identified to address reasonable accommodation and accessibility, by impairment type



Note: Results by country are available on the Mental Health Innovation Network's website

excludes “unable to determine,” which was much less consistent, but not considered important to the findings.

Discussion

There is substantial variability in the extent to which country reports discussed psychosocial disability (demonstrated by variable 1). Using the composite score, Australia’s score of 0.32 indicates more than six times the proportion of discussion dedicated to psychosocial disability compared to Thailand, Laos, or Ethiopia. In gross terms, South Africa devoted more than 10 times as many paragraphs as Myanmar, Ethiopia, or Laos.

While some of this variation may be attributed to the length of each report in general, it could also be an indication of the wide variety of prioritization of psychosocial disability in countries’ national disability agenda, as well as governments’ competence and confidence in reporting on this issue.

An additional consideration is the tendency for more and better focus on psychosocial disability when relevant people were included in the writing process of the report, as stipulated in article 35(4) of the CRPD. People with psychosocial disabilities may not have been part of the writing group in all countries. Even where their input was invited, governments’ decision whether to include their submissions in the final draft was ultimately outside the control of people with psychosocial disabilities. This was also reflected in the experience of our steering committee, whose members felt that where organizations of people with psychosocial disabilities were included from the start, their issues were covered better and more prominently.

The wide variation in the extent to which countries reported specifically on psychosocial disability—as opposed to integrating it into wider disability issues—should be taken into context. For example, the United Kingdom’s high score on specific mention of psychosocial disability is in general a good thing (as a neglected area needs to be highlighted), but the state fell short in consider-

ing psychosocial disability across all life domains beyond health—for example, in relation to housing, education, community life, and so forth—and alongside other types of disability. Where reports discuss states’ performance on disability in general, it is important for psychosocial disability to also be included, and not only in special sections (for example, by focusing only on specific rights like consent or access to mental health services). We believe that this would be reflected by a higher proportion of paragraphs including our search terms (variable 1) than the median of 5.6% found in this sample.

Variable 2 demonstrates that nearly half of the paragraphs discussing psychosocial disability appeared to use a theoretical approach grounded in human rights, although charity, medical, and discriminatory approaches were used in almost all country reports. This may be a reflection of levels of knowledge and attitudes about different models and approaches to disability in general rather than psychosocial disability in particular, which we would expect to be high among those writing the reports. That being said, in many countries (such as Australia, India, and South Africa), psychosocial disability and intellectual disabilities are treated distinctly from other types of disability, particularly in relation to autonomy and in relation to will and preference in decision-making, including for medical treatment. As noted in Australia’s report:

Consent to medical treatment is regulated by policies and/or legislation in each jurisdiction. Australia considers that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental illness, where such treatment is necessary as a last resort and subject to safeguards.¹⁸

With the introduction of the CRPD, the International Classification of Functioning, Disability and Health, and other disability models and frameworks, global actors are moving away from traditional medical and charity models. However, there needs to be a recognition that this process is more difficult for countries with limited resources

or different cultural attitudes and beliefs. Such countries may need additional support, especially when cultivating cultural responsiveness toward and acceptability of a global movement.

Based on variable 3, it is clear that many country reports did not make a distinction between psychosocial and intellectual disability, although this varied substantially between countries. In some cases, this approach may be appropriate (such as mentions of “physical and mental disabilities”), and in other cases, it is difficult to determine whether it reflects a poor use of language or an underlying failure to distinguish the two in practice, especially for countries where English is not a national language. Examples of ambiguous and derogatory language include “mental disability,” “mentally challenged,” “unsound mind,” and “mentally deranged.” For such high-level reports to not be clear about the distinction implies a poor level of understanding among the authors. We would suggest that knowledge of the distinction between psychosocial and intellectual disabilities—and of the nuances of neurological (for example, migraine), behavioral (for example, autism or attention deficit disorder), and cognitive (for example, dementia) conditions—is essential for authors of CRPD country reports.

It is clear from variable 4 that country reports did not describe policies ensuring the prioritization of the rights of persons with psychosocial disabilities. By extension, this could mean that organizations of people with psychosocial disabilities are facing barriers to advocacy efforts in national CRPD accountability mechanisms. Further research is required to elucidate the experiences of people with psychosocial disabilities and their organizations when engaging with CRPD report-writing processes. National-specific assessment would need to be done to verify this in each case. Variable 5 strongly indicates that state parties are not implementing, or at least reporting, reasonable accommodations and accessibility initiatives for persons with psychosocial disabilities (or intellectual disabilities). This is one variable where a direct comparison with other disabilities was possible, and it is clear that there is a dramatic gap in

progress for psychosocial disability compared with other areas of disability.

Our findings indicate that there is, in general, a poor level of reporting about psychosocial disabilities in country reports to the CRPD Committee. While there is need for further research to understand what the reasons for this might be, it is clear that states’ reporting capacity needs to be addressed. This requires that national reporting processes better engage with people with psychosocial disabilities and their representative groups, empowering their input and advocacy. The results of our research may be a useful tool for the CRPD Committee, relevant UN agencies (particularly members of the UN Partnership on the Rights of Persons with Disabilities), and civil society groups seeking to advocate more effectively for a greater focus on rights-based approaches to psychosocial (and intellectual) disabilities in policy, and in CRPD reporting in particular.

Strengths and weaknesses

Content analysis proved a valuable way to objectively assess the content of the country reports for volume and quality of content related to psychosocial disability and to reveal disparities in the representation of different disabilities. The variables that were included in our tool were derived from a consensus among a group identified as experts and experienced in the field, with backgrounds in policy, the UN system, academia, and service user movements. We feel that these allow the reports’ quality to be judged by how well they address issues that are relevant to psychosocial disabilities. What is harder to examine is the underlying reasons behind our findings. This question of the “why” would be best addressed through additional qualitative research. It would also be useful to analyze country reports in the context of shadow reports (where they exist). Although shadow reports may have no impact on a country’s report, the representation of psychosocial disability in these shadow reports may indicate the level of participation of people with psychosocial disabilities in national disability movements, thus helping target capacity-building

interventions. In addition, a review of subsequent country reports from the same countries could be used to gauge whether there is a trend of improvement in this area.

Our sampling frame was purposive, so we were able to compare results across, for example, income levels of countries, but we cannot claim that the countries chosen were representative of these income levels or that the political and policy environments are consistent across these countries.

The use of our tool raised some complex questions of interpretation, even though agreement was achieved between the independent reviewers. For example, Myanmar used the human rights approach in almost all cases where it mentioned psychosocial disabilities, meaning that it scored highly, despite mentioning such disabilities infrequently and without detail. The United Kingdom tended to write specifically about psychosocial disabilities in particular areas but did not address psychosocial disability across all life domains. While we feel we achieved a fair level of agreement about interpretation, there would be benefit to updating guidance for the tool for future use. There was great value in having a steering committee to guide the nuanced discussions that often arose, anchoring the final decisions in core approaches that we wished to reflect in the establishment of the criteria for the analysis. Inevitably, any element of change raises questions of replicability and consistency of method, requiring reflection in interpretation. The tool also relies on identifying relevant paragraphs through the use of a set of keywords associated with psychosocial disability, which may not be exhaustive. Some generic paragraphs not mentioning our search terms may theoretically be referring to psychosocial disabilities.

Variable 5 was our only variable that analyzed data for other disability types, and for this variable the difference was stark. However, while representation of psychosocial disability may appear low in other variables, we are unable to measure this against other types of disability. A version of the tool adapted for one or more other types of disability would allow this comparison in future analysis. In addition, this may highlight how strong the re-

ports were for other disabilities and whether those that were weaker for psychosocial disabilities were also weaker overall.

Conclusion

There is considerable variability in the quality of states' reporting on psychosocial disabilities when following CRPD accountability processes, despite broad recognition of the importance of the full and meaningful participation of people with psychosocial disabilities.¹⁹ We found a lower quality of reporting on psychosocial disabilities in low-income countries in particular, which may reflect the effects that limited resources have on reinforcing prejudicial social norms or a lack of exposure to contemporary debates around psychosocial disability in relation to CRPD compliance. While this research did not include information on the extent to which people with psychosocial disabilities participated in the reporting process, we recommend that the first step in addressing disparities in reporting be to improve engagement with representative organizations of people with psychosocial disabilities. International and national agencies working with government bodies can engage with government focal points to promote a more receptive environment for civil society participation.

Hand in hand with this recommendation is the recognition that meaningful engagement will require the empowerment of people with psychosocial disabilities by providing sufficient resourcing for existing and emerging organizations and building the capacity of national umbrella organizations. In all countries, organizations of people with disabilities would benefit from increased knowledge of UN reporting processes and the extent to which they should be included in reporting mechanisms. Though the evidence on what works to promote the leadership of people with psychosocial disabilities in low- and middle-income countries is still relatively limited, there are examples of success.²⁰ These examples usually point to organizations and movements with strong governance structures and clear values.²¹ Integral to the realization of the rights enshrined in the CRPD for people with psy-

chosocial disabilities is building their capacity and strengthening their voices at the national level, and improving their representation at the global level, so as to exploit fully CRPD processes for meaningful participation of people with disabilities.²²

It is perhaps most helpful to use equivalence with other forms of disability as the best benchmark for expectations of levels of participation and quality of reporting. By this measure, there are particular gaps in understanding and reporting around reasonable accommodation and accessibility for persons with psychosocial disabilities. Specific efforts need to be made to improve understandings and attitudes around mental health and psychosocial disabilities. Epilepsy South Africa has developed good guidelines that could be used as an example for making similar information available for psychosocial disabilities.²³ There also exist accessible online resources that could be adapted for use in other countries.²⁴ In all areas of disability practice and research, attention should be paid to ensuring that this historically neglected area is now able to make full use of this essential global mechanism for accountability for the rights of people with disabilities. More broadly, strengthening procedures for the meaningful participation of people with disabilities is likely to lead to improved accountability for their rights at the national and international level.

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PERSPECTIVE

Safe Abortion in Women's Hands: Autonomy and a Human Rights Approach to COVID-19 and Beyond

ANDRÉS LÓPEZ CABELLO AND ANA CECILIA GAITÁN

Introduction

While SARS-CoV-2 containment measures transformed all spheres of social interaction, the COVID-19 pandemic has subjected national health systems to unforeseen strain, leading to their virtual collapse in many countries. The international health crisis has exacerbated social inequalities, with a disproportionate impact on traditionally neglected people; unfortunately, its socioeconomic impacts are likely only to deepen in the future.¹

Sexual and reproductive health and rights are no exception. When the pandemic first began, the increasing pressure on health systems, the closing of health counseling centers, orders to avoid crowding in health facilities, and restrictions on movement due to lockdown or quarantine affected women's ability to fully enjoy their sexual and reproductive rights. In particular, these circumstances have jeopardized women's ability to access safe abortion in a timely manner.²

This is why dozens of high-level country representatives issued a joint statement in May 2020 expressing that sexual and reproductive health needs "must be prioritized to ensure continuity" and calling on governments "to ensure full and unimpeded access to all sexual and reproductive health services for all women and girls."³ In line with this statement, the World Health Organization (WHO) has noted that sexual and reproductive care is an essential health service that needs to be made available to populations. It urges states to reduce barriers that could delay care, consider the use of noninvasive medical methods for abortion, and "minimize facility visits and provider-client contacts through the use of telemedicine and self-management approaches."⁴ Nonetheless, WHO's guidance is not a global commitment or a settled issue, since in some places local governments have labeled abortion a nonessential service, curtailing women's access to services that are particularly time sensitive.⁵

The issue at stake is not only that restricting abortion access fails to uphold states' human rights obligations during a health crisis but also that an adequate response has the potential to empower women and avoid the over-regulation of abortion.

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States should seize this opportunity to deepen the trend of increased access to abortifacient drugs in pharmacies and through mail; increased self-managed medical abortions at home; and expanded use of telemedicine counseling for this purpose. This is not only consistent with scientific evidence on the safety, effectiveness, and acceptability of medical abortion but also a requirement of international human rights law, which demands that health goods and services be acceptable and, consequently, not subject to overmedicalization.

Innovation and efficiency, while upholding women's rights, is the way forward during the current pandemic. This is also a chance to break taboos around medical abortion and promote greater spaces for women's bodily autonomy during the current health crisis and beyond.

Abortifacient drugs at home, endorsed by the World Health Organization and international human rights law

According to WHO, medical abortion plays a crucial role in providing access to safe, effective, and acceptable abortion care and offers several advantages as a non-invasive and acceptable option to pregnant individuals, particularly in low-resource settings.⁶ Because of their proven safety and efficacy, mifepristone and misoprostol were included for the first time in the 2005 WHO Model List of Essential Medicines. Given limited available clinical evidence at the time, the list included a specific requirement for "close medical supervision."⁷

Since then, numerous studies have documented the safety and effectiveness of self-managed medical abortion, without the need for specialized medical care or direct supervision, which has been reflected in updates of WHO guidelines.⁸ For example, 2015 guidelines issued by WHO describe the importance of health professionals other than physicians in the provision of safe abortion and specify that women can play a role in self-managing medical abortion outside health care facilities, stating that it "can be empowering for women and help to triage care, leading to a more optimal use of health resources."⁹ This has been reaffirmed in subsequent

guidelines and protocols issued by WHO.¹⁰ Thus, retrieving the evidence gathered over the years, the 2019 List of Essential Medicines removed the note requiring "close medical supervision." According to the experts committee, this decision was "based on the evidence presented that close medical supervision is not required for its safe and effective use."¹¹

These issues—the fact that medical abortion has been confirmed to be safe, effective, and acceptable; that it can be delivered by health professionals other than physicians; and that pregnant women can actively participate through self-evaluation and self-management—are fundamentally connected to states' duties under international human rights law, which include taking explicit measures to promote and fulfill women's right to health.

In outlining states' obligations, international human rights bodies have paid special attention to WHO definitions on the minimum features of a health system. For instance, the United Nations (UN) Committee on Economic, Social and Cultural Rights has established that states have an immediate obligation to ensure the provision of medicines in accordance with the WHO List of Essential Medicines.¹² Meanwhile, the same committee's General Comment 22 on the right to sexual and reproductive health reasserts states' obligation "to provide medicines, equipment and technologies essential to sexual and reproductive health, including based on the WHO Model List of Essential Medicines." It also warns that ideology-based policies and practices should not hinder access to sexual and reproductive health services, including access to abortion medicines.¹³ Further, in 2020, the same committee highlighted that states must ensure access to up-to-date scientific technologies necessary for women in relation to their sexual and reproductive health.¹⁴ This demands a reliance on science instead of prejudices and requires that states refrain from hindering access to safe, effective, and acceptable abortion methods as established by up-to-date scientific consensus.

The Committee on Economic, Social and Cultural Rights has also noted that health goods and services must be available (with a sufficient number throughout the country, with trained per-

sonnel, and in accordance with WHO definitions), accessible (in geographic and economic terms and without discrimination), of quality (scientifically and medically appropriate), and acceptable (culturally appropriate, gender and life-cycle sensitive, respectful of personal autonomy, and confidential).¹⁵

Regarding the acceptability element, the committee has explained that all health facilities, goods, and services must be “respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements.” It has also warned that there is a breach of state obligations when a state fails to adopt “gender-sensitive approach to health.”¹⁶

As argued by Avedis Donabedian, “quality of care is judged by its conformity to a set of expectations or standards that derive from three sources: (a) the science of health care that determines efficacy, (b) individual values and expectations that determine acceptability, and (c) social values and expectations that determine legitimacy.”¹⁷ With regard to acceptability, the key issue is conformity to the wishes, desires, and expectations of patients and their guardians.¹⁸ This requires building evidence-based health systems that are respectful of patients’ autonomy and preferences regarding health services, including abortion. Health regulations that are not based on therapeutic considerations—that is, policies based on overmedicalization—are incompatible with this requirement. Scientific progress is for human well-being and not for human control. It must act as a facilitator of people’s bodily autonomy and must be attentive to their preferences so as to guarantee their personal dignity.

Public health policies to promote women’s rights and autonomy

Public health policies—such as those concerning the availability of abortifacient drugs in pharmacies, the expansion of telemedicine services, and the availability of outpatient abortion procedures—have a significant impact on women’s autonomy, which, in many countries, is especially restricted when it comes to their sexual and reproductive

health and rights.

The liberal conception of autonomy has multiple limitations that are evident when considering certain groups, such as women. Women’s sexual and reproductive health and rights, particularly the right to abortion, starkly reveal the cracks around the abstract autonomy model, which is focused on the will of the individual. Their ability to act “autonomously” in this realm is constrained not only by their individual will but also by the structural sociocultural and legal conditions in which they live.¹⁹ The stigma around—and, in some scenarios, illegality of—abortion disrupts the possibility of women making autonomous decisions, while conditioning their relationship with the health system.²⁰ The legal, social, and cultural restrictions on abortion that are prevalent in many countries constitute an indicator of the inequality to which women are exposed when it comes to making autonomous decisions about their bodies.²¹ This restricted autonomy is also expressed in the overmedicalization of services that only women need, such as services related to childbirth or abortion (when permitted by the law).

The availability of abortifacient drugs in pharmacies at an affordable price and the expansion of telemedicine and outpatient abortion services operate as facilitators of women’s autonomy. Indeed, restricting access to medical abortion to a hospital setting when it can be safely performed elsewhere, in accordance with the user’s preferences, indicates a disregard for patients’ autonomy. The failure to consider the various ways in which people relate to health services and self-care—together with the decision to exclude health care options that are effective, less invasive, and more sensitive to the wishes of individuals—embodies a discriminatory policy. To comply with the acceptability standard of health services, which is to respect people’s autonomy and dignity, health policies must consider the wide array of people’s preferences, without arbitrarily excluding some.

The overmedicalization of sexual and reproductive health services for women—such as through regulations that require services to be provided only by qualified physicians—is incompatible

with states' international human rights obligation to ensure that health services are acceptable. The UN Working Group on the issue of discrimination against women has expressed special concern in this regard, warning against laws and policies that "provide for overmedicalization of certain services that women need to preserve their health without a justified medical reason. These include requirements that only doctors can perform certain services, such as pharmaceutical termination of pregnancy or obstetric care."²² Overmedicalization not only disregards individuals' dignity (since people should not be subjected to invasive medical procedures when others more suitable and according to their preferences are available) but also contradicts the requirement that health goods and services be acceptable. This principle is tied to people's autonomy and the expectations and preferences of the individual seeking medical care. It demands that health systems adapt to people's needs and preferences when possible, as in the case of medical abortion.

As mentioned above, numerous studies have shown that medical abortion outside of health facilities is a safe, effective, and acceptable method for women who choose to abort. A 2011 review found that "there is no evidence that home-based medical abortion is less effective, safe or acceptable than clinic-based medical abortion."²³ The review examined three acceptability criteria—satisfaction with the method, likelihood of choosing it again, and likelihood of recommending it to a friend—and noted that home-based medical abortion may actually improve its acceptability. Likewise, it has been found that the possibility to take the medication at home "could enhance patient autonomy and privacy, and could provide women an opportunity to start the process with a partner or friend."²⁴ A qualitative study on misoprostol-only self-use conducted in Argentina—when abortion was legally restricted and mifepristone not available—revealed that women greatly appreciated the possibility of keeping their abortions private and being able to choose the day and place to perform it.²⁵ These findings are consistent with previous studies on women's experiences with medical abortion in other legally restricted contexts.²⁶

There may be many reasons why women prefer an abortion at home, one of which is the discriminatory practices within health care facilities, even in countries without restrictive laws. A study conducted in Scotland found that most women seeking abortion preferred the privacy of their own surroundings and that some women were fearful of being judged by health providers.²⁷ A 2017 study in Great Britain found that one-third of reasons for seeking abortion outside health care settings consisted of privacy concerns and either perceived or experienced stigma around abortion.²⁸ A recent qualitative study in rural Australia also showed that although women perceived abortion as an acceptable choice, they experienced a normative cultural positioning of abortion as shameful, stigmatized, and negative, which dissuaded them from discussing it with their physicians.²⁹

These findings are aligned with the alarms set by the UN Working Group on the issue of discrimination against women, which has expressed concern over the often humiliating treatment offered in health facilities.³⁰ Moreover, the UN Special Rapporteur on violence against women has highlighted that mistreatment in reproductive health services is "part of a continuum of the violations that occur in the wider context of structural inequality, discrimination and patriarchy."³¹

While discriminatory practices must certainly be eradicated, medical abortion at home may not be the panacea for public health policies everywhere. Some women may prefer a swift manual vacuum aspiration in a health facility, while others may prefer a medical abortion at home. Neither option is per se more valid than the other. These approaches should be available when appropriate, so that women may decide the best way to meet their needs without unwarranted guardianship.

Undoubtedly, women's experiences will be affected by more than the mere availability of a given abortifacient method. National legal contexts, health systems equity, health care affordability, and women's life trajectories, socioeconomic status, and identity are other determining factors in the effective enjoyment of their rights.

Women's access to abortifacient drugs beyond COVID-19

In response to the difficulties posed by the COVID-19 pandemic, France and the UK have modified their regulations to temporarily enable women to have medical abortions at home.³² According to the UK Royal College of Obstetricians and Gynaecologists, in the six weeks following this decision, approximately 16,500 women accessed safe medical abortion at home in England and Wales, at a time when many in-person services were suspended.³³ These policies are not only an adequate response in time of crisis but also the way forward after the pandemic, for they align with international human rights law and scientific consensus.

Before the current health crisis, there was a growing trend to liberalize access to abortifacient drugs. For example, Canada and Australia have recently allowed the sale of both mifepristone and misoprostol in pharmacies, while the UK has allowed women to complete the abortion process with misoprostol at home.³⁴ Also, in Argentina, where abortion was, until recently, legal only under some circumstances, at least since 2015 health protocols provide for outpatient medical abortions for free in public health facilities, while misoprostol remains available by prescription in pharmacies.³⁵

The pandemic may be an opportunity to advance and deepen the rights and autonomy of women. In April 2020, the Inter-American Commission on Human Rights entrusted states “to guarantee the availability and continuity of sexual and reproductive health services during the pandemic crisis,” while the Committee on the Elimination of Discrimination against Women instructed them to “continue to provide gender-sensitive sexual and reproductive health services.”³⁶ The UN Working Group on discrimination against women made similar recommendations and is drafting a special report on women's and girls' sexual and reproductive health and rights in situations of crisis.³⁷ Assessing states' performance in following these recommendations will surely shed light on concrete duties regarding women's human rights and the different health public policy options that can be implemented to ensure their full citizenship.

There may well also be a chance to promote health services that are sensitive to gender needs and are based on human rights rather than discriminatory preconceptions.

An adequate response to COVID-19 must prioritize women's sexual and reproductive health and rights and remove regulatory barriers to their fulfillment, paving the way for women's full autonomy. Once the present crisis is overcome, states should guarantee that the “new normality” is one in which women are able to regain control over their bodies, free from prejudice and taboo.

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Toward Human Rights and Evidence-Based Legal Frameworks for (Self-Managed) Abortion: A Review of the Last Decade of Legal Reform

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Abstract

Since the late 1980s, people have safely self-managed their abortions with medication, changing the landscape of abortion. This practice continues to evolve and expand and has been identified as a cause of decline in severe abortion-related morbidity and mortality. However, developments in medical abortion and self-management have yet to be reflected in the way abortion is regulated. Building on the need for evidence and human rights-based laws, this article explores developments in abortion laws from around the world between 2010 and 2020 to explore the extent to which they have contributed to an enabling environment for self-managed abortion. We focus on recent laws—those adopted in the past 10 years—for which we had access to information for analysis. We observe that laws in force still retain clinical settings and the involvement of medical professionals as the desirable circumstances for an abortion to take place and that even those that have liberalized access still retain some degree of criminalization for the pregnant person who carries out a self-managed abortion or for those who support the process. We conclude that there is enough evidence and support from international human rights standards to ground legal developments that enable self-managed abortion.

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Introduction

Since the late 1980s, people have self-managed their abortions with medication to safely end their pregnancies, ever since pregnant Brazilians discovered that a drug originally developed for gastric ulcers (misoprostol) could be used as an abortifacient.¹ Medical abortion continues to be widely practiced and has been identified as a cause of decline in severe abortion-related morbidity and mortality.²

For the purposes of this paper, we define self-managed medical abortion (SMMA) as the process that involves the provision of drugs from pharmacies, drug sellers, or online outlets, without a prescription from a clinician, followed by a woman's self-management of the abortion process, including care-seeking for any complications.³ While self-managed abortion is and has been a prevalent practice for centuries, increased access to abortion medicines and the growing network of organizations that support people who self-manage entail a significant change to the abortion landscape.⁴ The advent of telemedicine—the remote assessment and treatment of patients by health providers—has likewise increased the prevalence of abortion with medicines.⁵ But because SMMA does not involve formal supervision by a health care worker, its practice raises legal issues unique from those concerning telemedicine abortion.

Abortion outside the clinical context no longer refers to the emblematic unsafe methods of earlier times.⁶ Self-managed abortion requires that we reevaluate long-established relationships between “safety,” “legality,” and “self-management.” That is, self-managed abortion has disrupted the idea that legal abortion is safe and illegal abortion unsafe. Self-managed abortion also debates who can be a “provider” and challenges the meanings of safety that have been—for the most part—discussed within a biomedical frame.

However, developments in SMMA have yet to be reflected in the way abortion is regulated. In general, abortion laws (including those that have been recently reformed, as we show here) criminalize people who have abortions without the involvement of a health care professional or who do so outside the formal health care system.⁷ In

most countries, criminal law permits abortion only with the involvement of a health care professional. Furthermore, criminal law and other unnecessary regulatory restrictions create vulnerability and risk by censoring information or curbing access to essential medicines.⁸ This means that self-managed abortion, while safe and effective from a public health perspective, still poses risks in a legal sense. While the criminalization of people who self-manage their abortions using any method is unsupported by public health and human rights, SMMA has further exposed the inadequacies of these laws.

Regulation of abortion during COVID-19

In the context of service disruptions caused by the COVID-19 pandemic, which are estimated to account for seven million unplanned pregnancies, access to abortion is increasingly relevant.⁹ People have greater difficulty getting contraceptives because of interruptions to supply chains, restrictions on travel that prevent people from getting to health facilities, and the diversion of health care workers' time and attention to COVID patients.¹⁰ Indeed, millions of people under quarantine or shelter-in-place orders have reduced access to abortion, and a number of governments have restricted health care to “essential services” while excluding abortion.¹¹ In the Netherlands, for example, court cases are showcasing the need for simplified abortion access, reducing or eliminating the need for physical interactions with health care personnel.¹²

Some countries have already adopted measures to ensure access: the United Kingdom's Department of Health and Social Care has confirmed that it will allow people to manage medical abortions at home. Similarly, Marie Stopes in South Africa is supporting people in self-managing abortions at home.¹³ In the United States, the Food and Drug Administration has signaled that it will not enforce in-person dispensing requirements for abortion drugs during the pandemic.¹⁴ These measures show that burdensome requirements are unnecessary, and they confirm what SMMA feminist networks have known for decades: a different, less medicalized model is not only desirable but possible.¹⁵

These measures reducing barriers to access to medical abortion have been crafted as options within a formal health care system (rather than self-managed abortion) and are temporary and considered exceptional.¹⁶ It is important not to lose the momentum and to capitalize on this window of political opportunity to advance a simpler, less medicalized, and evidence-based model of abortion care.

Toward laws based on human rights and evidence

The 2019 report of the Lancet – O’Neill Institute Commission on Global Health and the Law shows how evidence-based laws, when effectively implemented and fairly enforced, can create the conditions for good health and, conversely, how laws that are not informed by evidence and human rights could instead undermine health and justice, entrenching inequality and discrimination.¹⁷ Unequivocally, the World Health Organization (WHO) affirms that “[g]iven the clear link between access to safe abortion and women’s health, it is recommended that laws and policies should respect and protect women’s health and their human rights.”¹⁸

Using the framework for evidence- and rights-based law proposed by the Lancet – O’Neill Institute Commission, this article analyzes developments in national abortion laws from around the world between 2010 and 2020 to assess the extent to which they have embraced the potential of self-managed abortion. We briefly outline the latest evidence and human rights that should guide any legal reform. We focus on recent laws—those adopted in the past 10 years—for which we had access to information for analysis.

While the Lancet – O’Neill Institute Commission recommends that laws be fairly enforced, implementation and enforcement are outside the scope of this paper. The degree of legal risk faced by people seeking SMMA and those who help them rests on enforcement, and legal risk can be disproportionately experienced by groups who face discrimination in other areas. Much research is needed to document and understand the expe-

riences of individuals who face legal consequences related to SMMA. However, the focus of this paper is the problematic nature of laws as drafted.

To identify the latest developments in abortion laws, we consulted the Center for Reproductive Rights’ *World’s Abortion Laws Map* and WHO’s Global Abortion Policies Database.¹⁹ We also consulted the newsletter of the International Campaign for Women’s Right to Safe Abortion. Self-managed abortion entails a constellation of actors and activities that are regulated not only by abortion laws but also by other areas of law and policy, such as drug regulations, laws on the provision on information, and others.²⁰ Therefore, our analysis is limited by the fact that we examined only abortion laws.

Growing evidence supporting self-managed medical abortion

Medical abortion is effective, safe, and acceptable and does not require specific training or specialization.²¹ There is extensive evidence showing that mifepristone and misoprostol or misoprostol alone can be self-administered to induce a safe, discrete and non-invasive abortion.²² These drugs have a consistently proven success rate of over 85% (95% if used together) through the 12th week of pregnancy, and WHO supports the use of these drugs for first-trimester abortions.²³ Furthermore, recent research indicates that SMMA can be an effective and safe option for abortion even beyond the first trimester (up to 24 weeks), with accompaniment group support and linkages to the formal health system.²⁴

Less burdensome models of access to abortion drugs (both within and outside the formal health care context) show the potential of medical abortion. Abigail Aiken et al. recently reported low rates of adverse events experienced by those who received medical abortion through telemedicine. In their study, women self-identified potentially serious adverse events, and most sought medical attention when advised to do so; no deaths were reported.²⁵ Self-administration of pills for early abortion with limited involvement of health professionals is effective and has similar outcomes to medical abortion

administered by professionals in health facilities.²⁶ In a study conducted in Ireland and Northern Ireland, almost all (97%) felt that the home use of pills had been the right choice, and most (70%) reported feeling “relieved” after the abortion.²⁷ Furthermore, the work of feminist organizations that bring the medicines to local communities and internet-based services that combine information with service delivery by postal or courier services has been instrumental in evincing the safety and effectiveness of self-management with minimal interaction with institutionalized systems of medical care.²⁸

The potential public health impact of medical abortion has already been documented. Indeed, Susheela Singh et al. have recognized the connection between the increased use of medical abortion and the safety of abortion. The authors state that “[o]ne of the most important developments in terms of the safety of abortion is the steady increase in the use of medical abortion, which is likely having an important impact on abortion-related morbidity and mortality.”²⁹

Within the international regulatory framework, WHO has embraced SMMA. In its 2012 publication *Safe Abortion: Technical and Policy Guidance for Health Systems*, WHO not only endorses mifepristone and misoprostol as a safe and reliable combination therapy for medical abortion but also notes that they are exempt from routine follow-up care in the absence of complications.³⁰ Since 2015, these drugs have been included in the WHO Model List of Essential Medicines.³¹ At the time of their inclusion in 2015, these drugs were considered “complementary.” In 2019, the 21st model list reclassified them as “core” medicines and removed the need for close medical supervision.³² Listing misoprostol and mifepristone as core medicines indicates that this combination should be a priority for governments and health care institutions to publicly finance and supply.

Furthermore, according to WHO, women themselves have an important role to play in caring for their own health through self-assessment and self-management.³³ Indeed, WHO recognizes that “self-management of medical abortion is an intervention that can take place without direct su-

pervision of a health-care provider; in this situation, the woman herself can be considered a health-care provider.”³⁴

Not only is it much less expensive than clinic-based care on average, but self-managed abortion offers a series of comparative advantages.³⁵ The ability to complete the procedure from home increases the potential for privacy, convenience, and control over the process. Indeed, Heidi Moseson et al. found that SMMA—rather than a “last resort”—was the “preferred option over clinic-based models of abortion care, due, among other reasons, to considerations about autonomy, privacy, confidentiality and perceived mistreatment by formal health systems.”³⁶ Researchers have found that “some people, such as those who have reason to distrust the medical system, may opt to self-manage abortion for reasons other than lack of access to a clinic, such as increased privacy and autonomy.”³⁷

As the evidence continues to grow, it is by now clear that SMMA holds great potential as a model for wider access.³⁸

Human rights standards

International human rights standards set the foundation for legal reform to enable SMMA. For decades now, human rights bodies have advanced norms that cover the various components of SMMA, from the right to sexual and reproductive health—including the right to abortion—to the right to benefit from scientific progress. We refer here to the three latest general comments issued by United Nations treaty monitoring bodies.³⁹

In March 2016, the Committee on Economic, Social and Cultural Rights adopted General Comment 22 on the right to sexual and reproductive health, which aims to assist state parties with the implementation of their international obligations regarding the right to sexual and reproductive health.⁴⁰ Among other matters, General Comment 22 affirms that states have an obligation to adopt “appropriate legislative” measures to achieve the full realization of sexual and reproductive health and rights.⁴¹

This general comment affirms that the right to

sexual and reproductive health is an integral part of the right to health and recognizes abortion services as a component part of the right to health.⁴² It notes that states have an obligation to repeal or eliminate laws, policies, and practices that criminalize, obstruct, or undermine an individual's or a particular group's access to health facilities, services, goods, and information, including abortion.⁴³ Laws that criminalize or restrict access to abortion are cited as examples of laws that must be repealed.⁴⁴

Furthermore, the general comment lists core obligations that include the prevention of unsafe abortion, the provision of medicines according to the WHO Model List of Essential Medicines (which includes misoprostol and mifepristone), and the right to access comprehensive education and information on sexual and reproductive health.⁴⁵

One of the most recent (and arguably crucial) components of the puzzle of international human rights law in terms of abortion is the Human Rights Committee's General Comment 36 on the right to life. This general comment, which interprets Article 6 of the International Covenant on Civil and Political Rights—one of the most important and widely ratified international human rights treaties of the United Nations system—holds that states “must provide ... legal and effective access to abortion” in expansive terms.⁴⁶ Additionally, it declares that states “may not regulate” abortion in a manner that compels resorting to “unsafe abortion” and that states “should revise their abortion laws accordingly.”⁴⁷

Furthermore, the Committee on Economic, Social and Cultural Rights' newly adopted General Comment 25 on science and economic, social, and cultural rights demands that states adopt a gender-sensitive approach to the right to enjoy the benefits of scientific developments. This approach is of particular relevance to the right to sexual and reproductive health and requires that governments ensure access to up-to-date scientific technologies, including “medication for abortion.”⁴⁸ Prior to the adoption of this general comment, the United Nations Special Rapporteur on cultural rights had already underscored that “[t]he rights to science and to culture should both be understood as including

a right to have access to and use information and communication and other technologies in self-determined and empowering ways.”⁴⁹

These international human rights standards set the grounds for the creation of an enabling environment for SMMA that includes the removal of all legal and regulatory barriers to abortion, access to essential medicines for abortion, and access to nonbiased, evidence-based information. While international bodies are limited in terms of the sanctions they can order, and much work is needed to further strengthen international standards, the general direction is fairly clear, meaning that these standards can and should be used to pressure states to invoke reform.⁵⁰

The global legal landscape

Over the past decade, several countries worldwide have adopted new legislation on abortion and liberalized access. However, the model of access proposed by self-managed abortion, which builds on the decriminalization and the de-medicalization of the process, is far from being enabled in these new abortion laws. Rather, the majority of laws still rely on an overmedicalized model of access that threatens with criminal sanctions those who self-manage and those who support people who self-manage. These laws clash with the evidence and the human rights standards described above.

Uruguay

Uruguay gained international praise in 2012, when it passed one of the most liberal abortion laws in Latin America. The Voluntary Termination of Pregnancy Act (Law 18,987) waives criminal penalties for abortion until the 12th week. There are a few legally prescribed exceptions: in cases of rape, a pregnant person can access an abortion without fear of criminal liability until the 14th week of pregnancy, and in cases where a pregnancy endangers the health of a pregnant person, it can be terminated at any point.

However, according to the abortion law, in order for an abortion to be legal—and thus not a crime, punished accordingly—a woman needs to

go through the following chronological steps: (1) a medical consultation with an obstetrician-gynecologist; (2) a second consultation with an interdisciplinary team who informs the woman of the procedure, its “inherent health risks,” and the available alternatives; (3) a mandatory waiting period of five days; (4) a consultation to confirm the woman’s willingness to follow through with the procedure; (5) the abortion itself; and (6) a post-abortion consultation.⁵¹ Law 18,987 does not substantially change the existing Criminal Code, from 1938, which still applies to all those cases in which an abortion does not meet the prescribed requirements set by the law.⁵²

In 2011, before the adoption of the law, Uruguay had introduced a “harm reduction” approach.⁵³ This approach consisted of providing people seeking abortions with a “before abortion” and an “after abortion” visit to a reproductive health polyclinic in which information on misoprostol and its use was provided.⁵⁴ This model was built on the fact that people were procuring and using misoprostol to self-manage their abortions despite misoprostol not being available over the counter for abortion (misoprostol was available in retail pharmacies for the treatment of gastric ulcers).⁵⁵ The availability of the drug in the informal market, now coupled with the provision of information and post-abortion care, has resulted in a model that is being replicated internationally.⁵⁶

After the passing of the law, in 2013, the Ministry of Health updated its medicines list (Formulario Terapéutico de Medicamentos) and removed the drug from retail pharmacies (for any indication), restricting the dispensation of mifepristone and misoprostol to intra-hospital pharmacies.⁵⁷ This closed the regulatory door to access medicines in the formal market for self-managed abortions outside of the burdensome process set by the law.

Chile

After two years of congressional deliberations, in September 2017 Chile adopted a new abortion act that allows abortion in certain cases. Previous to this, Chile was one of the few countries in the world

that did not permit abortion under any circumstances. The complete ban on abortion—initiated in 1989 by General Pinochet during the civic-military dictatorship—was lifted with this law.⁵⁸

The new law adopts the model of *causales* (grounds) and gestational limits and allows abortion when a woman’s life is in danger, when there are fetal anomalies incompatible with life, and in the case of rape (within 12 or 14 weeks, depending on the age of the pregnant person). The law requires that a doctor confirm whether the legal requirements are met for the first two grounds, and in the case of rape a psychosocial team must confirm the gestational age of the pregnancy and evaluate the woman’s statement regarding the rape.⁵⁹ The law requires the doctor to be a surgeon (*médico cirujano*), limiting the range of health care professionals who can provide abortions. Abortions outside these grounds still fall under articles 342–345 of the Criminal Code, which criminalize the pregnant person, whoever assists or “causes” an abortion, and the medical professional who intervenes.⁶⁰

Interestingly, Chile is one of the many countries where informal networks provide accurate information on how to self-manage an abortion. One hotline alone answered 20,000 calls between 2009 and 2013, and hotlines have been crucial for informing people of the correct and safe use of misoprostol for abortion.⁶¹ In 2014, misoprostol could be purchased on the informal market in Chile for prices ranging anywhere from US\$70 to 215, although on-the-ground information points to much higher prices.⁶² The introduction and widespread use of misoprostol in Chile has been singled out as one of the causes of the reduction in the rate of septic abortions, which was a major problem during the 1980s.⁶³ Feminist networks have been at the forefront of abortion access, advocating for the expansion of self-managed abortion beyond the first trimester.⁶⁴ However, the law did not follow suit.

Ireland

Until 2018, Ireland had one of the world’s most restrictive abortion laws. Since 1970, a “hidden

diaspora” of more than 170,000 Irish women has traveled to England for abortion, and an increasing number of women in Ireland are self-managing their abortions.⁶⁵

After the referendum held in May 2018 to repeal the Constitution’s Eighth Amendment, Ireland adopted a new law on abortion. The Health (Regulation of Termination of Pregnancy) Act 2018, in force as of January 2019, lifts the near-total ban on abortion imposed since 1983.⁶⁶ The act legalizes abortion on request up to 12 weeks of pregnancy after a mandatory three-day waiting period. The law provides no exceptions for cases in which the 12-week limit is crossed during the waiting period, or because of delays due to traveling from rural areas or waiting for further tests ordered by a doctor. After the 12th week, the procedure for accessing an abortion requires the involvement of two doctors (an obstetrician and another “appropriate medical practitioner”) and is permitted only in cases of a condition likely to lead to death of the fetus, a risk to the pregnant woman’s life or health, and an emergency. Two medical practitioners need to be of the opinion that the conditions are fulfilled, which gives doctors a wide margin of discretion, especially with regard to terms such as “[risk] of serious harm to health” that are not defined in the law. In 2017, for example, the Abortion Support Network reported that two women who had attempted suicide more than once were denied abortions.⁶⁷

Abortions provided outside of the procedure set by the law are criminally prohibited. While the act does not criminalize the pregnant person themselves, other people (such as family members, support networks, and doctors) who assist a pregnant person in obtaining an abortion outside of the provisions of the law can be subject to a prison sentence of up to 14 years.⁶⁸

Isle of Man

The Isle of Man Abortion Reform Act 2019 came into effect in May 2019.⁶⁹ This law allows abortion on a woman’s request in the first 14 weeks of pregnancy. Article 6 details the conditions that need to be satisfied for abortion services to be provided. During the period between the 15th and 23rd week

of pregnancy, abortion may be provided in cases of sexual assault, a risk to the woman’s health, fatal or severe fetal impairment, or serious social indications. Abortion is also permitted when the pregnancy would cause risk to the pregnant woman’s life or if the baby, when born, would suffer serious impairment or die shortly after birth.

Article 7 of the law lists the people who may participate in the provision of abortion services. The law expands the scope of people who can provide abortion to include medical practitioners, nurses, midwives, and pharmacists. They need to be authorized by the Department of Health and Social Care, demonstrate that they possess the appropriate skill in relation to the gestation period, and be registered in the corresponding council. Outside this list of professionals, anyone who participates in the provision of abortion services commits an offense punishable with a fine or seven years’ custody (sec. 7), and those who prescribe or supply medication for abortion also commit an offense punishable with a fine or five years’ custody (sec. 11). The law explicitly states that the provision of advice or information about abortion is not an offense, and this includes information about obtaining an abortion abroad or via electronic communications (art. 10).

When it comes to medical abortion, a pharmacist or a “relevant professional” can prescribe and supply the “relevant products.” Relevant professionals are those listed in paragraph (a) or (d) of the definition of “health care professional” in section 3 of the Health Care Professionals Act 2014: a registered medical practitioner or a member of the profession of nursing or midwifery who is a registrant.⁷⁰

New Zealand

In April 2020, New Zealand adopted one of the most liberal abortion laws in the world. The Abortion Legislation Act 2020 represents the first substantial change to abortion laws in New Zealand in 43 years.⁷¹ The issue was previously regulated by the Contraception, Sterilisation and Abortion Act 1977 and the Criminal Code.

The new act legalizes abortion on request until 20 weeks. In this instance, the woman can self-refer

to an abortion provider (rather than requiring a referral from her health care provider), and while the involvement of a health professional is required, it does not necessarily have to be a doctor. Expanding in this way the range of professionals who can provide abortions is in line with the evidence discussed in the second section of this paper. The act substantially expands the scope of registered health practitioners who can provide abortions: doctors, midwives, nurse practitioners, and registered nurses. It also removes the requirement that abortions need to be performed on licensed premises.⁷²

After 20 weeks, abortion is legal and available if the “health practitioner reasonably believes that the abortion is clinically appropriate in the circumstances.” To make that assessment, the health practitioner needs to consult at least one other qualified health practitioner and have regard to the woman’s physical health, mental health, and overall well-being.

The Abortion Legislation Act repeals the offense of procuring or attempting to procure an unlawful abortion set out in section 44 of the Contraception, Sterilisation and Abortion Act, the need for an abortion supervisory committee (section 10), and the requirement that abortions need to be certified by two certifying consultants. It also amends the Crimes Act 1961 and amends section 183 by establishing penalties of a maximum of five years of imprisonment for those other than health practitioners who procure, or attempt to procure, an abortion. The amendment explicitly states that a pregnant woman herself cannot be guilty of an offense under this section (as had previously been the case). However, the offense remains for non-health practitioners, meaning that those who are “unqualified” providers or people who provide support or assistance still face the risk of criminalization.⁷³

Thailand

Abortion is currently regulated in articles 301–305 of the Thai Criminal Code. The code, last amended in 1957, defines offenses in relation to induced abortion as “any actions causing the delivery of a dead fetus.” Section 301 of the Criminal Code states that “[a]ny woman causing her own abortion or

allowing another person to cause it shall be punished with not more than three years of prison or a fine of not more than six thousand Baht, or both.” Under article 305, abortion can be performed only by a physician for two specific conditions: risk to the woman’s health and pregnancy arising from rape.⁷⁴ Several problems arise in the interpretation and implementation of the law since, for example, there is no definition of health.

Despite the restrictive laws, it is estimated that around 300,000 to 400,000 abortions occur each year; “almost all of these are done ‘underground’ with appalling morbidity and mortality,” according to the *Thai Journal of Obstetrics and Gynaecology*.⁷⁵ The National Essential Medicines List includes the mifepristone-misoprostol combipack as an approved treatment for ending pregnancies in a hospital setting.⁷⁶

In February 2020, the Constitutional Court ruled that section 301 violates sections 27 and 28 of the 2017 Constitution, which endorse equal rights between men and women, as well as the right and liberty of everyone in their life and person. The decision reads, “The Constitutional Court resolves in the majority that Sections 301 and 305 of the criminal code should be amended to conform with the current situation.”⁷⁷ The ruling does not annul or derogate the law but gives the government 360 days to amend it.

Following this judgment, a new law entered into force on February 7, 2021.⁷⁸ This law amends the abovementioned sections by allowing abortion on request until the 12th week of pregnancy. The Medical Council of Thailand and the Royal Thai College of Obstetricians and Gynaecologists both recommend the 12-week limit.⁷⁹ Criminal penalties remain for those who have abortions after week 12 and outside of the grounds set by the country’s Medical Council (by a qualified professional in cases of sexual assault, threat to the mother’s physical or emotional health, and if the fetus is known to have abnormalities). The new wording of section 301 reduces the penalties to no longer than six months of jail and a fine no higher than 10,000 baht.

While constituting an important step, the newly adopted law follows the traditional model,

retaining criminal penalties and a medicalized model of access. Activists continue to advocate for further decriminalization reform.⁸⁰

Argentina

In August 2018, the Argentinian Senate held a historic vote on a law that decriminalized abortion during the first 14 weeks of pregnancy. After 23 hours of intense debate, the bill was adopted by a very narrow margin the lower house (129 in favor and 125 against) but was later rejected in the Senate (31 in favor and 37 against).⁸¹ A new bill was debated in December 2021, culminating in the passing of Law 26.710.⁸²

The new law represents a clear move toward the liberalization of abortion by recognizing a right to access abortion care on request until the 14th week of pregnancy. It specifically amends the Criminal Code (art. 86) to state that abortion is not a crime when done before the 14th week. After the 14th week, the law provides for a system of *causales*, allowing abortion in cases of rape or risk to the pregnant woman's life or health.

Crucially, the new wording of article 86 repeals the need for the involvement of a doctor in order for the abortion to be exempt from criminal penalties, representing a clear move toward demedicalization. However, under the new law, pregnant people and those who assist and support them outside the grounds and time frames provided by the law still risk criminal prosecution. The law also creates a new crime for health care personnel who hinder or obstruct access to abortion (art. 85 bis).

Similar to Chile, the country has a long history of networks of *acompañantes* (abortion access companions), which have been key in ensuring people's access to abortion and helping them self-manage their abortions.⁸³ The Socorristas en Red, for example, has provided training for doctors on the use of misoprostol and has strengthened collaboration between the formal and informal systems (for example, the network refers people to abortion-friendly providers if additional medical support is needed, and clinicians refers people to the network for early termination).⁸⁴ These groups

have expressed that they will continue to serve people who need abortions, seeing their work as an alternative—rather than a subsidiary—to institutionalized systems of care.⁸⁵ In 2018 alone, they accompanied more than 7,000 people in self-managing their abortions.⁸⁶

Conclusion

This “fragmented landscape” of abortion laws and regulations has been considered to make no legal or public health sense.⁸⁷ The restrictions on abortion (including self-managing) discussed above show that abortion is still construed as an exceptional matter that necessarily requires medical intervention or supervision.⁸⁸ Self-managed abortion and the growing body of evidence come to change the model of access to abortion but also question the portrayal of abortion as an exceptional matter that requires medical control or supervision.⁸⁹

Despite being a very common and safe experience (if given the conditions), abortion continues to be overregulated. However, the discussions around abortion are rarely restricted to health and human rights arguments, with technical, political, religious, and many other factors coming into play. Undoubtedly, we acknowledge that law reform is a convoluted process that requires a series of strategic political compromises. Clarifying what the basic tenets of legal reform should be (in line with the latest human rights standards and available evidence) can help separate the wheat from the chaff in abortion debates.

The findings of our review show that while the recently adopted laws are a move toward liberalization, much more work is needed to bring the domestic frameworks into line with the evidence and human rights. Most of the reforms embrace partial decriminalization or exception-based criminalization. This means that abortion remains punishable under the law in certain circumstances, such as when requirements of gestational age, waiting periods, or specific grounds are not met. Furthermore, laws continue to criminalize those who provide support to people who self-manage,

leaving a constellation of actors—who have played a crucial part in making SMMA safe(r)—exposed to the risks of criminalization.⁹⁰

First, all of the laws discussed above still retain some criminal provisions related to abortion. For example, while criminal penalties are repealed for women themselves in Ireland and New Zealand, family members, support networks, and friends who assist a pregnant person in obtaining an abortion outside of the provisions of the law still risk criminal prosecution. In line with the framework proposed above, the available evidence and human rights standards clearly indicate the need for the decriminalization of abortion, including for those who support self-managed abortion.

This, of course, does not leave pregnant people unprotected, as general criminal offenses that apply to all medical treatment, quality of products, and more would continue to apply to non-consensual or dangerously negligent procedures. There is no continuing role for specific laws on abortion care, and in those cases where criminal sanctions may remain appropriate, specific abortion offenses are unnecessary because existing general principles of criminal law are sufficient to support prosecutions.⁹¹

Second, we found that many of the laws still conceive of abortion as a “procedure” that is “performed” by somebody other than the pregnant person. As we saw above, some of the laws in force still retain the clinical settings and the involvement of (one or more) medical professionals as the desirable (and therefore decriminalized) setting for an abortion to take place. Uruguay’s law, for example, requires various consultations with medical professionals, a mandatory five-day waiting period, and a consultation with a multidisciplinary team before a woman can obtain a prescription and self-administer the misoprostol at home.⁹² We see this as part of a worrisome trend whereby laws expand access, but within a medicalized model that continues to create vulnerability and risk for people who self-manage and people who support them outside of the procedures set by the law. We conclude that while the introduction of abortion provision within institutionalized systems of care is to be celebrated, the demedicalization and decriminalization of

abortion should to go hand in hand.

Besides decriminalization, an enabling legal environment for self-managed abortion would require us to look beyond abortion laws. It would mean lifting legal and policy barriers to SMMA that fall outside of abortion laws. Namely, this includes removing all regulatory restrictions on access to misoprostol and mifepristone (making them available and accessible over the counter) and adopting robust legislation on access to information that ensures that evidence-based, scientifically accurate comprehensive information on how to safely self-manage abortions is made widely available without censorship.⁹³

While laws are deeply contextual, it is increasingly impossible to speak of a purely domestic abortion law, and lawmakers and framers often seek inspiration from other jurisdictions and from international law.⁹⁴ Highlighting the progress and shortcomings of recently adopted laws from around the world can help us create a roadmap for further reform in other contexts: abortion should not be a matter of criminal law, and people who access abortions and people who support and accompany them should not fear harassment, stigma, or criminalization. Lawmakers no longer can justify health care provider involvement or unnecessary restrictions. There is enough evidence and support from international human rights standards to ground developments toward an enabling legal environment for SMMA.

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Indigenous Birth as Ceremony and a Human Right

ASHLEY HAYWARD AND JAIME CIDRO

Abstract

Birthing can be an empowering experience for women. Within many Indigenous cultures around the world, birth is a ceremony to celebrate new life, acknowledging the passing from the spiritual world into the physical world. While initiatives to “indigenize” health care have been made, this paper argues that the United Nations Declaration on the Rights of Indigenous Peoples and the United Nations Sustainable Development Goals contain frameworks for Indigenous rights that include the right to incorporate Indigenous childbirth ceremonies into clinical practice. Examining the importance of birthplace, this paper details a current movement in Manitoba, Canada, to “bring birth home,” which recognizes that the determinants of health experienced in the early stages of a child’s development can have health implications for an individual’s future.

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Introduction

Women and children play a crucial role in society, so investing in improvements to their overall health and wellness is “not only the right thing to do, but it also builds stable, peaceful and productive societies.”¹ Birthing can be an empowering experience for women, but it can come with risks, including maternal and infant mortality. Mainstream medicine has attempted to reduce these risks by encouraging hospital births and introducing interventions such as inductions, optional caesarean sections, and various analgesics. While we must recognize that there is a place for necessary medical interventions, there are many cases in which such interventions have negative impacts. The concept of obstetric violence was introduced in 2007 as

*the appropriation of women’s bodies and reproductive processes by health personnel that is expressed through dehumanizing treatment, the abuse of medicalization, and the pathologization of natural processes, resulting in a loss of women’s autonomy and ability to decide freely about their bodies and sexuality, negatively affecting their quality of life.*²

Within many Indigenous cultures, birth is a ceremony to introduce new life into this world, acknowledging the passing from the spiritual world into the physical world, and Western medical interventions may not always be appropriate. As Amber Skye observes, the devaluing of Indigenous medical practices is one form of ongoing colonialization.³

While initiatives to “indigenize” health care have been made, this paper argues that the human rights frameworks contained in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the Sustainable Development Goals (SDGs) allow for the incorporation of Indigenous childbirth ceremonies into clinical practice. Examining the importance of birthplace, this paper details a current movement in Manitoba, Canada, to “bring birth home” and the life course epidemiology that recognizes that the determinants of health experienced in the early stages of a child’s development can have significant health implications for an individual’s future.⁴

United Nations Declaration on the Rights of Indigenous Peoples

UNDRIP is considered “the most comprehensive international instrument on the human rights of Indigenous peoples, including a wide range of political, economic, social, cultural, spiritual, and environmental rights,” and was adopted by the United Nations (UN) General Assembly in 2007, with the majority of states voting in favor, excluding Australia, Canada, New Zealand, and the United States.⁵ Notably, these four countries have large Indigenous populations. In 2010, Canada issued a statement of support endorsing the principles of UNDRIP; however, because of concerns about the declaration being “overly broad, unclear and capable of a wide variety of interpretations,” Canada maintained its formal vote against adopting the declaration.⁶

A declaration is not legally binding, nor does it present any new rights; in the case of UNDRIP, it only affirms the inherent collective and individual rights of Indigenous peoples around the world. The creation of UNDRIP was largely in response to criticism that universal approaches to human rights had failed to adequately include Indigenous peoples.⁷ Although some have argued that human rights frameworks are simply another colonial concept, Canada’s statement of support for the declaration was important for showing a willingness and commitment to transform Canada’s relationship with First Nations, Inuit, and Métis peoples.⁸ It was not until 2016 that Canada removed its objector status and announced that it would fully support, without qualification, the implementation of the declaration.⁹

UNDRIP recognizes the “dual reality of many Indigenous people who live in two worlds. In one world, they hold fast to their cultural traditions, beliefs, and values. The other world is that of a colonizing nation, and it is where many Indigenous peoples go for ... health care.”¹⁰ Article 24 of UNDRIP is essential to understanding these health rights. It states:

24.1 Indigenous peoples have the right to their traditional medicines and to maintain their health

practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.

24.2 Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.¹¹

This provision is especially important for Indigenous peoples in Canada, whose historical experience with health care access in the country involves traumatization, experimental procedures, and segregation.¹² Prior to the mid-20th century, pregnant Indigenous women gave birth in their communities, supported by family members, friends, Knowledge Keepers, traditional midwives, and birth workers.¹³ Often, the role of a midwife was viewed as a calling; it was a very spiritual and powerful position.¹⁴ The midwife continued supporting the family following the birth by living in the home for a period of time to tend to the infant and mother and to assist with the new mother's work.¹⁵

Despite article 24's call to protect the health rights of Indigenous peoples, there continue to be distinct risk factors that may affect Indigenous women's experience with pregnancy and childbirth. These include reduced access to standard prenatal care; inaccurate estimation of gestational age and subsequent complications of post-term pregnancies; preexisting medical conditions; young maternal age; marital status; malnutrition; and low educational attainment.¹⁶ While some may argue that the moving of Indigenous births from the home to the hospital in the 1920s by the Department of Indian Affairs supports Indigenous access to health services, this shift has led to a Western-based overmedicalization of Indigenous childbirth that often focuses solely on the physical component of well-being to the detriment of the emotional, mental, and spiritual components that are crucial to Indigenous health.¹⁷ The World Health Organization has confirmed that childbirth is becoming overmedicalized, particularly in low-risk pregnancies, including through the overuse of caesarean section.¹⁸ Under this medicalization

of childbirth, physicians are promoted as superior birth attendants, having been trained in Western science and technology.¹⁹ As Colleen Varcoe and colleagues state, the dominance of biomedicine results in the imposition of medically based maternity technologies, with Indigenous women being told that "their time honored midwifery and birthing practices [are] unsafe and that they must turn to the advances of western medical practice for 'modern' maternity care."²⁰ The impact of this message, and how it is operationalized, is significant for the physical and mental health of Indigenous women and families, and Indigenous women still face less desirable birth outcomes compared to other groups in Canada.²¹

The disparities in maternal health for Indigenous women in Canada that are intertwined with colonization and the resulting deep inequalities in socioeconomic status and health outcomes are exacerbated by violations of article 24. Across Canada, infant mortality rates are more than twice as high for each Indigenous group (First Nation, Métis, and Inuit) compared with the non-Indigenous population.²² For First Nations women living on reserves, more than half of the women (56.6%) must travel between 50 and 350 kilometers to give birth.²³ Further, in urban areas, the preterm birth rate is higher among First Nations infants compared to all other Manitoban infants living in the lowest- and highest-income areas.²⁴ Sudden infant death syndrome is the leading cause of death for First Nations and Inuit children, whose rates are more than seven times higher than that of the non-Indigenous population.²⁵ In the province of Manitoba, which has one of the highest Indigenous populations in Canada, "infant mortality rates for First Nations (FN) people range from 2.1 – 2.9 times higher than the rate for other Manitobans."²⁶ These statistics demonstrate that distinct needs are likely remaining unaddressed for the Canadian Indigenous population. One explanation for the disparity, offered by Robert Allec, is culture, but the author fails to identify exactly what aspects of culture might explain the difference.²⁷ Other explanations have been put forward in documents such as the United Nations factsheet "Indigenous Women's

Maternal Health and Maternal Mortality,” arguing that Indigenous women have an increased risk for maternal mortality compared to “other women”; however, these studies do not examine Canada specifically.²⁸

Internationally and irrespective of ethnicity, women’s experiences during childbirth within medical institutions are often distressing due to discrimination and overmedicalization. In 2010, a report by Diana Bowser and Kathleen Hill, which gathered stories from women in 18 countries, including Canada, revealed that many women felt disrespected and abused during institutional childbirth; their study revealed “subtle humiliation of women, discrimination against certain subgroups of women, overt humiliation, abandonment of care and physical and verbal abuse.”²⁹ Medical interventions have made childbirth a negative, and potentially damaging, experience. In Canada, there has been an increase in the use of induction, vacuum extraction, and caesarean section, in addition to the risk of injury from operative vaginal deliveries where vacuums or forceps are used.³⁰ Injuries range from minor cuts to more serious issues that might affect the woman’s long-term quality of life, including bladder and bowel control, sexual dysfunction, and perineal pain.³¹ According to one ethnographic study of hospital birth in a Canadian setting, “Whilst women are treated kindly and attention is paid to them in this hospital, there is very little respect for the birth process and the physiological nature of this event.”³² These issues, combined with the historically fraught relationship that Indigenous peoples have with medical institutions, leads many Indigenous women to seek non-facility alternatives for the birthing process.

Indigenous birth ceremony as compliance with article 24

A recent movement in clinical care seeks to offer family-centered maternity and newborn care (FCMNC) that recognizes that “Indigenous peoples have distinctive needs during pregnancy and birth.”³³ FCMNC was originally created to address the physical, emotional, psychosocial, and spiritual

needs of women, their newborns, and their families.³⁴ FCMNC recommends integrating cultural safety into prenatal care for Indigenous women and details some of the barriers to prenatal care, such as physical distance from care, lack of child care for other children, and fear or distrust of the health care system.³⁵ In its recommendation that hospitals and birthing centers develop protocols and policies to “support traditional birthing customs and cultural practices,” the Public Health Agency of Canada could be seen as attempting to implement UNDRIP’s article 24(1), though it does not make this explicit connection.³⁶ An understanding of birthing as ceremony—one that includes distinct customs, rituals, and traditions for Indigenous women—must be achieved as countries move to fully adopt and implement UNDRIP.³⁷ UNDRIP recognizes the inherent right of Indigenous peoples to practice and revitalize their cultural traditions and customs, and it can be argued that the loss of community birth is a cultural loss.³⁹ The loss of culture can also be categorized both as “distal (e.g. historic, political, social and economic contexts)” and as an “intermediate (e.g. community infrastructure, resources, systems and capacities)” social determinant of health.⁴⁰

Traditionally, pregnant Indigenous women had an important role in “carrying the spirit,” and the community came together to honor the spirit by “invest[ing] in the well-being of the mother.”⁴¹ The pregnant mother is viewed as a conduit between the spiritual world and the physical world, thereby making prenatal care a community endeavor.⁴² Therefore, a woman’s pregnancy and birth were the responsibility of the entire community rather than an individual family event. The community was expected to support the mother not only in antenatal care but also in emotional and spiritual support. Furthermore, cultural practices around birth, including ceremonies for welcoming and celebrating the new life and the sharing of traditional knowledge and teachings, helped establish strong community roots for the mother and newborn by encouraging healthy lifestyles and a sense of belonging for the family.⁴³ The child would have a clear sense of their identity and place within the

community, which, according to the Society of Obstetricians and Gynaecologists of Canada, “helps them to become resilient and responsible members of that community.”³⁴

Ceremonies in birth can also be in the form of stories that show a connection to the land. Rachel Olson details “the water ceremony” and the connection to birthplace and landscapes.⁴⁵ Pregnancy is understood as carrying “sacred water,” metaphorically referring to the amniotic fluid surrounding and protecting the baby but also connecting to the important role of the water breaking in labor. Anishinaabekwe (Anishinaabe women) are considered the caretakers of water, which is one of their most important roles in society.⁴⁶ Midwife and activist Katsi Cook echoes this significance, stating:

*In the Mohawk language, one word for midwife is iewirokwas. This word describes that “she’s pulling the baby out of the Earth,” out of the water, or a dark wet place. It is full of ecological context. We know from our traditional teachings that the waters of the earth and the waters of our bodies are the same water.*⁴⁷

Anishinaabekwe traditionally were encouraged to maintain a “good frame of mind,” since emotions would influence the baby.⁴⁸ In First Nations communities in northwestern Ontario, women began learning obstetrical care and cultural practices, such as “careful attention to the sacred handling of the placenta and umbilical cord; and [the] careful wrapping of the newborn in fur” by observation in their teenage years.⁴⁹

As Canada works to protect the inherent rights of Indigenous peoples across the country by fully implementing UNDRIP, it must also recognize the cultural significance of birth and ceremonies that are crucial for protecting the maternal health and birthing rights of Indigenous women.⁵⁰

Sustainable Development Goals

On September 25, 2015, the United Nations General Assembly adopted the 2030 Agenda for Sustainable Development Goals, titled “Transforming Our World: The 2030 Agenda for Sustainable Develop-

ment,” which came into effect on January 1, 2016.⁵¹ This document, which “provides a global blueprint for dignity, peace and prosperity for people and the planet,” consists of 17 goals and 169 corresponding targets.⁵² The SDGs were a response to the Millennium Development Goals (MDGs), which were perceived as embracing a top-down approach and which failed to involve Indigenous peoples in identifying the health issues that most affect their well-being.⁵³ Both iterations of the Development Goals prioritize health care for mothers and children in the global arena: Goals 4 and 5 of the MDGs aimed to reduce child mortality and improve maternal health, while Goal 3 of the SDGs seeks to “ensure healthy lives and promote well-being for all at all ages” and sets specific targets for a reduction in maternal and child mortality.⁵⁴ These goals can be reached only by implementing a rights-based and culturally sensitive approach that respects traditional health practices and supports Indigenous peoples’ own methods of providing services.⁵⁵

Pregnancy and childbirth pose risks for mothers, with 830 women dying each day from preventable causes related to pregnancy and childbirth around the world.⁵⁶ Although Canada boasts one of the world’s lowest maternal mortality rates, better access to health services in rural and remote communities, as well as improved funding and culturally safe health care services, are among the keys to improving the health disparities, including maternal mortality ratios, between Indigenous and non-Indigenous women.⁵⁷ Further, as stated in the previous section, there are striking disparities between Indigenous and non-Indigenous birth outcomes, including infant mortality rates. Some studies indicate that “on-reserve First Nations, off-reserve status Indians, and Inuit have rates of infant mortality ranging from 1.4 to 4 times that of non-Indigenous infants.”⁵⁸

In Canada, programs to “promote well-being for all at all ages” include the Strengthening Families Maternal Child Health Program, the Canadian Prenatal Nutrition Program, and the Aboriginal Head Start Program, but many Indigenous communities operate without these supports. In fact, only 14 of 63 First Nation communities in Mani-

toba offer the Strengthening Families Maternal Child Health Program.⁵⁹ Though Canada has a long history of being a leader in the global arena with respect to maternal, newborn, and child health and has committed to focus on prevention and early intervention, health disparities for Indigenous women continue to exist. Determining who is responsible and accountable for providing health care services in Canada to First Nations and Inuit is often difficult and compromised by competing financial demands.⁶⁰ Each provincial and territorial government is required to provide health care under the Canada Health Act; however, Canada also has a constitutional responsibility to provide health care to First Nations (“Indian”) and Inuit peoples.⁶¹

Moreover, as some have argued, there is a direct correlation between the lack of supports for Indigenous maternal health and the overrepresentation of Indigenous children in government care and government-appointed foster families who are often non-Indigenous.⁶² Marni D. Brownell and colleagues analyzed data from the Manitoba Child and Family Services, Department of Justice, and Population Health Registry to explore the relationship between having a history of Child and Family Services involvement during childhood (0–17 years) and being charged with a crime as a youth (12–17 years).⁶³ They found a substantial overlap between the child welfare and youth justice systems, with overrepresentation of Indigenous youth in both systems.⁶⁴

Implementing these UN human rights declarations and goals to address health disparities between Indigenous and non-Indigenous peoples in Canada is important, and reclaiming Indigenous birth practices is a palpable way in which to implement these rights.

Reclaiming Indigenous birth practices in Manitoba

Though adverse birth outcomes are more likely for Indigenous (compared to non-Indigenous) women in Canada, they are even more prominent for First Nations and Inuit women who live in rural or isolated communities.⁶⁵ The shortage of maternal

health personnel can prevent women from accessing the same level of maternity care as Indigenous women living in urban areas.⁶⁶ Lack of access to health care and systemic conditions can lead women to feel mistreated during childbirth.⁶⁷ This lack of local health care support for First Nations and Inuit women has been used to justify the First Nations and Inuit Health Branch of Health Canada’s maternal medical evacuation policy, according to which pregnant Indigenous women are routinely evacuated from rural or isolated communities to urban centers at 36 weeks’ gestation.⁶⁸ This policy separates women from their support networks and places them in unfamiliar environments as they prepare for labor and delivery.⁶⁹ Being alone and unsupported creates unnecessary stress and can create negative health consequences for both the woman and baby, such as anxiety, preterm birth, and low or high birth weights. This policy prioritizes Western biomedicine in obstetrical management of pregnancy and is inconsistently applied because it lacks clear documentation and details.⁷⁰

One tangible way to address these issues is through the use of Indigenous doulas, birth attendants, and midwives. Indigenous birth workers, both traditionally and in the modern context, provide support for women during active labor and throughout the birthing process. The resurgence of trainings for Indigenous women to act as helpers in birthwork or to provide full-spectrum doula care can be viewed as a significant step toward compliance with UNDRIP and the SDGs. The role of an older female relative is documented as a key component of pregnancy and childbirth, and critical cultural practices are essential to establishing and revitalizing the strong cultural connection and spiritual path for Indigenous children.⁷³ Doulas extend their role of emotional support companion to advocate for various social supports following the birth. Although doulas do not help with the delivery of a baby, they do support women with antenatal care. Midwives and traditional birth attendants (sometimes referred to as community-based midwives) overlap with doulas in many respects, as they are individuals hired to support women during the birthing process. The

amount of formal training may be the most obvious difference.⁷¹ Support for women during active labor and birth has been proven to reduce the use of medications and interventions, and the right to appropriate and respectful care during pregnancy and birthing is imperative to ensure positive long-term impacts for mothers and children.⁷²

This type of birth support is proposed by two Manitoba-based research projects. The first is the Winnipeg Boldness Project, a research and evaluation center that uses social innovation research as an incubator to develop ideas to improve outcomes for people in the Point Douglas inner-city community in Winnipeg. The Winnipeg Boldness Project initiated the first urban Indigenous doula short-term pilot program in Winnipeg, in which 12 Indigenous women were trained as birth helpers to support pregnant Indigenous women and families over a one-year period in order to understand the gaps in support for urban-based pregnant Indigenous women.

The second Manitoba-based research project is titled “Indigenous Doulas as a Culturally Based Health Intervention to Improve Health and Birth Outcomes for First Nations Women in Remote Communities Who Travel for Birth” (hereafter referred to as the Northern Manitoba Indigenous Doula Project). This project is a partnership between Wijiidiwag Ikwewag (formerly known as the Manitoba Indigenous Doula Initiative), the First Nations Health and Social Secretariat of Manitoba, and the University of Winnipeg that involves three northern First Nations communities. It pairs expectant First Nations women with local and urban Indigenous doulas and examines how Indigenous doulas can support First Nations women who are forced to travel for birth in Manitoba. While the project is currently collecting data on the experiences of Indigenous women who give birth with and without doulas, preliminary findings have emerged that concern the Indigenous doulas themselves. These findings demonstrate that Indigenous birth workers require multiple provisions to enable their support of mothers, including a stable service delivery model with concrete processes for referrals and payment, ongoing professional development,

and robust self-care plans, given that many Indigenous women are brought to this work in response to their own negative birthing experiences. Though these results are not about the improvement of mothers’ experiences, they do affect the support offered to Indigenous mothers.

Moreover, the Northern Manitoba Indigenous Doula Project has found that doulas provide necessary boundaries within the medical birthing experience (for example, by ensuring that nurses and doctors are respectful of women’s need for privacy and space to observe cultural practices) and empower Indigenous women to create a positive experience for themselves by choosing birthing experiences that incorporate rituals and celebrations. The doulas from the urban project also described their experience of personal transformation that “nourishe[s] [them] through this training and practice.”⁷³ Empowerment is a process by which those who have been historically disempowered are able to “increase their self-efficacy, make life-enhancing decisions, and obtain control over resources.”⁷⁴ In traditional societies, matriarchs played an important role, but through colonization, women’s place within society changed. “Broad[er] historical forces and policies that shaped [Indigenous women’s, girls’, and 2SLGBTQIA people’s] individual experience” are recognized as a tool of disempowerment of community structure.⁷⁵

There is a movement throughout medical care to empower patients to become more involved in their medical treatments and processes. The Canadian Medical Association (CMA) “recognizes that collaborative care is a desired and necessary part of health care delivery in Canada and an important element of quality, patient centred care.”⁷⁶ Collaborative decision making is also a cornerstone of patient-centered care.⁷⁷ According to CMA, collaborative care encourages providers to work together to provide the best care to patients based on trust, respect, and an understanding of one another’s skills and knowledge.⁷⁸ This model includes empowering patients to make choices related to their care in conjunction with their health care team. “The medical profession supports collaborative care, both in the hospital and in the community, as

one of the essential elements of health care delivery in Canada,” demonstrating that reclaiming birth ceremony is possible for Indigenous communities; however, the principles outlined by CMA show that more ideological shifts still need to be made.⁷⁹ Principle three demonstrates the belief that physicians are the most powerful in the relationship: “In the CMA’s opinion, the physician is best equipped to provide clinical leadership.”⁸⁰ This power imbalance that places medical professionals above patients continues to create a significant barrier for Indigenous women to have a voice in the care they are seeking.

Generally, midwives use the dichotomy of natural versus medical birth as part of an informed choice ideology when promoting their services to pregnant women. Though the movement in midwifery focuses on informed choice, it is distinctive from the informed consent model, which would allow Indigenous women to have a stronger voice in their health care. One distinction is that

what counts as authoritative knowledge in informed consent versus informed choice in midwives care differs; with the former, patients listen to health care providers impart “evidence” and clinical options to them in an accessible way and then must make a choice; the latter involves this too but midwives also grant authority to other kinds of knowledge—a woman’s own knowledge, feelings, and past experience about her body and previous pregnancies as well as her lifestyle and moral orientation.⁸¹

Women’s informed choice includes privileging other forms of knowledge and understanding, including that of Indigenous epistemologies. In Western traditions, there is a recognized hierarchy of beings, with humans at the top. Within Indigenous ways of knowing, humans are understood as “the younger brothers [or sisters] of Creation,” meaning that we need to learn from other species that have been on Earth longer and have had time to figure out how to live in harmony and reciprocity.⁸² By allowing for these knowledges in the process of informed choice, Indigenous women may be more empowered and feel like collaborators in their own birth journeys.

In some cases within Canada, we are begin-

ning to see attempts to shift biomedicine toward a more holistic approach based on Indigenous knowledge. In Akwesasne, Ontario, a group called Onkwehon:we Midwives Collective uses Indigenous knowledge to ensure a safe birthing process. The group’s objective is to “provide assistance to Indigenous expectant moms and their families with reclaiming control of their birth plans, along with continued education and support throughout all the phases of an Indigenous woman’s life.”⁸³ Another promising intervention is the Indigenous Women’s Health Initiative within the Society of Obstetricians and Gynaecologists of Canada.⁸⁴ This online space offers resources for health care professionals and community members to be more informed about providing culturally safe care related to Indigenous sexual and reproductive health and promoting and advancing health equity for Indigenous women.

These interventions show how appropriate care for Indigenous mothers and their children must look beyond health care outcomes to include social and cultural factors, such as identity and connection to place, when implementing new strategies to address the complex and distinct needs of an Indigenous population. This appropriate care, in turn, addresses the calls and declarations for Indigenous rights in Canada.

Conclusion

Returning birthing traditions to Indigenous communities in Canada—despite the complexities of funding and health care access—would respect and implement the commitments detailed in UNDRIP and the SDGs. Further exploration is needed on the correlation between the lack of supports for Indigenous women and the overrepresentation of Indigenous children in government care. Moreover, the literature would benefit from additional reviews on how privileging Indigenous epistemologies and ways of knowing in the context of Indigenous birth and maternal health can lead to positive health outcomes. Finally, further inquiry is required to explore encounters where tensions exist between health rights and cultural rights.

Efforts need to be made to honor the right to ceremony and rituals surrounding pregnancy and birth and to incorporate biomedical interventions only when necessary. Birth ceremonies are directly connected to the land, so recognizing the importance of birthplace (geographical location) and honoring the sacredness of birth is a significant way to recognize and implement Indigenous rights. These ceremonies would welcome children into the world in a good way by reinforcing their cultural identity and empowering the community to take care of the child, all of which would positively affect the life courses of Indigenous people and help remedy overall health disparities.

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Gender Inequality, Health Rights, and HIV/AIDS among Women Prisoners in Zimbabwe

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Abstract

Zimbabwe has successfully reduced its HIV prevalence rate and AIDS-related deaths in recent years, but women, particularly those who are in prison, remain at high risk. Poor prison conditions, discrimination, stigma, and the neglect of the sexual and reproductive health of women prisoners living with HIV result in poor health outcomes for women prisoners. Inadequate and inappropriate health provision in prison is a breach of their human rights and a public health problem. This paper analyzes the political commitment of Zimbabwe to address the underlying determinants of health by incorporating into its health laws and policies measures that promote the health rights of women prisoners living with HIV.

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Introduction

Recent years have seen a notable increase in women prisoners in Sub-Saharan Africa.¹ Prison conditions in this part of the world are conducive to the spread of infectious diseases such as HIV, tuberculosis, and COVID-19. Zimbabwean prisons are characterized by overcrowding, dated infrastructure, insufficient and intermittent access to sanitation and hygiene, and inadequate nutrition, among other problems.² Regional assessments and in-depth studies have indicated that despite women prisoners being a minority in a male-dominated prison environment, their health rights and those of their children who are incarcerated with them are poorly provided for, if not neglected altogether. Access to pediatric and gender-specific health care continues to be a challenge.³

According to a 2018 briefing paper, “the disparity between what is known and unknown about HIV in Zimbabwean prisons is alarming.”⁴ This is also true of other infectious diseases, such as tuberculosis, which have a longer history of prevalence in prisons and are closely associated with susceptibility to HIV infection.⁵ Women prisoners are at risk of HIV/AIDS since they generally come from communities that suffer poverty, discrimination, marginalization, and social prejudice.⁶ The connection between susceptibility to certain diseases such as HIV/AIDS and the denial of basic rights (such as the rights to equality and nondiscrimination) and other underlying determinants of health creates an imperative for governments to give effect to international human rights norms that help remove barriers to health. This paper analyzes the political commitment of Zimbabwe to address the underlying determinants of health by incorporating into its health laws and policies measures that promote the health rights of women prisoners living with HIV. It centers on the “political epidemiology” of HIV/AIDS in Zimbabwe—specifically the efforts of the Zimbabwean government to comply with international norms that address the social determinants of health of women prisoners.⁷

Zimbabwe is a low-income country, riven with civil unrest and hyperinflation, and home to more than one-third of the world’s population living

with HIV. Yet, thanks to innovative measures and community-based HIV prevention measures, it has achieved considerable success in reducing the prevalence of HIV/AIDS among its population. A significant intervention was the National AIDS Trust Fund (AIDS Levy), set up to fund HIV prevention and treatment.⁸ Between 1997 and 2013, the country achieved a dramatic reduction in HIV/AIDS prevalence, from 29% to 15%.⁹ Changes in sexual behavior among young adults and the roll-out of antiretroviral therapies have also helped. However, the benefits have not been evenly felt. Like other sub-Saharan countries, Zimbabwe has demonstrated gender-skewed infection rates, with women and adolescent girls most at risk of new infections and more vulnerable to HIV infection than males.¹⁰ Women prisoners in particular are especially at risk. Indeed, a 2014 World Health Organization (WHO) report predicted that half of all new adult HIV infections would be concentrated among key populations—men who have sex with men, sex workers, intravenous drug users, transgender people, and prisoners.¹¹

Globally, the number of people imprisoned and detained, including women, has grown significantly, and prison occupancy in most countries exceeds 100%. Until recently, women prisoners worldwide were housed in prisons built for men with few facilities that catered to their needs.¹² In Zimbabwe, as of April 2019, the 46 main prisons—with a capacity for 17,000 people—were accommodating 19,382 prisoners.¹³ Women make up 1.8% of the country’s prison population.¹⁴ There are three women-only prisons (Chikurubi, Shurugwi, and Mlondolozhi); the other prisons have a separate section for women.

The prevalence of HIV/AIDS, tuberculosis, and hepatitis C is generally much higher in prisons than in the general population.¹⁵ HIV prevalence in prisons in Zimbabwe is estimated to be double that of the general population, and higher among women prisoners.¹⁶ The infection rate among male prisoners is 26.8%, compared to 39% among female inmates. According to the Zimbabwe Human Rights Commission, there are serious inadequacies in Zimbabwean prisons, including the poor con-

dition of prison cells, inadequate access to health care, inadequate food supplies, poor diet, poor sanitation, and poor hygiene.¹⁷ Crowded conditions are especially dangerous to women, as they increase their exposure to violence, sexual abuse, and pregnancy and childbirth while in prison.

The “political epidemiology” of HIV/AIDS¹⁸

At a landmark colloquium in 1993, Jonathan Mann (who became the first director of the WHO Global Programme on AIDS), observed that “the critical relationship between societal discrimination and vulnerability to HIV, as well as other health problems, is the central insight gained from over a decade of global work.”¹⁹ According to Mann, it was the violation of fundamental rights that increased susceptibility to this disease. Rights to equality, freedom from discrimination, and basic subsistence were as indispensable to positive health outcomes as access to medical services and medicines. Mann is credited with the fact that “the promotion of human rights became a foundation of the global response to AIDS.”²⁰

In 1994, UNAIDS brought together 10 co-sponsors (UNICEF, UNDP, UNFPA, UNESCO, the World Bank, ILO, UNODC, WFP, UNHCR, and UN Women) to coordinate the global response to the disease, thus highlighting the economic, social, and political determinants of HIV.²¹ Minimizing the risk of HIV/AIDS requires far-reaching political measures to address the social and economic determinants of health, prompting scholars to describe this as the political epidemiology of HIV/AIDS.²² Political epidemiology tracks the way that health is affected by laws, policies, and their implementation and how these might be reformed to produce better health results.²³

Poverty is the single-most significant factor in HIV infection in the developing world, with women representing a greater share of those living in poverty.²⁴ The phrase “feminization of poverty” was coined to highlight this fact. While this is not a new concept, in the HIV/AIDS context it draws attention to the increasing numbers of women suc-

cumbing to poverty, increasing their risk of HIV/AIDS and incarceration. Insufficient “access to resources, lack of political rights, and limited social options” creates fundamental inequalities and vulnerability to poverty and HIV/AIDS.²⁵ Women lack the power to challenge the embedded discrimination of social institutions, from the family to the state.²⁶ In Zimbabwe, the disproportionate numbers of women infected with HIV has given rise to the “feminization of HIV/AIDS.” The factors creating this situation have been identified as “inadequate support infrastructure to women living with HIV, poverty, unfair gender role allocation, segregation and differentiation and the state of patriarchy.”²⁷ These issues cannot be resolved simply by targeting support to women; rather, they require addressing the rights to equality and nondiscrimination, which would result in substantive equality in health. This means that law and policies that address public health and HIV/AIDS need to be inclusive of the needs of women, including women prisoners, a constituency with little political influence to demand improvements to their health conditions. Unfortunately, prisoners are often “demonised by the public,” meaning that there is little public or political interest in protecting prisoners’ right to health.²⁸

Furthermore, health policies in general do not sufficiently cater to women’s sexual and reproductive health (SRH). In prisons, a lack of gender sensitivity leads to the different needs of women with regard to SRH—such as caring for infants and exposure to abuse and violence—being ignored.²⁹ Health care for women in prisons should comply with international human rights and recommendations on health care provision. States’ failure in this respect is a serious breach of women’s human rights and life-threatening for women living with HIV.

The right to health, HIV/AIDS, and women’s health

The WHO Constitution defines health positively as the “highest attainable standard of health for all.”³⁰ A legal obligation to protect a right to health was created in 1966 by the International Covenant

on Economic, Social and Cultural Rights.³¹ However, the implementation of social, economic, and cultural rights was weakened by the covenant's qualification that state parties must undertake to implement these rights only "to the maximum of [their] available resources, with a view to *achieving progressively* the full realization of the rights recognized in the present Covenant."³² The Committee on Economic, Social and Cultural Rights subsequently addressed the right to health and the health rights of women in General Comment 14, issued in 2000, which requires states to monitor the progressive realization of economic, social, and cultural rights and to implement a "core minimum" of each of these rights.³³ The general comment shifted the responsibility for satisfying the "minimum" of core socioeconomic rights to the state. This implies that if the state ignores a certain right, it is that the state rather than the claimant that bears the burden of proof.³⁴

General Comment 14 introduced a "gendered dimension of the right to health" by taking into account differences between men and women with respect to biology, socioeconomic conditions, and situatedness in the home and in society.³⁵ This is significant because scholars have pointed out that "there are critical gaps on normative standards regarding the human rights of women living with HIV in relation to SRH."³⁶ These gaps and other specific health requirements of women were identified and further highlighted by two crucial conferences held in the 1990s. The 1994 International Conference on Population and Development (ICPD) in Cairo and the 1995 Fourth World Conference on Women in Beijing created two programs that brought together human rights language, the underlying determinants of health, and women's reproductive health.³⁷ The ICPD Programme of Action emphasized the interdependence and indivisibility of civil and political rights and economic, social and cultural rights and successfully broadened women's reproductive health to include the "rights to bodily integrity and security of person, to non-discrimination and equality between women and men, as well as socio- and economic rights."³⁸ The Beijing

Platform for Action highlighted the impact of gender inequality, poor health services, nutrition, gender-based violence, sexually transmitted diseases (including HIV), poverty, and powerlessness on women's susceptibility to disease.³⁹ Importantly, one of twelve critical areas prioritized by the Beijing Platform for Action was the "feminization of poverty."⁴⁰

General Comment 14 requires states to have a national health policy that includes "a detailed plan for realizing the right to health" that ensures "equal access for all persons, including prisoners and detainees..., to preventive, curative and palliative health services."⁴¹ For women, this includes interventions to promote SRH, counseling services for diseases such as HIV/AIDS, interventions to improve child and maternal health, family planning, pre- and postnatal care, emergency obstetric services, and access to information. In the context of SHR, the health rights of women living with HIV should be informed by the principles of nondiscrimination, accessibility, informed decision-making, and accountability.⁴²

In Africa, the African Commission on Human and Peoples' Rights has also taken steps to promote the health rights of women and to target the disproportionate effect of HIV/AIDS on women. Its 2001 resolution on HIV/AIDS, "Threat against Human Rights and Humanity," made HIV/AIDS a human rights issue by linking the spread of the disease to discrimination and requiring governments to protect the rights of those living with HIV.⁴³ Furthermore, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol) encourages states to enact legislation to remove practices that have a negative impact on women's rights.⁴⁴ Under this protocol, women's sexual and reproductive health rights include the right to self-protection and the right to information about one's health status and that of one's partner, especially if the partner has a sexually transmitted infection such as HIV.⁴⁵ Additionally, health services should be accessible and include education and information programs.⁴⁶ In two subsequent general comments, the commission

calls on states to implement, in the legislative and policy framework, provisions specific to the HIV/AIDS status of women and women's SRH rights.⁴⁷ In a more recent report, issued in 2018, the commission again highlights concerns about the HIV/AIDS epidemic in Africa, such as limited access to services for vulnerable people, including women.⁴⁸ The report identifies women and prisoners as being among the groups needing specific protection and access to HIV/AIDS treatment and health services.

Health rights under Zimbabwe's legislative and policy framework

Zimbabwean law does not include a health entitlement that can be relied on by the general population (including women prisoners); however, the social determinants of health are recognized in the Zimbabwean Constitution and in the country's health strategies and plans.

The Constitution includes a Bill of Rights with several justiciable socioeconomic rights.⁴⁹ Among these is the right to basic health care services, including reproductive health care services, for all, including people living with chronic illness and anyone needing emergency medical treatment.⁵⁰ The Constitution also gives effect to General Comment 14's aim to protect a "core minimum" of economic and social rights, such as the right to food and water; however, the state's obligation extends to reasonable legislative and other measures within the limits of available resources, to achieve the progressive realization of the rights in this section. In the national objectives of the Constitution, which are not legally binding, the qualification is repeated—that the state's measures to prevent disease will be "within the limits of the resources available to it."⁵¹ This formulation dilutes both the right and the state's obligation. It also weakens the public health commitment in the 2016–2020 National Health Strategy to align the Constitution of Zimbabwe, the government policy blueprint, and the Zimbabwe Agenda for Sustainable Socio-Economic Transformation with international commitments not to divorce the living conditions of people from their health risks and status.⁵²

The Constitution also restricts access to

treatment to citizens and permanent residents, theoretically leaving foreign women prisoners living with HIV no access to programs for the prevention of mother-to-child transmission or HIV/AIDS and related opportunistic infections.⁵³ This policy is not in line with international standards—and a similar policy in Botswana did not withstand a legal challenge before a domestic high court. In a 2014 judgment, two Zimbabwe nationals incarcerated in Botswana won the right to receive highly active antiretroviral therapy, which is more effective than conventional treatments in treating HIV-related opportunistic infections.⁵⁴ The claimants were initially left out of the treatment program on account of their foreign status. The court held that the right to life enshrined in the International Covenant on Civil and Political Rights encompasses the right to health in the International Covenant on Economic, Social and Cultural Rights.⁵⁵ The "judgement emphasised the universality, indivisibility, interdependence and interrelated nature of all human rights."⁵⁶ The court included in its reasoning public interest considerations:

It can never be in the public interest nor can it ever be reasonably justified in a democratic society like ours that the provision of life-saving medication like highly active antiretroviral therapy is withheld with the ultimate result that the group of people so deprived becomes more infectious to others or die in our hands.⁵⁷

The state is responsible for the health of prisoners. If SRH services should be made available to foreign prisoners (for example, Zimbabwean nationals) in Botswana jails, it would be difficult to argue that withholding this treatment from foreign women prisoners in other African jails, including Zimbabwe's, would not be a violation of the right to life.

The 2018 Public Health Act of Zimbabwe seeks to align public health laws with the Constitution.⁵⁸ The preamble of the act states that its aims are "to provide for public health" and "for the conditions for improvement of the health and quality of life and the health care for all people in Zimbabwe"; respect for human rights; the adherence to rights and responsibilities; the promotion of justice, eq-

uity, and gender equity; and “the best interests of vulnerable groups.”⁵⁹ However, the act does not incorporate a rights-based framework consistent with the Constitution to protect health rights, to ensure health equality by addressing the specific health needs of women, or to include international law obligations for women with HIV/AIDS. It also does not address the rights of vulnerable groups such as prisoners.

The Zimbabwean government has addressed HIV/AIDS through several national strategic plans. The second Zimbabwe National HIV and AIDS Strategic Plan (ZNASP II), for 2015–2018, included women prisoners among the groups most vulnerable to HIV/AIDS. The plan dealt with the elimination of mother-to-child transmission and made reference to the prevention of mother-to-child transmission for women in prisons.⁶⁰ The current plan, ZNASP III, for 2015–2020, adopts a rights-based approach. It focuses on key populations (such as prisoners, people with disabilities, youth, women, children, and others who may be socially excluded) to ensure the reduction of new infections.⁶¹ ZNASP III is committed to the elimination of mother-to-child transmission to reduce maternal and child mortality rates.⁶² It “recognizes the human rights and non-discrimination of PLHIV” and notes that HIV/AIDS services must be gender sensitive across all key priority areas.⁶³ This includes the provision of comprehensive care, treatment, support, and follow-up for women living with HIV, their infants, and their family (including male partners). ZNASP III also recognizes that prisoners are a key population group vulnerable to infection and allows for informal lobby groups for prevention activities to address HIV/AIDS prevention and education in prisons.⁶⁴ However, a serious omission in ZNASP III is its failure to address the health needs of women prisoners living with HIV. Even when prisoners as a group are specifically addressed, the SRH of women prisoners are ignored.

Unlike ZNASP II and III, the 2016–2020 National Health Strategy does not address the issue of HIV/AIDS in prisons. Although women are mentioned in the strategy, the neglect of prisoners generally and women prisoners specifically shows

the failure of the strategy to adopt an intersectional approach.

Nondiscrimination provisions in international and regional law

Nondiscrimination and equality provisions in international and regional treaties provide the basis for state parties to eliminate health-related discrimination against women living with HIV and, by extension, women prisoners living with HIV.

Formal equality between men and women enshrined in international human rights law does not result in substantial equality in health, since the latter necessitates differential and appropriate health provisions that take into account women’s SRH.⁶⁵ The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) addresses some of the legislative measures needed to ensure substantive health equality for women.⁶⁶ CEDAW’s article 12, on the right to health, includes SRH; family planning services; services relating to pregnancy, confinement, and the postnatal period; and adequate nutrition during pregnancy and lactation.

CEDAW includes elements of both civil and political and economic, social, and cultural rights for women. By and large, the treaty retains the distinction between the two. Civil and political rights are immediately effective, while economic, social, and cultural rights are to be progressively realized within the “maximum available resources.”⁶⁷ This weakens states’ obligations to prioritize gender-appropriate health measures for women. However, two further recommendations by the Committee on the Elimination of Discrimination against Women clarify the duties of states with regard to the health of women living with HIV. General Recommendation 15 requires state parties reporting on health rights to explain the actions taken to stop discrimination against women living with HIV and to provide for their health needs. States’ reports should include measures taken to address both biological and socioeconomic issues affecting women’s health, including menstruation, reproductive function and menopause, risk of exposure to sexually

transmitted infections, the subordinate position of women in the home and workplace, women's nutrition and health, gender-based violence, early pregnancy, and genital mutilation.⁶⁸

Meanwhile, General Recommendation 24 affirms that access to health care, including SRH, is a basic right of women, and it includes the issues of HIV/AIDS and other sexually transmitted infections within the scope of the right to sexual health.⁶⁹ Significantly, the recommendation requires that a "gender perspective" be mainstreamed into all policies and programs affecting women's health and emphasizes the needs of women who are vulnerable and disadvantaged.⁷⁰

The Maputo Protocol also takes a robust approach to health equality to address the high HIV prevalence among African women. Article 1 states that "any form of distinction, exclusion, or restriction or any differential treatment based on sex and whose objectives or effects compromise or destroy the recognition, enjoyment or the exercise by women in all spheres of life."⁷¹ Moreover, the African Commission has published two general comments providing a much-needed level of specificity for states' obligations regarding women's health. General Comments 1 and 2 oblige states to address the roots of discrimination, social inequality, and gender stereotypes; to examine the role and reach of educational and information programs to make women aware of their health rights; and to address health issues specific to SRH.⁷²

Nondiscrimination and equality under Zimbabwe's legislative and policy framework

The Constitution of Zimbabwe includes an equality right for women similar to those enshrined in the International Covenant on Civil and Political Rights and the African Charter.⁷³ It prohibits laws, customs, traditions, and cultural practices that infringe on the rights of women.⁷⁴ As mentioned earlier, the Constitution mentions SRH only for citizens and permanent residents of Zimbabwe. However, no secondary legislation has been enacted to implement the provisions of the Constitution, the Maputo Protocol, or the African Commission's general comments, creating serious difficulties for

women prisoners, who are in a weaker position to demand health services adequate to their needs.

Health rights in prison and the health needs of women prisoners living with HIV

Treating HIV/AIDS in prisons has proved promising, but the rollout of antiretroviral therapies for persons living with HIV faces barriers in prison settings.⁷⁵ Prisons are not well resourced to provide complete treatments for anti-tubercular therapy or antiretroviral therapy for inmates with HIV-associated tuberculosis.⁷⁶ Gaps in the treatment regime for HIV can lead to resistance to first-line medications, making treatment more difficult and expensive in the long term.⁷⁷ Also, antiretroviral therapies are unlikely to produce expected health outcomes if the health of prisoners is compromised by "poor nutrition, substandard prison conditions and violence," as is the case in Zimbabwe.⁷⁸

Frequently, inmates do not know their HIV status, and their health issues remain undiagnosed. Therefore, prison health screening upon entry is indispensable for effective treatment. However, inmates, even if aware of their HIV status, are often unwilling to disclose it for fear of discrimination by other inmates and prison authorities.⁷⁹ Even though prisons might be the only point of access to health services for many detainees, prisons are often not trusted to carry out non-coercive testing programs, get consent for testing, respect confidentiality, or keep proper records. This is not to underestimate the difficulties inherent in the ethics of treatment. For example, informed consent assumes that the detainee has a comprehension capacity to understand the social and medical implications of testing positive for HIV, but the capacity for comprehension among incarcerated populations generally, is often diminished "due to low literacy, mental illness, substance abuse and other factors."⁸⁰

Few international standards seeking to protect the human rights of prisoners are binding, but they do set minimum requirements.⁸¹ Key among these instruments are the United Nations Standard Minimum Rules for the Treatment of Prisoners, which address the accessibility of health care; pa-

tients' rights and medical ethics; proper medical services from qualified staff; and the duty of the prison authorities to undertake inspections that ensure nutrition, hygiene and cleanliness.⁸² Other instruments include the *WHO Guidelines on HIV Infection and AIDS in Prisons* and the *International Guidelines on HIV/AIDS and Human Rights*, which were developed to stop the spread of infectious diseases in prisons.⁸³ In 2010, the United Nations issued a supplement to the aforementioned Standard Minimum Rules, entitled the United Nations Rules for the Treatment of Women Prisoners and Non-custodial Measures for Women (Bangkok Rules), detailing the health needs of women prisoners and women living with HIV.⁸⁴ These rules prescribe differential health provision for women pertaining specifically to SRH.⁸⁵ In addition, the health screening of women prisoners should include (voluntarily) the patient's reproductive history; drug dependency; and any previous sexual abuse or violence she may have suffered.⁸⁶ To stop the abuse of women prisoners, the rules prescribe proper, independent investigative processes and redress.⁸⁷ They also address HIV/AIDS, the prevention of mother-to-child transmission, and preventative measures for sexually transmitted infections. Aware of the stigma that HIV carries—which might prevent detainees from seeking treatment—the rules require that training for prison staff include gender and human rights.⁸⁸

Finally, at the regional level, the Southern African Development Community has developed the *Minimum Standards for HIV and AIDS, TB, Hepatitis B and C, and Sexually Transmitted Infections Prevention, Treatment, Care and Support in Prisons in the SADC Region*, which require a political commitment to ensure that prisoners' health is comparable to that of the general population and to implement national AIDS programs in prisons.⁸⁹ These standards include references to the abuse of women in prisons and the need to investigate and address claims of abuse.⁹⁰

Health rights in prison and the health needs of women prisoners living with HIV in Zimbabwe
Zimbabwe provides for the health of prisoners in

the Prisons Act 2018 and the Ancillary Prisons Regulations 2011.⁹¹ The treatment and health of prisoners is mainly in the hands of a medical officer appointed at the discretion of the minister for prisons and correctional services, whose role is to oversee the health of prisoners and report on the treatment of prisoners that might require consideration on medical or health grounds.⁹² The Prisons Act does not prioritize the health of prisoners or the conditions in prison that have an impact on health. No mention is made of the health requirements of women prisoners. Indeed, international and regional guidelines on prisoners' health and rights do not seem to have found their way into Zimbabwean legislation. The regulation dealing with HIV/AIDS is the National Aids Council of Zimbabwe Act, which established the National AIDS Council to administer and coordinate the national response to combat HIV/AIDS.⁹³ There is nothing else in Zimbabwean legislation that deals with HIV/AIDS and related aspects in prisons.

The absence of legislation that might cover the health of prisoners and SHR for women prisoners means that there is weak protection for women prisoners affected by HIV/AIDS. However, women prisoners might have an alternative legal avenue in the Zimbabwe Human Rights Commission, as this body is tasked with overseeing the promotion, protection, and fulfilment of human rights. Through its Monitoring and Inspections Unit, the commission has the authority to inspect the conditions of prisoners and all detainees, including refugees, and make recommendations concerning human rights standards in places of detention.⁹⁴ The commission benchmarks its observations against constitutional provisions on the right of detained persons to be treated humanely; the Prisons Act; and international law provisions (such as the prohibition of torture and degrading treatment or punishment, and the right to food and water). As an independent body, the Zimbabwe Human Rights Commission can shine a light on the health conditions and needs of women prisoners living with HIV. Unfortunately, the commission's powers, when the rights of detainees are violated, is restricted to making recommendations; therefore, its authority to protect

the health rights of women prisoners living with HIV is not very strong.

Conclusion

The global effort to reduce HIV/AIDS has been successful: the world has seen a 35% decline in HIV-related deaths and a 38% decrease in new HIV infections since its peak in 1998.⁹⁵ The recognition that HIV is more lethal to poor and marginalized communities has encouraged the United Nations and regional bodies to develop standards and practical guidance on how to respond to the health needs of women prisoners living with HIV. From the 1990s onward, health entitlements for women have included SHR, gender inequality, and access to specialized services in health.⁹⁶

Unfortunately, as evidenced by our analysis of Zimbabwe's legal framework,

these developments have not resulted in a significant shift in the country's laws to prioritize the health rights of women and the protection of women prisoners living with HIV. Zimbabwe has made an effort to adopt a "human rights, evidence and results-based approach" in its national HIV/AIDS response. This national strategy recognizes that the "fulfilment of human rights can only be achieved if there are adequate and relevant policies and legislation that enhance universal access to HIV/AIDS, and health services, gender equality and sensitivity of response, reduction of stigma and discrimination in all settings." Further, it aligns with national, regional, and international policy frameworks on the attainment of universal health care.⁹⁷ However, this strategy has not translated into provisions that are legally enforceable.

The enactment of the Public Health Act in 2018 provided an opportunity for the government to align the law with the 2013 Constitution, which enshrines a right to health. The act gives effect to the Constitution to protect, improve, and maintain the health of the population, including by preventing the spread of infectious diseases.⁹⁸ However, the act fails to provide stronger rights-based language related to health rights, particularly clauses relating to the prevention and containment of HIV among

women in prisons. Given the obvious and unique challenge of high numbers of people living with HIV in the country, it would have been desirable to have specific and robust provisions to address this pandemic. In addition, it is difficult for the Ministry of Health and Child Care to give effect to disease prevention provisions of the act at the administrative and operational level given the thin budget allocations in this regard.

In general, the health strategies adopted by Zimbabwe purport to take a human rights-based approach to HIV/AIDS and gender inequality, which is fundamental to preventing new infections. However, this approach needs broadening out to include prisons if it is to directly address women prisoners living with HIV.⁹⁹ So far, only one of the country's national strategies specifically mentions prisoners as a vulnerable group. Also, it is necessary to track the prevalence and incidence of HIV/AIDS in prisons, especially among women prisoners, so that the reach and effectiveness of national health strategies can be evaluated for its impact on this marginalized population. These gaps in Zimbabwe's health laws and policies regarding the SRH of women has an adverse impact on the health of women prisoners living with HIV.

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Fault Lines of Refugee Exclusion: Statelessness, Gender, and COVID-19 in South Asia

ROSHNI CHAKRABORTY AND JACQUELINE BHABHA

Abstract

Despite widespread recognition of the right to a nationality, statelessness and its attendant vulnerabilities continue to characterize the lives of millions in South Asia. During the onset of the COVID-19 pandemic, when states turned inward to protect their own citizens, refugees and de facto stateless persons found themselves excluded from humanitarian services and health care and were denied the ability to claim rights. Stateless women faced the additional burden of gender-based violence, a hostile labor market, and the threat of trafficking. This paper analyzes gender and statelessness as vectors of exclusion in South Asia, where asylum seekers are neither recognized by law nor protected by social institutions. We argue that citizenship constitutes an unearned form of social capital that is claimed and experienced in distinctively gendered ways. The pandemic has shone a bright light on the perils of statelessness, particularly for women, who face exacerbated economic inequities, the forced commodification of their sexuality, and exclusion from mechanisms of justice.

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Introduction

Far from being “great equalizers,” diseases reflect and reinforce preexisting hierarchies. Structural inequalities in wealth, housing, health care, employment, and social capital place the poor and the socially vulnerable at a higher risk of infection and death. At the same time, the fear and suspicion engendered by epidemics exacerbate the vulnerabilities of those perceived as “other” or “outsiders,” populations whose survival and dignity are already compromised by social exclusion mechanisms such as legal invisibility, geographic ghettoization, and social ostracism. For refugees resettling in South Asia, our area of focus in this paper, these forms of marginalization are an everyday reality. The denial of a viable and effective legal identity precludes the ability to even *claim* rights in states that already fail in their obligations to provide them.¹

Citizenship, in both its legal and social sense, represents, we argue, an unearned form of social power and capital. Where, as is the case in India, Pakistan, and Bangladesh, prevailing international law protecting refugees has not been ratified, forced migrants are left without the secure legal status awarded to recognized refugees, a deficit that magnifies the challenge of accessing state protection and securing social capital within the host community. The status of these forced migrants is thus best captured by the notion of *de facto* statelessness, which signals their lack of access to the protective responsibility of any sovereign nation. *De facto* statelessness in South Asia is a perilous status at the best of times, given the central role of the state as a dispenser of fundamental services and protections. It is a particularly challenging status during a global pandemic such as COVID-19, when hostility toward outsiders is exacerbated, the availability of essential humanitarian services is compromised, and an informal labor market generating subsistence income is brought to a halt.

To the impacts of *de facto* statelessness must be added those of other critical social determinants of health and well-being, including gender, which intersect to multiply the risks of stigmatization and exclusion. The entrenched exploitation and

control of female sexuality, as a commodity to be exchanged or dominated, accelerates during times of distress, as it has during this pandemic. This paper explores the gendered impact of COVID-19 on forced female migrants in South Asia, who already face strong exclusionary pressures because of their status as noncitizens of the broader polity.

Citizenship, statelessness, and gender

Theoretical framework

Citizenship is a status outside the reach of refugees in South Asia. The refusal of India, Pakistan, and Bangladesh to ratify the 1951 Refugee Convention, the primary and widely ratified international legal instrument for refugee protection, or its 1967 Protocol, denies asylum seekers in those three countries the opportunity to qualify for the legal status (and related documentary proof) of refugees. Instead, they are relegated to the precarious and degraded status of “illegal immigrants.” This protection deficit deprives these forced migrants of critical rights enshrined in these conventions, including protection from *refoulement* (return to a place where they fear persecution) and the rights to work, study, and receive public assistance.² Moreover, because these migrants lack access to a protective state, they are *de facto* stateless, even though they may have a *de jure* (legal) nationality.³ Both *de facto* and *de jure* stateless people are unable to access the privileges, services, protections, and rights that citizens can demand from their states. The denial of refugee status (with the future prospect of a path to permanent residence and thence citizenship) erects an impenetrable barrier between undisputed members of the collective and such “outsiders.”

This barrier extends beyond status and documentation. In his classic work on the topic, T. H. Marshall describes citizenship as a multilayered “status bestowed on those who are full members of a community.”⁴ Christian Joppke expands on this conception by exploring the complex interplay between status, rights, and identity embedded in our notions of citizenship today.⁵ The status affords formal and legal membership in a state; the rights generate the

ability to assert legitimate claims to the protection and services of the state; and the identity imparts a sense of social membership within a collective. Pregnancy and motherhood, for example, generate distinctive claims on state protective services, as does gender-based violence. Citizenship deficits affect women and men differently. Citizenship is also experienced and claimed in gendered ways. Because women are essential to the reproduction of the nation, and therefore represent it biologically and culturally, their bodies are prime targets for domination and destruction in times of crisis.⁶ The history of sexual violence in the context of conflict illustrates this point vividly: women's bodies are often the terrain on which enemies are subjugated and the superiority of nations claimed through the assertion of brute masculinity. The experience of Rohingya refugees from Myanmar, of whom over a million are now living as (legally) stateless persons in Bangladesh, is a powerful case in point. Thousands of Rohingya women were brutally raped by Myanmar security forces in "clearance operations" in 2016–2017.⁷ A report by Human Rights Watch and Fortify Rights argues that humiliation and cruelty were key elements of this systematic campaign of sexual violence. Not only were women assaulted, but their genitals were mutilated, their breasts were slashed off, and their children were murdered in front of them. Of the rape cases found by a Human Rights Council mission, 80% were gang rapes.⁸ However, it would take more than migration to Bangladesh to escape the violence. Between August 2017 and March 2018, a total of 6,097 incidents of gender-based violence were reported in the refugee camps in Cox's Bazar, which remain a hotbed of violence against women.⁹

To this traumatic history is added, now, the impact of restrictions and isolation generated by official responses to the COVID-19 pandemic. Women and girls in communities of forced migrants are—even more than their non-displaced female peers—at risk of violence and abuse in communities where hardships, lack of services, and the absence of mobility and distraction compound preexisting stressors. We explore these themes in more detail in what follows.

Refugees in South Asia

The plight of refugees in South Asia is determined by complex systems of registration and highly politicized asylum processes, generating different levels of access to state protections.

Bangladesh is home to over 1.2 million stateless Rohingya refugees from Myanmar who, legally, fall under the Foreigners Act of 1946, which classifies those who have entered without proper travel documents as "illegal migrants." In 2015, Bangladesh and the United Nations High Commissioner for Refugees (UNHCR) began registering these Rohingya asylum seekers as "forcibly displaced Myanmar nationals"—not a robust legal status (and certainly a far cry from registered Convention refugee status) but preferable in terms of access to critical services and legal documentation to the "illegal" status that the 250,000+ unregistered Rohingya occupy.¹⁰ Unregistered Rohingya live in informal camps and face much greater difficulty accessing the rather minimal health care and education that their registered peers have access to.¹¹ One study found that unregistered children were 10 times more likely to be working than those registered and living in formal camps, and that 86% of unregistered refugees—double that of registered refugees—reported food shortages.¹² The difference in status (and, consequently, socioeconomic conditions) between registered and unregistered Rohingya, both of whom remain stateless, demonstrates the importance of access to a legally recognized registration process.

India hosts over 200,000 refugees, a majority (60%) of whom are Rohingya, followed by Afghans and Sri Lankans. These refugees, too, are classified as "illegal migrants" under the Indian Foreigners Act of 1946, which gives expansive powers to the state to expel or detain those who enter without valid travel documents, directly repudiating the core Refugee Convention principle of non-refoulement. Because of the absence of a binding international legal framework, geopolitical considerations rather than humanitarian norms dictate how refugees in India are treated. For example, Tibetans fleeing the 1959 Tibetan uprising were granted asylum and given all the rights of refugees, while Sri Lankan Tamils

fleeing that country's brutal and prolonged civil war were placed and remain in heavily monitored camps.¹³ The denial of refugee status and the refusal of the Home Ministry to accept papers issued by UNHCR has blocked refugees' access to schools and universities, formal employment, housing, official sources of borrowing, and state services.

Pakistan has received over 2.4 million Afghan refugees, of whom 1.4 million are registered by UNHCR and 1 million remain unregistered. Registered Afghan refugees are entitled to a renewable Afghan Proof of Registration card that affords them temporary legal status within Pakistan. As is often the case for vulnerable minorities, the enabling aspects of the registration system exist in tension with a darker state goal. Sanaa Alimia argues that these "ID cards for Afghan refugees are a tool of surveillance that facilitates ... social and physical exclusion."¹⁴ Once the Proof of Registration card expires, the benefits associated with it—namely, the right to a temporary legal stay in Pakistan and protection against refoulement—do too, but the surveillance capabilities it affords do not. The process of applying for an extension is random and opaque, making the cardholder "illegal" for long periods during which he or she is at risk of violence and extortion by state officials.¹⁵ In 2016 and 2017, Pakistan forcibly repatriated 365,000 of the country's registered refugees and 200,000 of the unregistered refugees, in what Human Rights Watch called "the world's largest unlawful mass forced return of refugees in recent times."¹⁶ For refugees in Pakistan, COVID-19 is a legal existential threat—their very presence in Pakistan hangs in the balance, and many have expressed fear of being forcibly returned to Afghanistan despite the continuing violence because of the severe difficulties they face in renewing their registration cards. In August 2020, these "voluntary" repatriations were restarted.

Refugees, migrants, and minorities as the "other"

Throughout history, epidemics and disease have brought with them the intensification of prejudice.

Recent scholarship has focused on how epidemics are not just health-related phenomena but social and intellectual *constructs* that "[illuminate] wider relationships between social groups and between state and society."¹⁷ As fears about contamination and infection spread, those who are marginalized easily become the prime suspects in the witch-hunt to find the vectors. In tracing the social history of epidemics, Paul Slack finds exactly this need to isolate and accuse:

*Carriers of disease were identified and scapegoats stigmatised: foreigners most often ... since epidemic disease came from outside, but also inferiors, carriers of pollution of several kinds, among whom disease had its local roots.*¹⁸

In South Asia, the perception of the refugee and migrant as dirty and contaminated draws on a long history. During the plague in the early 20th century, those who fled from infected towns such as Bombay (present-day Mumbai) were blamed for spreading what was essentially an urban disease to the rest of the country. It was untouchables, migrants, and other groups considered deviant who were most likely to be reported to authorities because of suspected sickness.¹⁹ Studies of HIV/AIDS-related stigma have documented animosity not only toward sex workers but also toward truck drivers, migrant laborers, illegal migrants, and others whose mobility was blamed on them because they were allegedly "not satisfied with what they had at home."²⁰

A narrative about the "foreigner" spreading disease has dominated South Asian popular discourse during the COVID-19 pandemic. In 2020, several reports claimed that Rohingya refugees were deliberately infected and sent to different parts of India as agents of an Islamic conspiracy to spread COVID-19. The Home Ministry wrote a directive to all states in India directing them to track and screen Rohingya refugees because some were suspected of attending the congregations blamed for spreading the virus, although no proof of this has been found.²¹

Rohingya refugees in Bangladesh have faced similar scapegoating in the last few months,

shunned as “unclean” and vilified for allegedly spreading the disease. Chowdhury Rafiqul Abrar, a professor at Dhaka University, has noted the irrationality of this “virus spreader” allegation, given the two-month gap between Bangladesh’s first case (on March 8, 2020) and the first case in Rohingya camps (on May 14, 2020).²² In Bangladesh, newspapers have carried headlines about COVID-19 cases in Rohingya refugee camps, accompanied by assertions that “locals [are] in panic.”²³ These responses to COVID-19 are part of a long history where states shirk public health responsibility and direct fears and blame in an outward direction.

COVID-19: The South Asian context

Though the virus has transcended borders and affected people of all nationalities, ethnicities, and genders, some populations, such as African-Americans in the US, caregivers, and nursing home residents, have been far more affected than others.²⁴ Globally, the risk of contracting the novel coronavirus is similar for men and women, though mortality rates have been higher for men in most contexts.²⁵ Scientists have explored the reasons for these disparities by examining differences in the immune system, hormones, preexisting health conditions, and social determinants of health, such as help-seeking patterns, nature of employment, cultural practices, and, access to testing.²⁶

Given the low levels of testing, it is tough to determine the direct health impacts of COVID-19 on refugee populations. In Bangladesh, as of September 27, 2020, there had been 4,721 confirmed cases in Cox’s Bazar, and as of the end of October 2020, 336 cases across the 34 refugee camps.²⁷ One study projected that the introduction of a single case into the Cox’s Bazar camps would lead to at least 1,000 people infected, even in the best-case scenario, prompting activists and aid workers to warn that low reported infection numbers reflect low testing, not a low incidence of COVID-19.²⁸ Another found that 25% of refugees reported at least one symptom of COVID-19.²⁹ Of the confirmed cases within the camps, 73% were male and 27% were female. Of the nine deaths, however, six were female and

three were male. This likely indicates that women are being tested at far lower proportions and only in critical cases. The desire to avoid health care providers is evidenced by the fact that 42% of those who sought treatment for COVID-19 had first tried to treat themselves at local pharmacies.³⁰ Moreover, health-seeking behaviors and decision-making reflect gendered dynamics: 61% of women reported needing the permission of a male member of the household to access health services when they exhibited symptoms of COVID-19.³¹ Medical facilities are not sufficient, either, with only 1 intensive care unit, 34 isolation beds, and 2 ventilators serving all the people in Cox’s Bazar.³² Afghan refugees in Pakistan have seen a similar trend, with only 18 refugees testing positive but 5 of them dying.³³ The high fatality rate indicates a hesitance to seek medical services and testing except in the most critical of cases. In India, the limited mandate of the UNHCR and the limits on nongovernmental organization (NGO) staff who are not listed as “essential services” prohibit them from administering expansive health services for refugees or collecting data about the prevalence of COVID-19.

Refugees may also have co-morbidities that place them at higher risk of COVID-19. Infectious diseases disproportionately affect crowded refugee camps, with the camps in Cox’s Bazar only recently recovering from cholera and diphtheria outbreaks. Refugees have much higher rates of malnutrition and anemia, which reduce the ability of the immune system to fight diseases. In one study of Rohingya children in Bangladesh, 43% had chronic malnutrition, 24% had global acute malnutrition, and 48% had anemia.³⁴ Both anemia and malnutrition have been found to be associated with an enhanced risk of severe COVID-19 infections, showing the direct health impacts of their socioeconomic conditions.³⁵

Epidemiological statistics have to be evaluated in tandem with data on the gendered dimensions of the pandemic. The virus may not actively target women, but its impacts magnify preexisting inequities and expose fault lines that existed before the pandemic. Women in South Asia are more likely to be engaged in informal work with no job or wage security, a situation that has forced them to

accept lower wages and longer working hours.³⁶ As hunger and unemployment increase, malnutrition is set to become a major concern for girls, whose access to food is already lower than that of boys. The halting of girls' education and an increase in child marriage are two additional concerns, because impoverishment typically entails prioritizing resources for males and commodifying females to preserve family resources. As the mother of a 13-year-old girl explained to the Indian nonprofit organization Aangan, "We have no income in this lockdown but we still have expenses. Since Jyothi is young we will have to pay less money to the groom's family if we fix her marriage now."³⁷

These effects are felt even more intensely by refugees, the majority of whom in South Asia are de facto stateless, legally invisible, and severely disadvantaged in their capacity to claim their rights. Refugee women have been exposed to increased sexual violence in the camps alongside the reduction of crucial NGO services.³⁸ Isolation and stress have exacerbated domestic violence and child maltreatment.³⁹ Historically, the trafficking of women and children is known to have increased during times of crisis and heightened poverty, and is likely to do so during this pandemic, too, given the protection deficit that refugees face. Below, we argue that the combination of de facto statelessness, the deprivation of access to the protective resources of the state, and the impact of long-standing exploitative control of female sexuality generate profound and underestimated elements of pandemic-related threat to refugees in South Asia.

Gendered human rights violations among South Asia's refugees during COVID-19

COVID-19 has intensified the gendered vulnerabilities of displaced and marginalized women, as the fears and restrictions related to the pandemic response exacerbate social, political, and intra-household inequities. With the risks that come from legal invisibility and gendered subordination both within and outside their families and refugee communities, stateless women in South Asia are experiencing the fallout from COVID-19

in a distinctively stressful way.

Economic distress

As elsewhere, in the refugee settlements in South Asia, the risks of contracting COVID-19 have much to do with employment and economic status, and their knock-on effects on residential conditions. Refugees are compelled to work in the informal sector because their legal status prohibits employment. For women, the daily wage labor that they are typically employed in, whether agricultural or sweatshop or construction based, affords no opportunity to maintain social distance or accumulate savings. Informal workers—the vast majority of the working poor in South Asia—cannot afford to stay away from work for long and are much more likely than their more affluent and educated counterparts to be engaged in work that cannot be done remotely.⁴⁰ With social protection safety nets nonexistent for large numbers (as explained below), not working means destitution, with the nutritional and other health risks associated with it. In India, those Rohingya women who work are exposed to hazardous conditions. In Delhi, for example, particularly in the Kalindi Kunj camp, hundreds of women work as waste pickers sorting potentially hazardous medical waste, dangerous under any circumstance but far more so during a pandemic.⁴¹

In Bangladesh, too, stateless Rohingya, denied the legal right to work within the society, nevertheless face a compulsion to work determined by the modalities of aid distribution. Only refugees who are registered with the UNHCR are eligible to receive aid (including food, health services, and education) and to live in official camps. Unregistered Rohingya live in informal camps and face much greater difficulties in accessing health care and education.⁴² Not only are they forced to work to purchase food and health care because they are neither eligible for public assistance nor for aid, but they also have little option but to accept submarket wages, as their illegality dampens their bargaining power. Some stateless families feel compelled to rely on the labor of their children. Children outside the registered camps are 10 times more likely to be working than those in formal camps, with over

20% of unregistered families reporting that their children have to work instead of being in school.⁴³

Economic distress causes other forms of gendered discrimination. For example, activists have been warning about an increasing gender gap in education. Prior to the pandemic, only 18% of Afghan refugee girls were enrolled in schools—half the enrollment rate of boys (39%) and less than half the attendance rate for girls in Afghanistan in the same year—with families saying that they would prioritize the education of their boys over their girls.⁴⁴ This pattern of discrimination is not limited to education. In Afghanistan, where women and girls are much more likely to suffer from malnourishment and nutrition deficiencies, studies have found that male members of the household receive bigger portions and that families feed their sons better than daughters when resources are limited.⁴⁵ COVID-19 makes resources even more scarce, and it is likely that girls' education, nutrition, and well-being more generally will be sacrificed to ensure priority for male family members.

Limited access to health care

Statelessness not only exacerbates the risk of infection; it further limits already constrained options for access to medical care, including maternal and child health. With pre-pandemic rates of stillbirth reportedly as high as one in every five deliveries in some Indian refugee camps—10 times the national stillbirth ratio of 22 per 1,000 births—the prognosis is deeply concerning.⁴⁶ High rates of malnutrition, severely inadequate maternal and child health services, and transport restrictions are likely to negatively affect a whole generation of Rohingya women and children in India and Bangladesh. Maternal health care is also seriously deficient for Afghan refugee women in Pakistan who are not entitled to any form of subsidized medication.⁴⁷ Even before the pandemic, Pakistan had one of the highest maternal mortality rates in the world. A 2009 study found that 41% of deaths among women of reproductive age are due to maternity-related causes, 92% of which are preventable. Only 18% of deliveries are attended by medical personnel.⁴⁸ Now, with no particular attention to the acute needs of

some constituencies, maternity wards have been closed in Islamabad and Khyber Pakhtunwa, where the refugee population is concentrated.⁴⁹

In Bangladesh, the enforced ghettoization to which the Rohingya community has been subjected is cited by Rohingya women as one of the major barriers to seeking maternal health care, and a central reason for high levels of home delivery in unsafe and unhygienic conditions. The United Nations Population Fund estimates that only 22% of deliveries in Rohingya families occur in health facilities. Unregistered refugees face even greater challenges. Even before COVID-19 amplified their vulnerability, unregistered families faced higher rates of child labor, far lower numbers of supervised deliveries, and ubiquitous food shortages.⁵⁰ Before the pandemic, 86% reported food shortages, double that of registered Rohingya, raising concerns about malnutrition, which increases the risk of COVID-19 infections and death. Unregistered mothers are unable to obtain birth certificates for their children or to register them. Without appropriate state intervention to ensure birth registration and access to birthright citizenship if needed, the deficits of statelessness can, like a genetic disability, be transmitted from one generation to the next. The effects of these status differentials due to registration have become increasingly apparent, and unregistered Rohingya women and children will bear a greater burden of the fallout from COVID-19.

In Pakistan, pandemic-related lockdowns have operated as de facto regimes of incarceration, reminiscent of Giorgio Agamben's states of exception in which law is indefinitely suspended.⁵¹ Afghan refugee villages in Lower Dir and Nowshera exemplify this oppressive dynamic. In the early months of the lockdown, they were completely shut down so that the forcibly contained refugee population was placed in quarantine, with the army guarding all entry and exit routes. Medical stores, bazaars, and food stores were closed.⁵² The age-old trope of exiling the "other," identified as contaminator par excellence, has been reenacted with a vengeance. The enclosure of refugees in areas that no longer have regular access to food and medicine demonstrates the extent to which refugees have been

stigmatized.

Sexual and gender-based violence

The lockdowns imposed to halt the spread of COVID-19 have also taken a heavy and violent toll on the mental health of affected constituencies. Isolation accelerates stressors across a range of vectors, and research has shown that contextual stressors that create disadvantages for men within the family, such as losing breadwinner status, can “[influence] individual behavior by reinforcing traditional symbolic structures of male dominance and thus [motivate] violent behavior among men.”⁵³ Reports documenting this familiar dynamic of violence as a male coping mechanism are proliferating. In Cox’s Bazar, where over 1.2 million Rohingya refugees from Myanmar are accommodated in overcrowded and highly unsanitary camps, the lockdown has been accompanied by an increase in gender-based violence. Hundreds of incidents were reported each week during the early weeks of the pandemic in March and April 2020.⁵⁴ Spousal abuse, in particular, has risen steeply, accounting for 76% of total reported cases of gender-based violence in Cox’s Bazar.⁵⁵ In a Bangladesh situation report published in August 2020, UNHCR reported a backlog of 5,000 child protection cases, most of which were registered after the pandemic response. It found that refugee children were exposed to heightened levels of abuse and neglect and were being pressured to work because of dire financial circumstances.⁵⁶ For stateless women and children, however, reporting crime carries the risk of being charged with illegal entry under the Foreigners Act. Thus, Rohingya women are trapped in a situation where their perpetrators have de facto immunity while they are de facto rightless.⁵⁷ The exclusion of stateless Rohingya women and children from public protections and laws available to the majority population in Bangladesh places them at greater harm.

Violence is a product of stressors, triggers, and spatial conditions that allow the abuse to occur. The pandemic lockdown has forced abusers and victims into isolation together in small living spaces, allowing abuse to go unchecked and unseen. The 2019 Joint Response Plan by UNHCR cites congestion

as the central challenge in Cox’s Bazar, finding that refugees living in close proximity are at heightened risk of communicable diseases, fires, and domestic and sexual violence.⁵⁸ In some camps, the surface area is as little as 0.63 square meters per person, while in Kutupalong it is 10.7 square meters, far below the Sphere recommended shelter standard of 30 square meters.⁵⁹ Sexual violence outside the household is also aggravated by flaws in refugee camps’ design, with women voicing complaints about a lack of adequate lighting and toilet-door locks that have long rendered camp sanitary facilities sites of gender-based violence. Women interviewed by the International Organization for Migration said that they used to access water and hygiene facilities at strategic times, such as when men were at work, but that this has become impossible during the pandemic because of the increased presence of men at all hours of the day.⁶⁰ The greater presence of men who are no longer going to work has generated a heightened fear of sexual violence outside the home.⁶¹

Reduced ability to seek help

Ironically, even tragically, the public health response to COVID-19 has simultaneously increased the risk of gendered harms and decreased the ability to seek help. Depriving Rohingya refugees of their ability to provide for themselves forces them into prolonged dependency on aid organizations, a particularly serious survival issue during crises such as that provoked by the COVID-19 pandemic, when most NGOs have had to decrease their presence and suspend their work to comply with public health guidelines. Indian NGOs were not designated “essential services” by the government, and they faced prohibitions on their movement during the first few months of the lockdown. Although Prime Minister Modi had called on these organizations to provide help to the most underprivileged, that message was often at odds with local law enforcement officials who did not let them operate. NGO staff were regularly stopped and in some cases even beaten by police for violating the lockdown regulations.⁶² The UNHCR has distributed food packets to refugees in New Delhi, but other efforts across the country have

been sparse and sporadic, forcing refugees to take on debts and draw on their savings. Importantly, the UNHCR has not been awarded formal status in India and is allowed to provide assistance only to asylum seekers from non-contiguous countries who currently live in urban areas (mostly restricted to urban Delhi). A similar situation arises in Bangladesh, where the UNHCR has suspended the work of 80% of its staff. By the agency's own admission, "the closure of learning centers, child friendly centers and other venues for children has resulted in further exposure of children to protection risks, giving rise to increased behavioral challenges and the adoption of negative coping mechanisms."⁶³ About 88% of the Rohingya population have been highly or totally dependent on aid organizations for life-saving assistance.⁶⁴ But since the arrival of the pandemic, UNHCR has had to reduce its presence by about 80%, and only "emergency food and medical supplies" are being supplied to those whose lives are in immediate danger.⁶⁵

Another challenge in Cox's Bazar is the internet ban imposed by the Bangladeshi government, which was lifted only in August 2020, after heavy criticism from the international community.⁶⁶ Since September 2019, the government had banned the sale of mobile phone SIM cards to refugees, confiscated over 12,000 SIM cards, and ordered telecom companies to severely restrict internet and phone connections in the camps.⁶⁷ These widely criticized regulations had dire consequences during the pandemic. They slowed down the COVID-19 response because information could not be disseminated online, and they prevented refugees from sending or receiving remittances at a time when work was scarce. They obstructed already restricted opportunities for women to seek assistance, as evidenced by the fact that the International Rescue Committee recorded a 50% decrease in gender-based violence reporting by women in February–March 2020, despite evidence that incidents of violence were increasing.⁶⁸ Other hotline and phone communications started by anti-gender-based violence advocates also reported low traffic because of the government's communication ban, demonstrating, once again, how gendered differences generate

differential impacts on access to state services and protections.⁶⁹

COVID-19-induced trafficking: The predictable consequence of a protection deficit

As we have shown, refugee women are exposed to heightened exclusion as a result of their statelessness and to aggravated risks of violence because of draconian lockdown policies. Now that lockdowns are being lifted, however, this community is also disproportionately affected by poverty as employment opportunities and social protections shrink.

One consequence of this process is likely to be a significant increase in the trafficking of female refugees. Natural disasters, conflicts, and economic shocks are known to precipitate trafficking. The 2004 Indian Ocean tsunami and the 2015 earthquake in Nepal triggered a dramatic increase in the trafficking of young people, especially girls.⁷⁰ The same phenomenon occurred during the 2008 recession because large numbers of women were willing to take risks when they had no alternative sources of livelihoods.⁷¹ At the time of this writing, little confirmed empirical evidence of this trend exists. However, the factors known to be associated with the flourishing of trafficking networks are evident. By highlighting them, we seek to draw attention to the significant risks that ongoing policies and concomitant failures to dramatically scale up social protection investments will enable.

COVID-19 is worsening both the supply-side and demand-side factors for trafficking. On the demand side, the economic losses caused by the lockdown accelerate the pressures on employers—such as farmers, builders, and sweatshop owners—to seek out cost-cutting production strategies: highly exploitable labor, such as that generated by trafficking networks, fits that bill. On the supply side, the risk of destitution places immense pressure on families to make choices that avert complete calamity. Where loans are taken, they need to be serviced; where illnesses occur, payments for drugs are needed; everyday consumption requires a source of ready income in the absence

of accumulated savings. All these factors weigh heavily on refugee populations. And in some contexts, cultural norms favor the exchange of female labor—for domestic work, for agriculture, and for sex work—over its male equivalent.⁷²

Statelessness can increase but also *compel* engagement in exploitative labor. In India, the refusal of the Home Ministry to accept papers issued by UNHCR has prevented refugees from receiving the police certification needed to rent or buy accommodation and has forced them to live in slums or at the mercy of local landlords who often demand rent through services.⁷³ Before the advent of the pandemic, the poorest Rohingya refugees had bound themselves to *kabadi* (scrap-dealing) mafias engaged in trafficking refugees from Bangladesh and in usurious moneylending practices.⁷⁴ Afghan refugees in India have also been harassed by landlords during the pandemic and coerced to pay rent despite the order of the central government that tenants must be given at least one month's relaxation from rent. Dependence on informal moneylending networks is likely to increase as humanitarian assistance dwindles and informal employment opportunities grind to a halt. Bonded labor systems have historically targeted refugees and migrants who are ill informed about and unfamiliar with the region. In India, refugee women and children in particular have been targeted because they are viewed as less able than citizen laborers to assert their rights and organize against bondage and exploitation.⁷⁵ Anticipating the likely surge in the use of trafficking as a refugee survival mechanism in the face of COVID-19, several civil society organizations have pressed their respective governments to make available to refugees the national cash and ration schemes introduced following the lockdowns. However, the central government of India has refused to accede to these requests, and the Delhi High Court has rejected petitions to provide emergency services to refugees.⁷⁶

In Pakistan, too, dramatic decreases in income and increases in employment and economic pressures will affect refugee women differentially. Many refugee families are at risk of eviction due to the inability to pay rent, and hunger is increasing,

putting vulnerable women at risk of sexual exploitation and transactional sex. At least half the Afghan refugees in Pakistan live “hand to mouth,” working as daily wage earners, but since the advent of the pandemic, their livelihoods have been destroyed.⁷⁷

The situation in Bangladesh is equally grave. Unemployment, the halting of education, and the reduced provision of food, water, and other services in refugee camps will have devastating effects on Rohingya families.⁷⁸ The Bangladeshi government has consistently blocked refugee self-sufficiency, preventing Rohingya refugees—including many with marketable skills—from accessing the domestic labor market. In one study, 93.5% of Rohingya households reported a decrease in income between 2017 and 2018, with 80% reporting no current income.⁷⁹ The pandemic restrictions are further impoverishing Rohingya families, forcing them into debt. During the pandemic, over a third of Rohingya households have borrowed money for food, health care, and shelter. Those refugees—2% of women and 27% of men—who were earlier working (albeit irregularly) outside the camp or through cash-for-work programs have either lost their employment or have been temporarily furloughed.⁸⁰

Statelessness can aggravate an already challenging situation by providing a spurious justification for punishment instead of protection for trafficked persons who have been rescued. The Indian police have on multiple occasions detained and deported refugees found to have been trafficked. In a much-publicized case in 2019, police in the state of Mizoram detained 12 Rohingya refugees—8 women and 4 boys—before returning them to Assam, the state they had been trafficked from.⁸¹ Because stateless women have no access to justice mechanisms where complaints about trafficking can be raised, the expected post-pandemic increase in trafficking is especially concerning.

Conclusion

South Asia's rejection of basic nondiscrimination and protection principles for refugees, as set out in the 1951 Refugee Convention and other cardinal human rights treaties, creates conditions of

profound rightlessness. The state—through its monopoly over the power to classify subjects into “legitimate” and “illegitimate”—enacts violence through exclusion. This sets the backdrop for the de facto statelessness faced by the refugee women described above. We argue here that statelessness, whether de jure (as in the case of Rohingya) or de facto (as in the case of other forced migrants deprived of refugee status), and gender are two neglected fault lines of exclusion that generate grave harms in the aftermath of COVID-19. A first step toward providing and guaranteeing fundamental human rights to those who are seeking asylum is the ratification of the 1951 Refugee Convention and its 1967 Protocol, which would give these individuals the ability to make legitimate claims on the state and would place states under greater scrutiny if they fail to uphold the enshrined principles. Another important step would be allowing the expansion of nonprofit and humanitarian organizations on which such stateless individuals might rely for basic necessities. Guaranteeing these organizations “essential worker” status during crises, for example, would protect those who are reliant on them from resorting to negative coping mechanisms such as child labor or trafficking. On a more systemic level, however, investments need to be made in the provision of nondiscriminatory education, access to safe housing, and avenues for work that do not compel dependence on aid organizations in the first place.

Legal and political inclusion is, as argued above, only part of the picture but still a crucial step toward generating social membership in the collective. Illegality can spur social exclusion, as evidenced by exploitation at the hands of informal employers and landlords, just as political messaging and prioritization can give a green light to popular discourse that marginalizes refugees on the basis of their “illegality” and religion. Returning to the Joppke citizenship framework discussed at the outset of this paper, the ostracism of refugees as “contaminators” amounts to a denial of social membership and of a sense of legal identity that compounds the precarity associated with the de facto statelessness of South Asian refugees. The intersectional vulnerabilities produced by statelessness and gender

expose refugee women not only to the challenges facing all poor and marginalized communities affected by the pandemic but to additional challenges such as decreased mobility, lack of legal and social recourse in cases of abuse, the threat of trafficking, and exacerbated xenophobia. The grave yet avoidable harms produced for women by the social and legal exclusion described above raise an immediate agenda for intervention, for state and nonstate actors alike. Without dedicated attention to the prevention of future gender-based violence, exploitation, and irreversible health detriments facing South Asia’s refugees in a post-COVID-19 world, the pandemic’s impacts will endure for decades to come.

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Sanctioning Chile's Public Health Care System for Not Providing Basic Services to the Elderly: The Inter-American Court's *Poblete Vilches* Ruling

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Abstract

This paper analyzes the Inter-American Court of Human Rights' ruling in the case of *Poblete Vilches et al. v. Chile*. Poblete Vilches, a senior citizen, died in February 2001 due to septic shock and bilateral bronchopneumonia after being treated in a public hospital in Chile. The ruling held the state of Chile responsible for a number of human rights violations. The paper evaluates the interpretation of the American Convention on Human Rights as carried out by the Inter-American Court of Human Rights. It concludes that the sentence explicitly developed criteria in relation to informed consent as a derivation of the right to health and implicitly recognized, from a gerontological perspective, a manifestation of structural abuse toward older persons and their supportive environments. The gerontological gaze brings new challenges for the development of older persons' rights. The ruling is unique in the inter-American human rights system, as recognized by the court itself.

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Introduction

This paper analyzes the reasoning of the Inter-American Court of Human Rights in its judgment in *Poblete Vilches et al. v. Chile*, issued on March 8, 2018, which interpreted the human rights of older persons in the context of medical and social care.¹ The court pronounced on the right to life and personal integrity and the right to health for older persons based on the recognition of economic, social, cultural, and environmental rights, invoking for the first time the Inter-American Convention on Protecting the Human Rights of Older Persons.

The Inter-American Court of Human Rights is an autonomous judicial institution tasked with the application and interpretation of the American Convention on Human Rights (ACHR). Decisions of the court are justified and final, and they may not be appealed. States parties to the convention—as in the European human rights system—are obligated to comply with the court's judgments.² The ACHR establishes and limits the jurisdiction of the Inter-American Court. According to the facts of the case, Mr. Vinicio Poblete Vilches (hereinafter Poblete) was admitted to the Sótero del Río public hospital on January 17, 2001, due to severe respiratory failure. On January 22, he was moved to the surgical intensive care unit. A surgical intervention was performed while he was unconscious, without the prior consent of his relatives. Nevertheless, doctors performed a surgical intervention while he was unconscious, without the prior consent of his relatives. On February 2, Poblete was discharged without further instructions.³

Three days later, on February 5, Poblete was admitted for a second time to the same hospital, where he remained in the intermediate care unit due to lack of available beds, despite the clinical record specifying his admission to the intensive care unit. Poblete died on February 7, 2001, at the age of 76, due to septic shock and bilateral bronchopneumonia.⁴ According to the sequence of events, there was a failure to comply with medical care standards regarding to informed consent required under *lex artis*.

Unlike the European and universal human rights systems, the inter-American human rights system has a binding instrument for the protec-

tion of the human rights of older persons (the Inter-American Convention on Protecting the Human Rights of Older Persons). Therefore, the Inter-American Court's references to the European Court of Human Rights in this ruling can only be partial, because the reference frame is different.

The objective of this paper is to analyze the arguments used by the Inter-American Court in its application of the Inter-American Convention on Protecting the Human Rights of Older Persons, identifying the gerontological elements in the *Poblete* case.

Experts in gerontology have increasingly turned to the courts in their battles to protect the human rights and health of older persons. Yet while a significant literature analyzes legal mobilization on these issues, it tends to focus predominantly on domestic legislation and cases. This paper analyzes the effect of these issues when they reach the Inter-American Court. It begins by describing the court's ruling in *Poblete Vilches et al. v. Chile*, which offers an authoritative interpretation of older persons' rights to life, personal integrity, health, and autonomy. As our analysis demonstrates, the court balanced medical, ethical, and legal considerations in its judgment. The paper then considers how rulings such as this one can drive legal reforms to protect and promote the rights of older persons on the American continent.

To date, *Poblete Vilches et al. v. Chile* is the only case concerning the rights of older persons to reach the Inter-American Court, and it shows the trajectory from domestic jurisdiction to the regional human rights system, and vice versa.⁵ On October 1, 2012, through Law 20.584, Chile changed its domestic legislation on the rights of the patient; this was before the Inter-American Court issued its ruling in *Poblete*.

Development of the topic

In its ruling, the Inter-American Court developed two rights. The first of these is the right to life and personal integrity of older persons, and the second is the right to health, which encompasses the right to health of older persons and the right to informed

consent of older persons and their relatives in the field of health care.

It should be noted that this case represents the court's first-ever recognition of the right to health as an autonomous right.⁶ The ruling also represents the court's first decision on the rights of older persons in matters of health.⁷

Right to life and personal integrity of older persons

The court held that the right to life constitutes a "prerequisite for the enjoyment of all other rights."⁸ The court used a systematic argument (whereby laws regarding the same matter must be construed with a reference to each other; what is clear in one statute may be called in aid to explain what is doubtful) and referred to a previous ruling of the European Court of Human Rights.⁹ According to the court, a state holds international responsibility for death in a medical context when the following conditions are met: (1) a treatment is denied to a patient in a situation of medical emergency or essential medical care, despite the risk that this denial poses for the life of the patient; (2) there is serious medical negligence; and (3) there is a causal link between the act and the damage suffered by the patient. Verification of the state's international responsibility must also consider any situation of special vulnerability of the affected person (in this case, the patient's status as an older person) and any measures taken to avoid that situation.¹⁰

The court also quoted article 5(1) of the ACHR, noting that the protection of the right to personal integrity requires the regulation and implementation of health services. It further noted that states "must establish an adequate regulatory framework that regulates the provision of health services, establishing standards of quality for both public and private institutions."¹¹ In the particular case at hand, the court held that repeated omissions in the care provided to Poblete and the failure to treat his specific health conditions contributed to the deterioration of his health.¹²

Right to health of older persons

The court argued that civil and political rights and

economic, social, cultural, and environmental rights are interdependent and without hierarchy and that they must be understood integrally.¹³ It made direct reference to the observations made by Chile in 1969, during the drafting of the ACHR, in which the state considered that a certain legal obligation must exist with regard to economic, social, and cultural rights.¹⁴ On this same point, the court ended with a comment of a teleological nature, referring to the international and national *corpus iuris*.¹⁵

The court also argued that article 26 of the ACHR creates two types of obligations: progressive and immediate. Progressive obligations mean that states have a concrete and constant obligation to proceed as expeditiously and efficiently as possible toward the full effectiveness of economic, social, cultural, and environmental rights; they also imply an obligation of non-retrogressivity with regard to the rights that have been realized. Meanwhile, immediate obligations "consist [of] adopting effective measures in order to guarantee access, without discrimination, to the benefits recognized for each right."¹⁶

The court cited several international tools, such as the Charter of the Organization of American States, the American Declaration, and the international *corpus iuris* on the right to health.¹⁷

With regard to situations of medical emergency, the court referred to General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights, noting the minimum standards of quality, accessibility, availability, and acceptability.¹⁸ Quality is understood as the "adequate infrastructure required to meet basic and emergency needs," including life support devices and qualified human resources.¹⁹ Accessibility is understood in its "overlapping dimensions of non-discrimination, physical accessibility, economic accessibility, and information accessibility."²⁰ Availability implies sufficient material and human resources and the coordination of facilities and networks.²¹ Acceptability refers to the fact that health services "must respect medical ethics and culturally appropriate criteria ... [and] include a gender perspective, as well as the conditions of the patient's life cycle. The patient must be informed of

his diagnosis and treatment and, in this regard, his wishes must be respected.”²²

Lastly, the court held that “older persons have the right to increased protection, [which] requires the adoption of differentiated measures.” It upheld “the right to a dignified old age and consequently the measures required to this end.”²³ Again, with a systematic argument, the court quoted the Committee on Economic, Social and Cultural Rights, namely its General Comment 6 and General Comment 14, which guide states to maintain measures of prevention and rehabilitation in order to preserve the functional capacities of older persons, thereby reducing costs in health care and social services.²⁴ In the ruling, some relevant concepts—such as functionality, autonomy, care, chronic patients, and patients in the terminal stage of life—appeared but were not defined.

Right to informed consent of older persons and their family members

Regarding older persons in the health care context, the court noted the existence of several factors that increase their vulnerability, such as physical limitations, limited mobility, economic status, and severity of a disease. It further noted that due to frequent imbalances in the doctor-patient relationship, it is essential that the patient be provided with the information needed to understand their diagnosis and possible treatments.²⁵ In this regard, it pointed out that “informed consent forms part of the accessibility of information ... and, therefore, of the right to health (Article 26 [of the ACHR]),” establishing the right to information in article 13 of the ACHR as an instrument to ensure and to respect the right to health.²⁶

The court interpreted informed consent according to international standards in health care.²⁷ It noted that health providers must, at a minimum, provide information to the patient on the following: (1) “an evaluation of the diagnosis”; (2) “the purpose, method, probable duration, and expected benefits and risks of the proposed treatment”; (3) “the possible adverse effects”; (4) “treatment alternatives”; and (5) the progression of the treatments.²⁸ In addition, the court held that informed consent by

representation is granted when the patient is unable to make a decision regarding their own health.²⁹

The court concluded with a teleological element, “dignity” (article 11 of the ACHR), which is linked to autonomy, stating that dignity consists of “the possibility of all human beings for self-determination and to freely choose the options and circumstances that give a meaning to their existence, based on their own choices and convictions.”³⁰ This is related to the protection of the family (article 17 of the ACHR), which plays a central role in the existence of a person and in society in general.

Conclusions from the interpretative argumentation

Recent decades have seen profound transformations in international human rights law, motivated by considerations of international *ordre public*, and which confirm that human rights are applicable to all people irrespective of where they live. At the beginning of the 21st century, the “reason of humanity” took primacy over the reason of the state, inspiring the historical process of *humanization* of international law.³¹ As a consequence, we can see explicit ethical guidelines, improved domestic laws, and international legal norms.³² In addition, the Inter-American Court’s ruling reflects the constant process of improvement in interpretive legal techniques. The establishment of human rights in societies does not occur automatically; rather, it implies states’ acceptance of the restriction of the power they exercise over citizens, as well as the acceptance of jurisdiction of international institutions in a very sensitive area.³³

Most of the arguments embraced in the court’s ruling were systematic. But the court also used precedent and theological elements.

Concerning the right to health, the court used precedents from other rulings, as well as a genetic argument in relation to Chile’s position regarding the legal applicability of the right to health, which the state had expressed during the drafting of the ACHR.

Finally, the ruling held the Chilean state responsible for the violation of Poblete’s rights to

health, to life, and to personal integrity; the violation of Poblete's and his family members' right to informed consent and access to information on health-related matters; and the violation of his family members' right to personal integrity.³⁴

Issues from a gerontological perspective

Among the many issues relevant to gerontology, the Inter-American Court's ruling proposed overcoming stereotypes and stigma against older persons in the social and health care spheres. It is clear that a cultural and social structural change, as well as a new way of relating to and with elderly people, is required.³⁵ It is necessary to undertake a paradigm change toward older persons, who have the right to assistance benefits, that views such persons as subjects of law who can make demands of the state.³⁶ In this sense, a person's age is not an indicator of medical diagnosis or prognosis, unlike other areas, such as functionality, to which the ruling did not refer.³⁷

The Inter-American Convention on Protecting the Human Rights of Older Persons refers to prejudices and stereotypes, requiring state parties to "create and strengthen mechanisms for the participation and social inclusion of older persons in an environment of equality that serves to eradicate the prejudices and stereotypes that prevent them from fully enjoying those rights."³⁸ It is worth noting that the *Poblete* case is an example of structural abuse, where social stereotypes form the basis of abuse and directly affect the rights to life and to integrity. According to the National Service for the Elderly in Chile, structural abuse is "that which occurs from and within the structures of society through legal, social, cultural, [and] economic norms that act as a background for all other forms of existing abuse."³⁹

The court's ruling referred to events that occurred in Chile in 2001, when the national and international normative standard was lower in matters of health care for older persons.⁴⁰ Today, a similar case would likely be resolved with a more demanding standard. At the time of the events, the World Health Organization had not coined the term "healthy aging," which is based on the pil-

lars of health, safety, and participation, and there was no recognition of older persons' autonomy in health-related matters.⁴¹ On the other hand, the Madrid International Plan on Action on Ageing promotes the idea of considering the increase in life expectancy as an opportunity.⁴² According to the plan of action, older persons should enjoy the right to security, including health benefits and care; it also recognizes older persons' rights to participation, autonomy, and informed consent. These standards were not implemented by the court because they are not mandatory.

The aforementioned instruments generate changes at the level of sociocultural and legal standards. At the international level, this includes guidelines on good clinical practices in geriatrics that encourage integrated care for older persons and the Inter-American Convention on Protecting the Human Rights of Older Persons, among others.⁴³ At the national level, it includes Chile's Universal Access Plan to Explicit Guarantees in Health, in force since 2005, which promotes the enactment of Law 20,584 on the rights and duties that people have concerning actions related to their health care, replacing the paradigm of biomedical paternalist care with a model of autonomy.⁴⁴

In this sense, an evaluation of the clinical situation of health care for older persons should incorporate a comprehensive view of the individual that considers not just biomedical aspects but also the person's social, biographical, functional, affective, and cognitive characteristics. Care for older persons should be continuous and integrated and should seek to enhance their functionality and prevent iatrogenesis, regardless of the level of care at which they are being treated. This care must pay special attention to the prevention of risks associated with hospitalization, particularly for those who are frail. The opinion of older persons must be incorporated into decision-making; to this end, a competence evaluation must be performed, and advance care planning should be a priority. Good communication tools among the different actors are encouraged, benefitting not only the relationship between patient, family, and medical team but also the patient's transitions between types of

care. Regarding the communication and delivery of information, special attention should be paid to the level of health literacy of those involved, and communication strategies should be adapted so that people can actively participate in their health care. This requires a commitment from states both in the training of human resources at the undergraduate and postgraduate level and in the continuous review and adjustment of existing practices and resources, all of which are key for the nonrepetition of violations.⁴⁵

With regard to the right to life—in relation to the denial of emergency medical treatment by medical personnel—the Inter-American Court found that Chile did not adopt necessary, basic, and urgent measures to guarantee Poblete’s right to life. The state could not justify its denial of basic emergency services. The court argued that such assistance would have at least prolonged Poblete’s life and thus concluded that the omission of basic health benefits affected his right to life.⁴⁶ Health care teams must provide technically viable and justified alternatives in light of the clinical condition of older patients. Still, the court’s decision does not constitute a vote in favor of therapeutic obstinacy, which would ultimately imply unnecessary suffering for the patient, as well as the misuse of health resources. In this sense, it is the duty of the health care team to consider death as a part of life, and, consequently, the team should offer appropriate support and consolation to relatives after the patient’s death.⁴⁷ Chile embraced this orientation when it ratified the Inter-American Convention on Protecting the Human Rights of Older Persons, declaring:

*the life-course approach will be understood as the continuity of a person’s life, from the beginning of their existence to the last stage of life, which, conditioned by different family, social, economic, environmental and/or cultural factors, configure the life situation, with the state being in charge of developing this approach in its public policies, plans and programs, with a special emphasis on old age.*⁴⁸

Regarding informed consent, such consent is part of the growing recognition of the autonomy of older

persons. This implies considering informed consent as a principle that allows for existential and practical choices that arise from one’s personal identity, life history, and environmental conditions. In general, the term “autonomy of the will” is understood as the ability of legal subjects to establish rules of conduct for themselves and in their relationships with others within the limits established by law.⁴⁹ And the term “autonomy and individual responsibility” is understood as the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.⁵⁰ The Inter-American Convention on Protecting the Human Rights of Older Persons maintains that independence and autonomy constitute general principles for the interpretation of the convention.⁵¹ An important dimension of autonomy occurs in the health field, where decision-making capacity and responsibility constitute guiding principles for the relationship between the patient and the health care team, in an effort to avoid verticalization and asymmetry of information. In technical terms, the Universal Declaration on Bioethics and Human Rights defines these concepts as the power to make decisions about one’s own life, assuming responsibility for those decisions, and respecting others.⁵² Regarding people who lack decision-making capacity, special measures must be taken to protect their rights and interests. This declaration unites the concept of autonomy and responsibility, moving away from a conception of freedom that exalts the individual. The obligation to take “special measures” does not fall exclusively on health service users but instead applies to other subjects as well, since these special measures must protect “their rights and interests.” At the same time, the autonomy of the subject is appreciated because it is essential for the integration of decision-making processes, such as informed consent. Consent (agreement of wills) relates not to the narcissist satisfaction and autonomy of the patient but to the realization of their possible therapeutic wellness.⁵³ Therefore, we must incorporate more demanding standards associated with clinical

protocols, including informed consent, into geriatrics, particularly in relation to hospitalization.⁵⁴

The ruling of the Inter-American Court of Human Rights in *Poblete Vilches et al. v. Chile* marks an important milestone regarding the recognition of the rights of older persons, especially in the spheres of life and health. Further, it emphasizes the importance of ensuring that older patients' wishes are heard and that guidelines are in place concerning how to proceed in cases where a person is unable to express their wishes. The principle of informed consent is not irrelevant with regard to older people. Since the tragic events that happened to Poblete and his family, national and international legal instruments have taken a positive turn, moving toward greater recognition of the rights of older persons, with dignity as their guiding light.

Conclusion

First, the *Poblete* case is important for its effective application of the Inter-American Convention on Protecting the Human Rights of Older Persons. This is a critical development in the international context, since the Organization of American States differentiates the legal protection of older persons from that of disabled people. The ruling is a major step forward in terms of the promotion of positive stereotypes of older persons, as embraced by the World Health Organization—namely active aging, positive aging, and healthy aging.

Second, international public order and the Inter-American Court of Human Rights in particular have made efforts to move forward in the recognition of older persons' rights. The Inter-American Court declares this case as groundbreaking and, for this reason, a greater specialization in older persons' rights can be reasonably expected over time, in which a person's biographical identity is accepted as an ethical and gerontological core of reflection.⁵⁵

Third, regarding the court's argument, specifically the systematic element, the inter-American human rights system requires that the arguments used by the Inter-American Court to interpret the ACHR be legal and within the framework

of a previously enshrined right. Therefore, the Inter-American Court is not acting within its jurisdiction if it uses extra-systemic arguments, such as quoting the European Court of Human Rights. This bad practice of the Inter-American Court does not comply with the international standards of the system or with the cultural realities of the continent.

Finally, this ruling applies some of the same principles enshrined in the Inter-American Convention on Protecting the Human Rights of Older Persons, among them dignity, autonomy (expressed through informed consent), solidarity and empowerment of family and community protection, and effective judicial protection.⁵⁶ These legal principles will bring new perspectives in future trials in the region.

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Decolonizing Health Governance: A Uganda Case Study on the Influence of Political History on Community Participation

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Abstract

This paper presents a case study of how colonial legacies in Uganda have affected the shape and breadth of community participation in health system governance. Using Habermas's theory of deliberative democracy and the right to health, we examine the key components required for decolonizing health governance in postcolonial countries. We argue that colonization distorts community participation, which is critical for building a strong state and a responsive health system. Participation processes grounded in the principles of democracy and the right to health increase public trust in health governance. The introduction and maintenance of British laws in Uganda, and their influence over local health governance, denies citizens the opportunity to participate in key decisions that affect them, which impacts public trust in the government. Postcolonial societies must tackle how imported legal frameworks exclude and limit community participation. Without meaningful participation, health policy implementation and accountability will remain elusive.

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Introduction

Community participation is a critically important component of building public trust in health governance, as well as a key feature of the right to health.¹ It refers to the free, active, meaningful, and inclusive processes through which people make decisions on issues that affect them, their families, and their communities.² Colonialism deeply affects a country's social fabric and inherently changes social, cultural, political, and economic structures in a way that continues to be felt decades after independence.³ Using elements of Jürgen Habermas's theory of deliberative democracy and the right to health as normative frameworks, this paper examines the legacies of colonialism in Uganda and how they have affected community participation in health system governance. We propose that health system decolonization requires embedding community participation through policies that incentivize historically marginalized and excluded groups to better disperse decision-making power, which is a consequential first step in truly achieving self-determination.

Colonization disrupts people's connection to the land and forces a new country identity on existing cultures, communities, and families, and does so through policies that seek to control, stigmatize, and intervene in their lives.⁴ Decolonization calls for the dismantling of several layers of complex and entrenched colonial structures, ideologies, narratives, identities, and practices, as well a reconstruction process that focuses on reclaiming humanity, rebuilding bodily integrity, and reasserting self-determination.⁵ The political, economic, social, and cultural control that was leveraged on an occupied nation breaks down local social fabrics and creates inequality and public mistrust in the governance system. As a result, some populations become more and more excluded, and these historical cycles of disempowerment lead to further exclusion.⁶ Colonialism also shapes the health system and all governance processes within, with a history of colonization acting as a key determinant of health for many vulnerable population groups.

Decolonizing health systems allows for a return of community participation that establish-

es true partnerships between communities and decision makers through empowerment cycles. Getting rid of the lasting impact of colonization calls for raising citizen awareness of rights and obligations and building collective action that promotes self-determination through dedicated policy frameworks and incentives that help ensure the dispersion of decision-making power in health policy.⁷ This diffuses decision-making power among more stakeholders and ensures that health services reflect local needs, which increases communities' control over maintaining and improving their health.⁸ However, establishing these processes in contexts of exclusion and marginalization requires time and sustained support that allows for the reconfiguration of societal-level power dynamics.⁹ This is crucial for strengthening public trust in health governance, which is a central building block of health systems' ability to provide services efficiently, effectively, and equitably.¹⁰

Like many countries in Sub-Saharan Africa and around the world, Uganda struggles with a recent colonial past and its legacy. In many former colonies, the effects of often brutal and forced colonization influence all aspects related to governance well into postcolonial self-rule.¹¹ Table 1 shows how many sub-Saharan countries were under colonial rule from as early as the late 1890s and began achieving independence only in the 1960s. For South Sudan, this came as late as 2011. Today, almost all low-income countries in Sub-Saharan Africa have serious health governance challenges, and most still struggle with their colonial legacies.

We argue that achieving the highest attainable standard of health is intrinsically linked to Habermas's theory of deliberative democracy. Communicative action, the power of speech, legitimacy, and the principles of legitimacy and the public sphere shape community participation and affect the way that communities engage with the health system and enjoy their right to health. Many postcolonial societies with weak deliberative democracy values continue to struggle with democracy because colonization impacted self-determination, which limits popular sovereignty, especially in context of extreme poverty and resource con-

straints.¹² This exclusion delegitimizes the public space, which is coopted by officials who were not elected by the people. This weakens democracy and increases authoritarian leadership, hence impacting public trust in the health system's governance.¹³ Democracy and human rights are co-original and can act in virtuous cycles of empowerment when they integrate previously excluded groups and lead to the type of systemic change that dismantles colonial structures at the ideological and practical level. Finally, community participation is central to the realization of the right to health, as stated in the United Nations Committee on Economic, Social and Cultural Rights' General Comment 14.¹⁴ By framing participation disparities as rights violations, public health advocates can draw on international legal standards to frame responsibilities and evaluate policies, shifting the analysis of health reform from a focus on the quality of care to one on

social justice.¹⁵

Colonial governments' dominance of their colonies required achieving control over the territory, which in turn involved the erosion of self-determination and the imposition of a rule rooted in the colonizer's beliefs and practices.¹⁶ Oftentimes, this translated into the enforcement of a foreign culture, religion, and social mores and customs through the slave trade, misappropriated natural resources, exploitative trade relations, and unfavorable means of producing wealth.¹⁷ Such foreign systems of rule of law limited local peoples' self-determination and sovereignty, for subjected communities were beholden to laws that they had not participated in making. The repressive systems that crushed Indigenous legal and health systems also disregarded local traditional values, which were then replaced by those of the colonial rules. These systems include the health system, which was organized by

TABLE 1. Sub-Saharan countries and dates of their independence

| Country | Colonizer | Independence date |
|----------------------------------|-------------------------------------|-------------------|
| Benin | France | 1960 |
| Burkina Faso | France | 1960 |
| Burundi | Belgium | 1962 |
| Central African Republic | France | 1960 |
| Chad | France | 1960 |
| Comoros | France | 1975 |
| Democratic Republic of the Congo | Belgium | 1960 |
| Eritrea | Italy, United Kingdom, and Ethiopia | 1993 |
| Gambia | United Kingdom | 1965 |
| Guinea | France | 1958 |
| Guinea-Bissau | Portugal | 1973 |
| Madagascar | France | 1960 |
| Malawi | United Kingdom | 1964 |
| Mali | France | 1960 |
| Mozambique | Portugal | 1975 |
| Niger | France | 1960 |
| Rwanda | Belgium | 1962 |
| Senegal | France | 1960 |
| Sierra Leone | United Kingdom | 1961 |
| South Sudan | Sudan | 2011 |
| Tanzania | United Kingdom | 1961 |
| Togo | France | 1960 |
| Uganda | United Kingdom | 1962 |
| Zambia | United Kingdom | 1964 |
| Zimbabwe (Rhodesia) | United Kingdom | 1980 |

the colonizers based on their own ideas and beliefs around the type and number of services that should be provided to the local population.

As the Ugandan case study demonstrates, postcolonial countries continue to grapple with the impacts of colonial values on their legal and health systems. Laws criminalizing abortion and same-sex unions are just some examples. The missionary hospitals and schools introduced during colonial rule continue to account for almost 20% of Uganda's health and education systems.¹⁸ The values that guide these systems, instituted through colonial rule, disregard current scientific knowledge and human rights and represent key challenges to the delivery of empowering and liberating health and education systems. Uganda provides a good case study on the influence of political history on community participation.

Methods

This paper uses a qualitative, historical case-study methodology and is guided by an analysis of the political history of community participation in Uganda from the precolonial, colonial, and postcolonial periods.¹⁹ The literature review included publicly available documents located through online searches for academic articles, government documents, nongovernmental organization (NGO) reports, and other gray literature. The publications considered were published in English and used rights-based approaches to health system strengthening. Additionally, publications that described or contextualized the historical events that shaped Uganda's political setup and health system were included in the study.

We analyzed data through a content analysis using two normative frameworks: (1) Habermas's concept of deliberative democracy and (2) the right to health framework. Both frameworks center around the concept of community participation whereby people and communities are at the center of decision-making processes in health. These frameworks emphasize the tenets of the power of speech, legitimacy, and the public sphere, and they advance the argument that the decolonization of

health systems is important for allowing community participation in health systems to thrive.

Our analysis focused on understanding the colonial period's subrogation of community participation and public trust in health governance. By applying the normative guidance provided by Habermas's deliberative democracy framework and the right to health framework, we uncovered the need for decolonization that emphasizes community participation as part of building public trust in the health system.

The Uganda case study

Uganda provides an opportunity for studying the historical and political influences of colonialism on community participation as an integral part of the right to health and health governance generally. Uganda has transitioned through the precolonial, colonial, and present-day periods of developing a democracy and a health system. The formation of its national development agenda in the post-colonial period and the rolling out of its decentralized health system also offers an opportunity to examine the colonial influences on the structures for community participation through the lens of constitutional provisions, local government legislation, and other policy frameworks that provide the foundation for operationalizing community participation. Through periodization into precolonial, colonial, and postcolonial, the history of the country allows us to critically assess the extent to which community participation was lost during the colonial period. This then provides a basis for examining the decolonization steps needed to bring back community participation as part of good health governance. As we argue, it is difficult to separate Uganda's current health system from its colonial and political history, as the latter continues to influence the architecture of the health system today.

Precolonial community participation

During the precolonial period, communities organized around kingdoms, in which community participation was a key social tenet.²⁰ For example, in the Buganda Kingdom, kingship was made into

a kind of state lottery in which all clans could participate.²¹ The community consolidated its efforts behind a centralized kingship, and this provided the community an opportunity to expand. Everyday life was organized around communal efforts. Social capital was critical for mobilization, which included rotating groups for labor sharing in the clearing, planting, weeding, and harvesting stages of agriculture, as well as emergency-oriented arrangements, such as local burial assistance groups that provided material and psychosocial support to bereaved families.²² Community participation evolved around self-help projects, which enhanced communities' economic and social welfare through a scheme called *bulungi bwansi* ("for the good of the community").²³ Community participation was therefore interwoven into the fabric of precolonial Ugandan society. It also included some features of deliberative democracy and the right to health.

The practice of traditional medicine was the only health system that existed in Uganda during the precolonial period.²⁴ Traditional medicine practitioners included herbalists, bonesetters, psychic healers, birth attendants, faith healers, diviners, and spiritualists who used Indigenous knowledge to develop materials and procedures.²⁵ Despite the colonial government's suppression of traditional medicine practitioners, traditional medicine survived colonization and continues to play a role in Uganda's present-day health system. The question of regulating these practices remains a major health governance issue for Uganda's health system. Communities have continued to demonstrate trust in traditional healers, despite the documented public health hazards that they have caused.

The key lesson from this period is that in the quest for a normative community participation structure that decolonizes health governance, Indigenous ideas and innovation should be taken into account. This is especially important when trying to understand the public sphere and how culture, attributes, beliefs, and norms can inform the normative structure of community participation.²⁶ In applying the human rights framework, validating and empowering these Indigenous spaces is important for advancing the right to participation as

enshrined in international human rights law.

Community participation during Uganda's colonial period

Uganda was a protectorate of the British Empire from 1894 to 1962, and although the economic, social, and political landscape changed dramatically, the country retained a degree of self-government that was uncommon.²⁷ Different Indigenous communities now inhabiting the country were brought together during the colonial period following the declaration of a British protectorate over Uganda in 1894.²⁸ Political dispensations unified traditional kingdoms that had enjoyed sovereign powers until then. New lawmaking processes were developed in Britain and enforced first in Buganda and quickly expanded to other kingdoms. The period saw many developments that would later shape the discussion on community participation in health governance amid British rule and the continued influence of the kingdoms.

The colonial administration imposed its own system of administration through indirect rule, whereby the British administered the protectorate through local chiefs and kings, who surrendered sovereignty in return for British protection. Because the colonialists obliged certain communities to merge, the uniformity of former autonomous chiefdoms was lost along with traditional practices of community participation.²⁹ The traditional discursive spaces were dismantled as the British enforced their rules and introduced forced labor and exploitative tax systems.

During this period, Britain signed a number of agreements with both Buganda as a kingdom and later Uganda as a protectorate that spelled out governance issues between the colonizers and the colony.³⁰ Through these agreements, Britain shaped the structure of government, including provisional administrative decisions and the administration of justice and maintenance of order.³¹ However, the structures introduced were devoid of key elements of deliberative democracy, such as a public sphere. Local communities were excluded from formal decision-making, which was now the exclusive competence of the colonial rulers. At the signing

of the 1900 Buganda Agreement, for instance, the Buganda signatories were allowed only to append signatures, and there is no evidence of them being included in the development of the agreement itself.³² Therefore, the Buganda Agreement was not a legitimate instrument when seen through the lens of deliberative democracy.

The agreement then became part of Uganda's modern legal system. Interestingly, it also introduced the concept of public interest, which was not discussed but mentions cursorily that government was to be the custodian of resources on behalf of the people. Today, the families and communities affiliated with those who benefited from the Buganda Agreement continue to dominate land ownership. Given the centrality of land as a resource, a large amount of decision-making power is now concentrated among a few families, and critical processes such as the allocation of land for health facilities and leadership in community participation structures are still separated from the people who would benefit the most from them.³³ These families act as power centers and exert control in many governance processes, including those related to the health system.

The next significant step that the British government took to solidify its rule in the Protectorate of Uganda after the Buganda Agreement was the establishment of the 1902 Orders in Council.³⁴ The Orders in Council dealt with matters of constitutional significance and were the benchmark against which many laws in colonial and postcolonial Uganda were built, as they provided the first legal instrument for establishing a legal framework of government for the entire protectorate.³⁵ Their major limitation was that they brought in UK legal frameworks without any adaptation to the local context. This was in complete disregard of the importance of community participation in legal decision-making for a country. Lord Denning, in the case of *Nyali Ltd. v. Attorney General*, challenged this practice when he used an analogy of an oak tree and concluded that one cannot transplant an oak tree from English soil and plant it on Kenyan soil and expect it to flourish well like it did before.³⁶

Article 15(1) of the 1902 Orders in Council established the judicial system, including the High Court, which was to have full civil and criminal jurisdiction over all persons and matters in Uganda. The court system is critical for health governance given the important role of litigation in health issues, as witnessed in present-day Uganda. The relevance of courts in health governance is visible in the important court decisions and pronouncements in relation to accessing health care. The Constitutional Court, for instance, has ruled that the government's failure to provide adequate maternal health services violates human rights protected in international treaties and the Ugandan Constitution, including the right to health, the right to life, the rights of women, and the prohibition of inhuman and degrading treatment.³⁷ The courts have also declared the criminal legislation concerning mental health as violating rights and have called for provisions that better enhance the rights of persons with disabilities.³⁸ The colonial procedural challenges in the usage of courts to advance health have seen some of these cases take as long as nine years to be decided.

Although the 1902 Orders in Council put in place the basic elements and structures of government, they did not further democracy in the protectorate. Uganda remained under direct control of the British, and there was no Indigenous representation within the government. The concept of democracy calls for the representation of people in government, and their exclusion signals an absence of it. The subjugation of community participation and the direct importation of British laws denied Ugandans the opportunity to participate in key decisions that affected them. As Kwanele Asante has argued, a non-rights-based approach absolves state parties of their duty to ensure that patients (communities) are substantively involved in the development of key health policies.³⁹ We agree with Asante that diluted community inclusion not only absolves states of their human rights duties with respect to the right to health and right to participate, but also renders communities unable to hold policy makers and governments accountable for inade-

quately discharging their right to health duties.

The control of sleeping sickness—the focal medical policy between 1900–1908—is an example of the implications of the aforementioned colonial governance structures for health. Sleeping sickness is caused by the tsetse fly, commonly found in tropical climates, including the region around Lake Victoria in Uganda. Kirk Arden Hoppe recounts how from 1906 onward local ordinances devoid of community participation were imposed by British rulers under the guise of disease control. For example, the Entebbe Township Ordinance of 1906 permitted the inspection and punishment of Ugandan canoe owners and crew who were found to have a tsetse fly on board. Punishment was in the form of a fine or one month's imprisonment. The 1907 Uganda Fishing Ordinance made it illegal to fish on Lake Victoria and to possess or sell lake fish, which was an important source of nutrition and income for local Ugandans. In 1908 and 1909, health regulations were issued to consolidate and later evict 33 island communities in Lake Victoria to the mainland. Although framed as a disease control initiative, these regulations were a covert method of strategically depopulating people from an area (the Lake Victoria region) rich in hunting, fishing, and charcoal.⁴⁰

These laws and regulations further marginalized Ugandans by depriving them of interdependent civil, economic, and social rights, including autonomy and the social determinants of health. Ugandans affected by these rules had no avenue for recourse to hold colonial decision-makers accountable, which is an essential component of the right to health. However, by the time of independence, Uganda had begun to witness some form of democracy that would see citizens participate in decision-making on issues affecting them.

Health governance in the colonial period

The colonial period saw the introduction of the formal health system through the establishment of mission hospitals. By 1909, three health centers in Mulago, Mengo, and Masaka were established for the treatment of venereal diseases, a new epidemic

that affected mostly Europeans doing the postcolonial work and Indians who had been brought in to develop the infrastructure. Controlling venereal disease was a core medical policy of the colonial government from 1908 until the 1920s.⁴¹ The Mulago health center was later developed into a general national referral hospital for venereal diseases. More hospitals and dispensaries were established in provincial and district headquarters throughout Uganda. These institutions were planned from the central level and without any community participation. Moreover, the epidemic of venereal disease was an opportunity for the colonial government to exert social control and to impose notions about sexuality and Christian values brought by missionaries.⁴² These ideas, differing from local conceptions of venereal disease, were later enshrined in the Venereal Diseases Act of 1977.⁴³ One example of how the Venereal Disease Act violates the right to health is the requirement that a person with a sexually transmitted disease identify the person who infected him or her. Such forced disclosure tears at the social fabric of a community.

However, it was also during the colonial period that Uganda first witnessed a form of decentralization, when the British secretary for colonial administration made it colonial policy to promote the creation of local governments. This decentralization influenced Uganda's health system through the introduction of health subdistricts.

The colonial control systems equated the practice of traditional medicine with witchcraft. As a result, the colonial government introduced the Witchcraft Act in 1957, which had provisions for the prevention of witchcraft and punishments for persons practicing witchcraft. In this way, the law attempted to strip Ugandans of the informal health system offered by traditional medicine. In 1997, the Supreme Court of Uganda, in the case of *Salvatori Abuki and Richard Abuga v. Attorney General*, held section 7 of this legislation unconstitutional for permitting the banishment of persons convicted of practicing witchcraft from their homes.⁴⁴ This judgment is a good example of some of the efforts to decolonize legislation introduced during colonial

times. The judgment emphasized the importance of measuring the colonial laws against Uganda's constitutional values.

Much of the health-related legislation that remains on the books today was imposed through the doctrine of legal reception, in which the British legal culture was transferred to Uganda. Laws such as the Public Health Act (1935), the Mental Treatment Act (1938), the Venereal Diseases Act (1977), the Penal Code Act (1950), and many others still affect health governance in Uganda. Starting in the 1930s, the colonial government shifted its medical focus to public health policy.⁴⁵ During this time, many laws relating to public health were adopted and have not been comprehensively reviewed since. Changing socioeconomic conditions call for legal frameworks to be updated, and often strengthened.⁴⁶ Some of these laws have been criticized for being restrictive in the area of reproductive rights, such as with regard to sexual orientation and access to safe and legal abortion.⁴⁷ In such cases, as part of decolonization, it is important to open a participatory dialogue around legal review to address gaps between policy, law, and practice.

It is also important to note that while colonial laws have stayed on the books, a number of areas that these laws targeted—such as harmful practices by traditional healers—continue today. For example, the recent wave of ritual murders, including child sacrifice, have prompted Ugandan parliamentarians to call for a law regulating the activities and practices of traditional healers and herbalists.⁴⁸ Abortion practices criminalized in the colonial Penal Code Act continue to contribute 1,200 deaths out of the total 6,500 maternal deaths each year.⁴⁹ There are also shared positive experiences and preferences by the population to use traditional healers because of their easy access, the ability to pay in installments or in kind for services rendered, and the kindness of traditional birth attendants.⁵⁰ These are important indications of the need to ensure community participation in the development of new regulatory frameworks that could address the country's current health governance needs.

Postcolonial Uganda and community participation

Uganda gained independence on October 9, 1962, with signs of constitutionalism.⁵¹ A constitution had been worked out as a result of negotiation among the major political actors.⁵² Direct universal suffrage was put in place except for Buganda, where representatives to Parliament were indirectly elected through the Council of Buganda. On the first anniversary of independence, the Constitution was amended by Parliament to provide for a ceremonial president to replace the governor-general.⁵³ Overall, postcolonial Uganda had a mix of struggles to establish democratic structures and an early turbulent time with civil wars and coups that saw the obliteration of the earlier democratic structures that would have facilitated community participation in the health system. The post-colonial Uganda descended into dictatorial regimes in the tenures of Milton Obote, Idi Amin, Yusuf Lule, and Godfrey Binaisa, a period that did not feature community participation in decision-making for the country. In 1971, for instance, President Idi Amin Dada contradicted most of the constitutional provisions of 1962 and 1966. He denied Ugandan citizens democracy and ruled by decree.

Developments in the health system included the creation of the Ministry of Health, which had been formed just before independence to replace the colonial medical department responsible for medical services.⁵⁴ In addition, missionary health organizations provided health services in rural and urban areas through cost sharing.⁵⁵ The most important factors affecting the provision of socialized health services were the prevailing economic and political conditions in the country.

The government and its Ministry of Health had an ambitious program to build 22 100-bed hospitals, which was feasible due to the country's economic prosperity between 1962 and 1971, during the first tenure of President Obote.⁵⁶ The country had four recognized health care service types and levels: (1) primary health care, consisting of centers and clinics; (2) secondary health care, consisting of district hospitals; (3) tertiary health care, consist-

ing of general referral hospitals; and (4) quaternary health care, consisting of two national referral hospitals.⁵⁷ There were regional referral hospitals throughout the country. The role of health in Uganda's development was one of high priority. The country's planning strategies had health services and education as one of three important development goals.⁵⁸

Uganda's health system was going through some important reforms, but there is no evidence of community participation in the making of the policies or the implementation of health reforms during this period. The challenges that resulted from this nonparticipation were the adoption of reforms based on technical considerations without the integration of community perspectives. As a result, some of the health governance structures (such as health unit management committees) do not respond to community needs, and communities do not view them as "theirs." This approach advances a colonial legacy of focusing on communities as passive beneficiaries.

The political and economic turmoil of the 1970s and 1980s also severely curtailed community engagement in the health systems. Social services, including health, broke down.⁵⁹ The working environment in the health sector became hostile, and many physicians migrated to other countries for security and economic reasons. Medicines, equipment, and hospital facilities were in limited supply, and the quality of health care fell drastically. At the same time, an unregulated private sector mushroomed rapidly to fill the services gap created by the poorly functioning government facilities that dominated the colonial health system architecture. This situation dashed any hopes of building a health system grounded in community participation.

After independence in 1962, efforts to strengthen national and cultural identities began to reemerge. For instance, it is now clear that the government is interested in providing support to the practice of traditional medicine. The repeal of the 1968 Medical and Dental Practitioners Act in 1996 created a situation in which traditional practitioners are tolerated as long as they do not claim to be registered medical practitioners.⁶⁰

During this postcolonial period, a number of colonial laws have been successfully challenged before Ugandan courts as unconstitutional and in violation of human rights standards. For instance, section 130 of the Penal Code Act has been held unconstitutional insofar as it refers to persons with mental disabilities as idiots and imbeciles.⁶¹ In this case, the petitioners successfully argued that the Penal Code subjected persons with mental disabilities to inhuman and degrading treatment, contrary to articles 24 and 35 of Uganda's Constitution.

Discussion

This paper has demonstrated that understanding a country's historical context is key for decolonizing its health governance. Through the Ugandan case study, we have identified key events that are central in defining a basis for decolonizing governance in health systems. The colonial legacy in Uganda imposed values and systems that undermined self-determination and sovereignty, which eroded even the most cherished precolonial systems that would provide a base for community participation as part of health governance.

While there was no defined formal space for participation in the delivery of health services in precolonial Uganda, the few existing informal spaces for community participation demonstrate the importance of community participation in decision-making on issues that affect them. However, during colonial times, there was clear subjugation of community participation in Uganda's governance, which left a legacy that problematized precolonial arrangements; failed to appreciate and uphold the strength of Indigenous systems; created a conflicting situation within Ugandan society; and diminished public trust in health governance. There are still some practices of community joint work through *bulungi bwansi* that are still visible even in other postcolonial countries such as Rwanda, which takes the form of *Umuganda*.⁶²

The precolonial systems that brought communities together were particularly important for vulnerable groups such as women, who had spaces for addressing their social issues, including health.

The introduction of laws such as the Buganda Agreement took away key land resources from the communities, severing their means of welfare and access to the social determinants of health. This agreement also made them subject to royal rule, eroding their autonomy, community systems of health governance, and voice in health decision-making. This marginalized many Ugandans, made them vulnerable to ill-health, and imposed barriers to forming, contributing to, and accessing health care. These challenges continue to exist among landless communities.

The direct importation of British laws and the continued influence of Britain in Uganda's governance denied Ugandans the opportunity to participate in key decisions that affected their health. Laws were devoid of the legitimacy envisioned by Habermas, and the previous spaces of community participation in precolonial Uganda were eroded. The imposition of a judicial system through the Orders in Council not only undermined the Indigenous justice system but also introduced a judicial system that still adjudicates on right to health cases with procedural complexities. The current legal technicalities that undermine the enforcement of the right to health and limit judicial interpretation of justice issues in the health system at the national level can be traced from the colonial legacy.

A number of colonial laws are still being applied, and while some laws have been amended, a number of them have not been subjected to the discursive test as advanced by Habermas. The most contested aspects of sexual and reproductive health and rights—such as access to safe and legal abortion, sexual orientation, comprehensive sexuality education, access to family planning, and control of venereal diseases—are still regulated through colonial legislation such as the Penal Code Act of 1950 and the Public Health Act of 1935. These laws perpetuate colonial attempts at social control and the degradation of Indigenous community fabrics.

The decolonization process requires that Uganda undertake a legal audit of all its laws and policies to assess them through the lens of human rights and current scientific evidence. The Uganda

Law Reform Commission should create public spheres as spaces for discussing the areas of weakness in these laws. The parliamentary lawmaking process should equally have opportunities for people to speak and deliver opinions on aspects that the laws should address. The outcome should be laws that meet the test of legitimacy as guided by Habermas's views of deliberative democracy.

The current model of delivery of health services is still built largely on the colonial model. Missionary hospitals dominate the provision of health care, delivering care aligned with religious values, which permeate training schools organized by religious groups that were introduced by colonizers.

The colonial period also introduced missionary NGOs that deliver health care through a cost-sharing mechanism that has persisted as part of Uganda's health system. These NGOs remain a major force in promoting religious-values-based health care delivery and have in many cases openly opposed the implementation of progressive sexual and reproductive health and rights policies. Such efforts have impeded the implementation of a human rights-based approach as part of Uganda's health governance. Part of the decolonization process would require that Uganda, as a postcolonial country, revisit its NGO policies and ensure a regulatory framework that insulates NGO mission work from a biased model of delivery of health services based solely on religious values. This process could include a deliberate effort to build, support, and include the work of Indigenous NGOs that advance a science- and rights-based approach to health services delivery and advocacy as part of government programming. Such Indigenous NGOs can provide a forum for community participation in the delivery of health services and in decision-making around priorities for the health system.

The current structure of Ugandan health facilities is still rooted in the architecture of the colonial masters, and the upgrading of hospitals and other health facilities has been slow. The division between the delivery of physical health and the delivery of mental health introduced during colonial

times continues to be the model today. This separation has led to mental health being undermined and overlooked in mainstream programming. The decolonization process requires that the design and capacities of national referral hospitals, regional referral hospitals, and other health facilities be upgraded from the colonial estimations that were based on Uganda's population and public health needs then. In undertaking this process, the government should end the practice of making plans and decisions in technical offices without engaging local communities. The design of such health facilities should be infused with ideas of the context-specific needs of the communities where such health facilities are being proposed. This will in many ways help ensure that health facilities are designed for and embraced by the communities they serve.

The colonial training models for health professionals have continued to guide medical training in Uganda. Colonial high schools and post-high school institutions continue to dominate Uganda's education system. In many of these schools, future health professionals receive training based on religious values that were imposed by colonial governments. The danger of such an approach has been the churning out of health professionals and policy makers who base their decisions on religious values as opposed to science and human rights. The decolonization process requires that the education system be scrutinized through a comprehensive stakeholder consultation process to ensure the maximum participation of all those affected. Impacts of the colonial legacy should be expunged and replaced with the present needs. The various training curricula should be revised and upgraded to address current training needs that result in professionals who base their decisions on evidence- and rights-based approaches. Training of trainers' modules and workshops should be undertaken to examine the best postcolonial methodologies for training health professionals. Such methodologies should be grounded in contextual needs to ensure relevancy.

Conclusion

In conclusion, for the decolonization of health governance in postcolonial countries, a conceptual framework combining deliberative democracy and the right to health is needed. Decolonization calls for arrangements that strive for community participation, Indigenous ideas, and national sovereignty. This process should also take into account Habermas's concept of deliberative democracy, which emphasizes the importance of focusing on the tenets of power of speech, legitimacy, and the public sphere.

As part of the conceptual framework grounded in the right to health and deliberative democracy, decolonizing community participation must be premised on the recognition of each person as a valid speaking partner with a unique and valuable knowledge to contribute. Thus, respect for the inherent dignity of persons and self-determination must inform all participatory processes and strategies, and each person's expertise, experience, and input must be valued. Local ownership and community context should inform decision-making in the health sector. This calls for efforts to examine the history and diversity of the community as important elements for shaping effective and efficient community participation as part of the right to health. Respecting local knowledge, the ability of communities, and their potential is key for decolonizing health systems that are participatory. Overall, participation should go beyond mere consultation and should build community capacity and foster public mobilization and awareness.

This paper has illustrated how Uganda's history and political context has shaped the nation's current system of health governance. We have argued that when decolonizing a postcolonial country's health governance, its health system cannot be divorced from its political setup. It is thus important that the political history is mapped to identify opportunities for operationalizing decolonization in health governance.

This paper has also demonstrated that a combination of deliberative democracy and right to

health principles provides both structural and procedural parameters for community participation as part of decolonization in health governance. The application of these standards, however, is highly dependent on the context of each country and community. It is therefore important to indigenize this theoretical framework. We recommend that countries undertaking decolonization strive to embed the principles of the rule of law—including respect for the right to community participation and self-determination—in order to dismantle colonial legacies.

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VIRTUAL ROUNDTABLE

Equitable COVID-19 Vaccine Access

ELS TORREELE AND JOSEPH J. AMON

Introduction

The rapid development of COVID-19 vaccines is an amazing achievement. It shows how much can be accomplished when human ingenuity, solid medical research capacity, and private-sector product development infrastructure are given extensive public support, from basic research to massive subsidies along the research and development (R&D) and manufacturing pipeline.

However, this historic accomplishment is hardly a success if vaccines are not available widely and equitably. Eighteen months into the pandemic, nearly 1.5 billion vaccine doses have been administered in the world. Yet 75% of vaccine supply has gone to just 10 countries.¹ Fewer than 25 million vaccine doses have been administered in the whole African continent, whose total population is 1.36 billion. While wealthy countries are competing to buy sufficient stocks to vaccinate their entire population multiple times over, many of the poorest countries are unable to procure enough vaccines to protect even their health workers. In high-income countries, children are being vaccinated, despite little likelihood of significant morbidity or mortality, while millions of vulnerable, often older, individuals in low-income countries are getting sick and struggling to find basic elements of care such as oxygen and hospital beds.

This extreme vaccine inequity and injustice is not just a moral failure, as called out by World Health Organization (WHO) Director Tedros Ghebreyesus; it is also an economic and human rights catastrophe, and self-defeating. Scientists have warned that the pandemic is likely to be prolonged and worsened unless this disparity is overcome, and Tedros has recognized that a rights-based approach is essential.² New variants of the virus are already emerging that could threaten the feeble progress made so far to contain the disease.

Amidst this global challenge, we are encouraged by a growing mobilization, led by access-to-medicines and health rights activists, to demand solutions to overcome what has been called “vaccine apartheid” and to challenge the artificial vaccine scarcity resulting from pharmaceutical monopolies (namely in the areas of intellectual property and manufacturing capability) and vaccine nationalism. In this roundtable, HHRJ talks with leading health experts and activists about this battle, the challenges, opportunities, lessons learned from previous access battles, and progress being made.

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Roundtable

ET and JA: *Thank you all for participating in this virtual roundtable. Let's get started with two questions: How unprecedented is the current situation? Compared to other challenges (for example, HIV drugs and expensive cancer therapies), what makes COVID-19 vaccine access inequities different?*

Carolyn: Related to both questions, it's clear that the emergence of the COVID-19 pandemic was more sudden and more urgent and more widespread, impacting everyone around the world directly.

Akshaya: Agreed. The scale of the COVID-19 vaccination challenge, especially the global ambition to reach people around the world as quickly as possible, feels unprecedented. The logistical challenge of administering billions of doses to people—many living in rural communities, others in conflict-affected settings, and others in places with weak health care infrastructure—is daunting. And that is compounded by the scarcity of supply, and their highly unequal access. So far, the vast majority of vaccine doses administered have gone to people in a small number of mostly high-income countries.

Reveka: In addition to the suddenness and scale of the pandemic, what has also struck me is the role of social networks and media pressures that defied evidence-based policymaking and undermined the population's trust in both science and politics. And while we must note that new vaccines have been developed in record time, their availability is too low to ensure equitable access for all—even for those considered high-risk groups. So yes, scarcity is a big problem. But also greed: from governments hoarding vaccine doses to pharmaceutical companies refusing to make intellectual property (IP) and critical health technologies available to others.

And there are other factors that makes access to COVID-19 vaccines different. Carolyn mentions everyone being at risk, and that's key, but it was wealthy countries that were first and most severely affected. And they had the power and money to

respond by securing (massive amounts of) vaccines even before safe and effective vaccines were available. While it is understandable that governments, under pressure by their constituents, saw the need to take these steps out of a sense of political survival, the result was to undermine global solidarity.

Michel: Let me add a couple of points on top of what others have contributed. First, the geopolitical context: whereas the North-South divide characterized the 2000s, today's world is more multipolar. China, the Russian Federation, and India, each in their own ways, have become heavy influencers of the geopolitical and economic multilateral agenda. Africa, despite its diversity, is uniting to emerge as a partner—no longer just a recipient—of aid.

Second, we're living in an era of rising nationalism, defiance toward multilateralism, and decreased commitment to global (or even regional) solidarity. The result is vaccine nationalism. The ethical or "moral" debate has disappeared, and even also the pragmatic considerations on global health and economy. The most scandalous and ethically problematic issue at the moment is the inequity of available vaccines to protect health care workers and populations most at risk—and beyond these priorities, to protect the broader population. High-income countries are rushing to vaccinate as many people as possible, while low- and middle-income countries are struggling to access vaccines for health care workers. The issue here is the inability of the global community to act together.

Fatima: Let me make the point more specific: in South Africa, we are now witnessing, firsthand, vaccine apartheid. Colleagues my age in the Global North are getting vaccinated, but in South Africa health care workers, the elderly, vulnerable workers, and others at high risk are still waiting for vaccine supplies. This is apartheid—wealth, geography, and patents matter more than people's lives.

ET: *The nature of the COVID-19 pandemic and the political context in which it is taking place are clearly quite different from earlier access challenges. How can we find solutions to the vast inequalities*

that exist in terms of access to vaccines and other technologies?

Yap: What strikes me is that we are not looking at the solutions that have worked in the past. For HIV, countries like India were brought to the table to mass produce antiretrovirals so that the population in need could have access to them. Today, not much is being done in that direction. There is no willingness to truly transfer the vaccine technologies and allow India and African countries to produce vaccines at a lower cost for their communities. No one wants to touch pharmaceutical patents.

Jockey: I agree. The business model that the multinational pharmaceutical industry has been applying remains unchanged, using IP and monopolies to protect and expand their profits. A major civil society win during the HIV/AIDS access campaign was to confirm, and apply, the right of countries to override pharmaceutical patents if they stand in the way of public health—for instance, through compulsory licenses. Today, the dominant discourse is one of voluntary measures, allowing companies to retain full control of the technologies.

Amy: Another unique feature is that for vaccines, the sharing of technology and know-how is critical to manufacturing at scale quickly. That simply wasn't the case for antiretroviral drugs and other medicines that have been the subject of access campaigns. What we need to address COVID-19 vaccine access is not just action on IP (for example, a World Trade Organization TRIPS waiver) but requirements that companies share knowledge and technologies across borders. So we have challenges that are far greater than in these earlier campaigns and efforts.

Michel: The main approach to access to treatment in the case of Ebola, SARS, avian influenza, and HIV epidemics was rooted in a North-South dynamic based on "solidarity," which resulted from geopolitical and economic interests and was realized through a lens of development assistance and aid. COVID-19 has exposed our global interdepen-

dence with regard to health as never before, as well as the limitations of such an approach.

ET: *I gather, Michel, that you are referring to the failure of COVAX, which essentially is built on that same premise, and governed by mainly Western donor countries and institutions. What is especially noteworthy in terms of the breakdown of solidarity is that the same donor countries that set up COVAX competed with it and with one another to secure most of the limited supply of vaccines, leaving supply for the poorest countries at the back of the queue. In early April 2021, COVAX announced the delivery of 38 million doses to over 100 countries, whereas the rest of the world (mostly wealthy countries) had already administered over 550 million doses.*

Carolyn: Many developing countries realized too late that they could not rely on COVAX for timely access to COVID-19 vaccines and that they would have to secure their own doses in order to respond to the epidemic in real time. But their capacity to negotiate bilateral deals is variable, and they are coming late to the game, even if they have the funds to purchase.

Fatima: At the end of March 2021, South Africa—the African country most affected by COVID-19—was still waiting for its first delivery through COVAX. We ended up obtaining a clinical trial supply of the Johnson & Johnson vaccine that allowed the vaccination of 250,000 health care workers. At the end of March, we were waiting for supplies to arrive through bilateral deals and through the African Union, all of which are highly secretive, non-transparent, and not being disclosed to the public. This is shameful.

Reveka: At the beginning of the pandemic, we were all joining forces and proclaiming that one cannot be safe until we are all safe. But those with the capacity to do bilateral deals with manufacturers did so in parallel. It is a clear sign of failing multilateralism, and frankly unacceptable that states openly disregard international mechanisms for sharing

doses and undermine global solidarity, with, to a certain degree, the acceptance or even demand of a big portion of the population.

JA: *Institutional failure and breakdown of solidarity are themes that many of you raise.*

Sharifah: Unlike when the struggles for HIV drugs took place, at this moment there is very little trust in global institutions. Many of them are severely weakened and underfinanced, and this reduces the scope for agreements on global solidarity. I'm afraid national lockdowns too have focused priorities inward. It is harder to mobilize citizens toward global priorities because in many countries the crisis has been framed within national contexts.

Akshaya: I think the institutional failure is also a function of how international aid is understood: as charity. South Africa's delegation to the World Trade Organization (WTO) said recently at the WTO General Council, "the problem with philanthropy is that it cannot buy equality ... If there are no vaccines to buy, money is irrelevant." If there isn't a shared recognition of human rights as fundamental, then there's no hope for an effective institutional response.

Judith: The global governance architecture that stands in the way of COVID-19 vaccine equalities is similar to other access challenges. Despite a strong normative human rights foundation, the fragmentation of international law and weak accountability for obligations of international cooperation inhibit the enjoyment of the right to vaccines on the basis of global equality. One concrete example is the seemingly entirely separate spheres of international human rights law and international trade law. The result of this fragmentation is the failure to suspend IP protections under TRIPS, and the hoarding of vaccines by wealthy countries. The United Nations (UN) Committee on Economic, Social and Cultural Rights has labeled the current situation as discrimination in the right to access to vaccination at the global level.

JA: *Judith, the Committee on Economic, Social and Cultural Rights' statement is provocative, but the statement doesn't develop this argument at all, and the only other mention of discrimination is about state obligations. Is this simply a rhetorical flourish, or is there an opening here for a more meaningful discussion of the transnational obligations of states?*

Judith: In fact, the Committee on Economic, Social and Cultural Rights has devoted significantly more attention to unpacking transboundary obligations during COVID-19 than it has in previous contexts. Much of this interpretive guidance is found in the committee's three statements on COVID-19, and it remains to be seen how it will be applied in international human rights review processes, including the periodic state party reporting process for the International Covenant on Economic, Social and Cultural Rights (which is resuming in 2021), under individual complaints procedures, and by the Human Rights Council, including during the Universal Periodic Review. Transboundary obligations were also very prominently highlighted in early WHO guidance on human rights in COVID-19; yet since then, WHO leadership and guidance has tended to talk in terms of moral failures and inequitable distribution, rather than maintaining its early embrace of transboundary human rights obligations.

Carolyn: One could surely hope that this crisis which envelops us all and which has laid bare so many weaknesses of national and international institutions and systems could open the way for the broader discussion on obligations at all levels. Transnational obligations have had very short shrift, but they are clearly critical to the realization of the phrase "no one is safe until we are all safe." So what is the responsibility of wealthy countries—which have bought all the available vaccine production—to ensure safety for all? Who is responsible for ensuring that countries are able to test their citizens and really control pandemics effectively? Where is the space for fleshing out these obligations and ensuring accountability? Can the

crisis engender meaningful discussion and action on these issues?

Michel: Interestingly and probably unfortunately in this case, international trade law preceded international human rights law. However, there may appear cracks in the strong legal patent protection. The recent announcement by the Biden administration that it may endorse an IP waiver on pandemic vaccines in "extraordinary times" definitely opens a window of opportunity, even if it has no immediate consequences on access to COVID-19 vaccines. The Independent Panel (www.theindependentpanel.org) calls on the WTO and WHO to urgently convene manufacturing countries and manufacturers to discuss the voluntary licensing of COVID-19 vaccines and technology transfer. It also says that if the call is not followed by action within three months, a waiver on IP should be imposed by the WTO.

JA: *Back to institutional failures—it's not just weak multilateral organizations but also the way that pharmaceutical companies have acted, and maybe a rather timid civil society voice as well?*

Reveka: We cannot forget that the pharmaceutical companies have a lot of power. We need them to research and develop new medical products, and they should not (a priori) be the enemy. Sadly, this pandemic has brought to light brutally the tensions between a private sector (which received significant public investment) that prioritizes profit and the public health imperative of protecting the world. Maybe greed can be considered by some as too strong a word, but it is unconceivable for a medical humanitarian actor that any organization or private actor in the current pandemic will put making a dollar first, before stopping the biggest health crisis of our time. The problems of capacity and IP all stem from the lack of acknowledgment of medical products as collective public health goods. International agreements do not have—even in extreme cases, even temporarily—adequate mechanisms to override existing agreements that constrain access, and there is little interest to push for technology

transfer or to increase the capacity in countries and regions lagging on the development and safe production of medical products.

Michel: While the voice of civil society is heard in Geneva and on social networks, it has not been as strong pressuring leadership at the country level as it was during the HIV/AIDS crisis. There are many reasons for that, but it's quite a paradox, if you think of the obvious dominance of inequities in the vulnerability and socioeconomic impact of COVID-19.

Sharifah: Michel, I think that part of the challenge for civil society is that COVID-19 is not the only unprecedented crisis that the world faces. There are currently numerous global crises—and social movements—related to climate change, Black Lives Matter, MeToo, etc. These movements bump into one another and risk crowding out solidarity movements from the Global South, such as refugee movements and access to essential medicines. On the left, we have failed to galvanize these movements as part of a broader struggle against common enemies, through a collective human rights framework. Issues such as access inequities in the COVID-19 vaccine have to compete with other movements for space and attention from people everywhere, which makes it much harder for them to make an impact.

Akshaya: I am less pessimistic than some of my colleagues. I'm incredibly inspired by the diversity of people who are speaking up in favor of universal vaccine access and pushing for a People's Vaccine. COVID-19 vaccines should be treated as a "global public good" accessible to all. But admittedly it remains an uphill battle.

ET: *Could it be that another contributing factor is that there is not necessarily a common view among health advocates on what is needed? While the call for a People's Vaccine resonates globally as a political call to treat medical technologies as a global common or public good, and make them available where needed, there does not seem to be a shared*

view on what exactly is needed for that. For instance, Yap—you have argued for a needs-driven approach to vaccination based on local context and epidemiology, instead of the "one size fits all" approach of vaccinating 70% of the population everywhere. Can you say a bit more about that?

Yap: In many African countries, we are just starting to vaccinate a tiny part of the population, and there is not necessarily a pressing sense of urgency to get vaccinated, as COVID-19 does not necessarily represent the biggest (health) challenge that people are facing. Few countries are still in lockdown, and many have so far managed the pandemic reasonably well through the implementation of other infectious disease control measures.

Michel: I believe there is an even broader point here, related to the weakness of our global institutions to deal with pandemics. There is currently no global strategic guidance on how vaccines should be deployed and on what coverage should we aim for. Ignoring WHO's equitable allocation framework, wealthy countries are moving on the assumption that vaccinating as many people as possible within their countries will allow the national economy and social life to reopen. And for now, they seem relatively blind to how health will remain interdependent on what is happening in other countries and continents.

Another point that seems to stand in the way of a concerted global advocacy effort is that, in my view, we need to separate the debate on immediate allocation of existing stocks from the issue around broader access, including scaling up manufacturing in the mid-term. The two issues do not raise quite the same ethical considerations and should not be confounded in terms of strategy or tactics.

Reveka: I want to come back to the question of what the optimal response strategy would be. Politics and social pressure sometimes lead politicians to make decisions that are not based on solid evidence. This also affects civil society and our ability to articulate demands. We have seen many examples of ques-

tionable scientific practices, like publishing critical data through corporate press releases instead of independently verified scientific publications, or decisions taken based on weak studies, which then later need to be overturned, or without transparency on the underlying data, which results in people losing confidence in science and wondering whether the accelerated development of vaccines was done with the required rigor. It is discouraging to see medical journals publishing articles and studies ahead of peer review that have serious flaws. Similarly, politicians are pushing to include products not demonstrated to be as effective as routine medical practice, and then there is lack of informed consent, and other ethically questionable practices that have occurred in this pandemic, all of which are likely to undermine the population's trust in scientific processes or at least introduce confusion and doubt.

JA: *Fatima, can you talk about what's happening in South Africa?*

Fatima: In South Africa, the situation is indeed acute. With over 1.5 million confirmed cases and over 53,000 deaths (which represent nearly half of the 115,000 deaths across the whole continent) by the end of March, the impact of COVID-19 on our society had been dramatic. People are desperate to get access to vaccines, but as I have mentioned, we have hardly had any access to vaccines so far. But I agree with Yap's broader point: the key issue is the prioritization of groups most affected, not based on wealth, medical insurance, nationality, or gender but on vulnerability and risk. Global allocation protocols must include all people in each territory—prioritized on the basis of health occupation (frontline workers), age, and comorbidities.

Looking at South Africa's response to the COVID-19 pandemic, it is different from—and similar to—past challenges, such as that regarding HIV/AIDS:

- Due to the nature of a mutating, highly transmissible virus, the socioeconomic and public health impact has been visible to everyone. Both

the impact on communities and the responses of governments and businesses have been in the spotlight.

- Unlike HIV/AIDS, we have not had to deal with government denialism about the science and evidence; however, we have had to deal with a lack of transparency in relation to the timely sharing of scientific decisions on vaccine selection, in addition to multiple lockdowns and regulations that have chilled freedom of expression and assembly rights and, in some cases, made little public health sense. This has all contributed to a lack of social cohesion.
- Civil society and faith organizations have, as for previous diseases, had to work on addressing hesitancy among communities, both in terms of testing for COVID-19 and in terms of accepting the need to vaccinate against infection.
- Unlike with other diseases, many governments rapidly allocated resources when they realized the impact of the pandemic on the global economy, and made funding available for vaccine research. Governments decided to prioritize and fund rapid and necessary research, but they need to replicate that for other diseases too, especially neglected diseases.
- Regulatory authorities have worked at breakneck speed, which shows they could do the same for other diseases.

But the main difference is that we thought we would be able to do better this time around, given the suffering and death that we experienced with HIV, where lifesaving testing and treatment were withheld because of the conduct of our government then, as well as the pharmaceutical companies that held the rights to lifesaving medicines.

ET: *You have all painted a pretty bleak picture of the current state of affairs concerning the world's response to the pandemic, in particular around access to vaccines, and the failure of global institutions to foster equity and fairness in the face of nationalism, greed, the breakdown of solidarity, etc. Are there reasons to be optimistic moving forward?*

Jockey: There are a few things that give me hope. While some of us have challenged patents as a barrier to affordable and equitable access to health products for years, the COVID-19 pandemic may be a turning point that forces local and global policy makers to rethink the broken IP system. Approaches that were long sidelined—such as compulsory licenses and the public production of essential health technologies—are openly discussed, even within countries like Germany and Canada. The proposal by India and South Africa, with the growing support of a majority of countries, for a WTO TRIPS waiver is an example. And while of course this proposal is opposed by wealthier countries and by pharmaceutical companies, the pressure is mounting on the WTO to take action to break the gridlock.

Countries have also started to look at capacity in local production and to support R&D. This will be useful in the long term and for other diseases in the future if they continue and expand support to local capacity. Investment in local R&D and local production, including technology transfer, is important, in addition to getting rid of IP barriers. The initiative of TRIPs waiver measures raised at the WTO is a good attempt. But, in my opinion, it should not be limited to COVID-19. It should not be a case-by-case solution. It should be a general measure that is enforced automatically without needing permission from WTO members when we have similar challenges in the future.

Fatima: Despite being extremely disheartened by the conduct and lack of transparency of some governments and vaccine manufacturers, I am encouraged by the accelerated vaccine research being done by public health scientists and researchers, the advocacy for access globally, and the solidarity among older and newer activists with the science and public health community and worker associations. I am also inspired by the battle being waged at the WTO to once and for all show the world why treating medicines as a commodity is not normal and fuels inequality in access to lifesaving interventions.

Sharifah: I didn't expect to get a vaccine so soon, so that is extremely positive. But the most critical fight is that of increasing vaccine supply within the Global South. I think this must be done in a more sustained manner that includes increasing manufacturing capacity so that the Global South can rely on a broader number of countries beyond Brazil, China, and South Africa. We could use this crisis as a catalyst to create a broader manufacturing base for more essential medicines. Most likely, though, the fight that we can win is to increase the capacity of COVAX.

I really welcome the fact that the US administration and New Zealand are now pushing for a TRIPS waiver. However, reflecting on the last TRIPS waiver, which took a significant amount of time to develop, there is a need to ensure that these negotiations break the mold of international law-making. Countries need to do three things: First, because the WTO makes law only by consensus, we need more countries on board, especially European countries, which are still officially opposed to the waiver. Second, we need to prioritize the WTO negotiations for a waiver because the world doesn't have time. And third, in the interests of promoting the rights to health and life, we need to ensure that countries don't water down the provisions of the current proposals, thereby making them unusable for countries of the Global South in the future. We have seen this before in previous negotiations, so we need to be alert to this as human rights activists.

Yap: Like Sharifah, I am hopeful that eventually African countries will be able to locally produce vaccines, whether the American, British, Chinese, or Russian vaccine. Where there is the will, there is a way. If Western countries have not yet understood that the strength of a chain is measured from its weakest link, then they will soon learn that until the entire world is free of the virus (and its variants), no country can rest—none. I am also optimistic that African philanthropists will further support their governments in acquiring the technology (not the dose only) to locally produce vaccines to face ongoing and upcoming pandemics.

Amy: Right now, we are replicating the worst days of the early campaign for HIV/AIDS drugs access: major international organizations are focusing their energy on efforts that rely on the largesse of rich-country governments and vaccine manufacturers, with no plan adequate to meet global health needs. I don't know how many remember, but before the wave of HIV/AIDS advocacy around the world changed the approach, UNAIDS had something called the "Accelerating Access Initiative," which did nothing of the kind. They would claim success when they got a company to agree to a 60% discount for drugs that we know today can be made for less than 1% of that list price. Those deals could never meet the need and had all kinds of limitations. Activists instead worked to reveal the actual costs of production for these medicines and campaigned to get countries to address patent barriers, to prevent the United States and other rich countries from sanctioning countries that used generics, and then worked to build supply chains for those generic drugs, as well as treatment programs. Today, we've forgotten all about that early model. That's what we need in this setting too—a global campaign for universal access to safe and effective COVID-19 vaccines and therapeutics, designed with public health goals in mind.

Carolyn: That is a very interesting parallel, Amy. When ACT-A and COVAX were established, I had hope that the need for equity in access to diagnostics, therapeutics, and vaccines across the world would inform the response to this global pandemic. I grew less hopeful over time.

The reality of the rampant vaccine nationalism that characterized the approach of the very countries that agreed to the principles outlined for ACT-A was chilling. I became quite cynical that we—the countries of the less wealthy world—had a realistic chance of seeing equity in vaccine access. The lack of resonance of the #PeoplesVaccine campaign, as well as the blocking of the application for a TRIPS waiver at the WTO by those countries that have preordered two, three, or five times the amount of vaccine required by their populations,

reinforced my cynicism. Selfishness and political self-interest appeared to be the principles governing vaccine access, which are anathema to public health and human rights. India's move to block the export of AstraZeneca vaccines simply paralleled the approach of the wealthier world.

Yet the recent move by the United States to drop its opposition to the TRIPS waiver suggests that activism might still work. Perhaps humanity can act with reason rather than selfishness. We will see.

JA: *In addition to the justice and moral arguments for equitable access, there's also an argument appealing more to people's self-interest: that unless we ensure access to vaccines to all on a timely basis, including people in developing countries, we are at risk that vaccines will rapidly become ineffective because of the emergence of COVID-19 variants. What do you think are the most critical things to do now to avoid such a scenario?*

Amy: In my view, the most critical need now is to scale up vaccine manufacturing in a manner that can reliably meet global public health needs. Ideally, we would do this in a way that is distributed around the world and yields the most benefits in terms of innovation—which means production in different regions and enough public control over the process to ensure fair prices and the sharing of information, as well as that new innovation can be undertaken without a centralized corporate veto. Without public funding, we would not have these vaccines, and some of them, particularly the mRNA ones, could allow both rapid adaptation to variants and dramatic advances in vaccines for other diseases.

If we focus on building a real technology transfer facility that protects the public interest and that operates globally—for example, through WHO—we would have a model that could also be useful for climate technologies and other health technologies in the future. This is the time to figure out what the contracts for public research funding, or for scaling manufacturing plants, should look like to protect the public's interest. COVID-19 will

not be our last pandemic, and climate change represents an even larger challenge that we should be thinking about in everything that we do.

Michel: The first fight to win is that of the coverage of health care workers everywhere, which requires redistributing the vaccines that are currently available. This is what we need to do today.

The second, which we can start tomorrow, is indeed as Amy says: to significantly increase manufacturing capacity for the short term. This will require discussions on voluntary and compulsory licensing and technology transfer, in addition to the urgent need to fund such regional manufacturing platforms and define their public/private and national/regional status.

At the same time, and as a third point, we must design and agree on a global vaccination strategy: What is it that countries should aim to achieve in terms of coverage? Who are the most vulnerable to protect? Who are the key people to protect to reopen the economy? And as Yap already noted, this may vary from region to region.

My next two points are for the medium to longer term: How can we make sure that the inequities that we are seeing now do not resurface when the world has to re-vaccinate people because of expired immunity or because of the emergence of variants escaping neutralization by antibodies elicited by current vaccines?

And finally, critical for the future and linked to the previous point: Which R&D and manufacturing system should the world build or redesign for pandemics after the crisis, based on lessons learned? And how can the world agree on revisiting the system(s)? One thing is clear: if the system remains the same, the risks of tragic inefficiency will remain for the future.

I am hopeful that the unprecedented health and socioeconomic impact of the pandemic will be a sufficient trigger for a renewed multilateral debate. The increasing interest that countries express toward the idea of a pandemic treaty or framework convention may be an early positive signal, despite the major geopolitical tensions that prevail.

Times of crisis are also times of opportunity.

The window of opportunity is narrow, but the next six months will be months of intense discussions on preparedness and response at national and international levels. The World Health Assembly, the G7, the G20, the UN General Assembly, and many other fora will be drawing lessons from the last year and engaging in negotiations to develop a new international system for preparedness and response. The Independent Panel for Pandemic Preparedness and Response is clearly recommending shifting from the current market-driven system for R&D on vaccines, diagnostics, and therapeutics for pandemics to one based on the fundamental consideration that these are global common goods.

Fatima: The recognition of the crisis by the UN Human Rights Council, UN experts, the UN secretary-general, WHO, the WHO director-general, UNAIDS, World Bank leaders, Anthony Fauci, the Vatican, the African Union, the International Court of Justice, the Africa Centres for Disease Control and Prevention, and the Anglican Church of Southern Africa is promising—it marks a reckoning with power rooted in IP. While the supply crisis in the European Union, Canada, and the United Kingdom has shown that there has to be a shift in the way that global leaders and CEOs respond to the lack of adequate supplies of safe and effective vaccines, these countries are literally—even with such a massive supply crisis—allowing companies to continue to sit with the knowledge that could save lives, restricting its widespread scale-up and use, and telling black and brown people to wait until 2023 and 2024 in some cases. This is absurd—a ridiculously unfair world order—yet we have been here before.

COVAX and C-TAP may be critical—but at the current rate at which they are able to source supplies and foster cooperation, they will not be the solution for the access crisis, especially in the Global South. They are also too deferential to pharma power and influence and rely on volunteerism, which is not sustainable in my view. Our challenge is to get as many supplies to the Global South as soon as possible—and this is why the TRIPS waiver, other compulsory licensing measures, and the vol-

untary transfer of technology need to be vigorously pursued. It is critical to have manufacturing capacity, to dispel the myths of the implications of the TRIPS waiver, and to use other means of sharing technology fairly (especially for research funded by public sources). Most importantly, we have to remind everyone of the impact that interrupted and insufficient access in poorer and middle-income countries will have—especially as more variants are discovered.

Reveka: I believe that we are in an impasse; we need doses to come quickly to be useful. Until production matches need, we will continue to struggle to find a way for the equitable allocation of available doses. It is difficult to say to someone in the United States or United Kingdom that they have to wait for their shot because, for example, health workers in Cameroon need to be vaccinated, when maybe that person in the United States or United Kingdom has lost someone and is afraid of the pandemic or they just need the economy to open and go back to work. Increasing the availability of doses is key, and we can do that if decision makers work together to push for faster technology transfer, lift IP barriers, and keep an eye on pricing and transparency.

Yap: I am optimistic that, eventually, communities will push hard enough to get what they need considering that they don't all need the same things.

ET: *In addition to the global access challenges, do you see other inequities, challenges, or discriminations playing out at the country level?*

Carolyn: The exact inequality challenges we see at the global level are playing out at the local level—and also in terms of the overall pandemic response. Work-from-home orders apply only to the wealthier citizens who have access to computers and the internet. In my country, Jamaica, testing for COVID-19 is very limited within the government system, and private testing is expensive, so it is available only to those who earn high wages. Testing in workplaces such as factories and courts

is nonexistent or minimal. Education from home is hardest on those children whose parents are barely literate or have no internet access or devices on which their children can log in to attend classes.

And evidently, we are seeing this also play out for vaccine access. While the Jamaican government has presented its vaccine rollout plan, it works best on the internet appointment link, as the phone number for appointments is not usually answered. Those with transportation can afford to go from vaccine center to vaccine center in hopes of getting the last couple doses in a vaccine vial that would otherwise go to waste—and they often get them.

Those with private doctors get their names on official lists for vaccination, while those without private family doctors don't even know this is possible. My heart hurts for the lessons that the world and my country have not learned from this pandemic.

Judith: I agree—we can see it also in the United Kingdom. Even if vaccination take-up has exceeded expectations, with over half the adult population, and 87% of those over 50, having received a first vaccine by March 2021, the rollout did face challenges in terms of inequalities in both the vaccine prioritization process and take-up.

There has been some effort to reach and support these and other communities with low vaccine take-up or particular support needs (for example, persons from minority groups, persons living in economically deprived areas, persons with learning disabilities, homeless persons, asylum seekers, and refugees and migrants). This includes financial support for local health authorities to tackle vaccine inequality; vaccination clinics for learning disabled persons in the city of Liverpool; pop-up vaccination clinics in places of worship and community centers; and campaigns and messaging involving ethnic minority stars to encourage vaccine take-up.

Amy: There are absolutely shameful disparities in access to vaccines in the United States, everywhere. In my home state of Connecticut, which is celebrated as a success story, my neighbor's 16-year-old

daughter just got vaccinated, but half of all people who are over 75 or Black have not been vaccinated. We just have not built the systems to reach people, even though we know how to do it. Community groups, especially the smallest and the most local, have been hugely successful in reaching communities that are not well connected to the health care system, for example through door-to-door campaigns. We have also seen some good initiatives like mobile vans and pop-up clinics in churches. But they have not been brought to scale, and states are also opening up again, putting these same communities at grave risk. Because we have a history of vaccine hesitancy in the United States, we know how to address it. You need trusted intermediaries to help people learn about and get comfortable with the vaccine, and you need to make access easy. Most state and local governments aren't taking this approach.

Fatima: The risk of exacerbating inequalities as a result of differential access through the public and private health care systems also exists in South Africa—for instance, if we allow vaccine producers to sell directly to middle men and private providers. Thus far, however, there is no user fee, so vaccines will be free; and thus far, there is a single access and allocation plan through the government. This is a victory for civil society—we have argued and pushed for this for a year. Also, the government is now including undocumented persons too—another victory. Of course, we still have to see the first shipments of vaccines arrive and then be distributed widely.

A key challenge I foresee is when we will be barred from traveling from Southern Africa to other parts of the world because we have no vaccine passports or proof of vaccination for some time to come—even while we wait and wait for supplies. Additionally, with new variants, the risk we face is when others who are vaccinated in the Global North start traveling here—we do not know enough from an epidemiological point of view what this might mean for our country and its people.

ET: *Carolyn, how will this play out in the Caribbean—tourists can come in, but residents can't leave?*

Carolyn: I am not aware of any initiatives for vaccine passports in any region of the Caribbean, but given the region's economic dependence on tourism, I would not be surprised if the idea gains currency here. Already, there is talk that vaccination will be mandatory for some workers. A COVID-19 vaccine passport seems like a simple step away. I do not agree with either mandatory vaccination or vaccine passports. They are a breach of one's right to control one's own body and health. If my access to vaccines is limited because of my economic circumstances in my country, or the economic circumstances of the country I live in, then to require me to have one to travel is a complete breach of my right to equality. I think particularly of seasonal workers (such as hotel staff, farmworkers, seamen, and cruise ship workers) who depend on travel to provide for their families but who, by virtue of their youth and health, are unlikely to get vaccinated in countries with limited vaccine supplies. What a gross discrimination that would be for their right to equality of access, right to work, etc.

Michel: COVID-19 has clearly been a revealer of the many profound inequities that exist between and within countries. A revealer of the deep reality of the social, economic, political, cultural, and commercial determinants of health. There have been inequities in who is more vulnerable to infection and to progressing to severe forms of the disease, in who is more affected by public health countermeasures, and—now—by who has access to vaccination.

Any global initiative to prepare and respond better to future health pandemics requires not only that health be understood as a technical and medical issue but that it be repositioned at a political level in its economic, security, developmental, and social justice dimensions.

On the passport question, I am rather pragmatic, and—unsurprisingly for those who know

me—I believe in harm reduction. I live in the European region, and the question is no longer about whether, but how. The pressure is too high to be countered. It will happen. If the UN does not do it, airlines will do it first. So let us focus our attention on how to minimize the unequitable impacts it may have, rather than say no. Let's imagine how we can make the tool into a real "pass" that can help travel and reopening the economy, but not be a constraining requirement.

Reveka: I disagree, I think we should stop talking about vaccine passports until we have enough data on (1) protection from transmission; (2) duration of that protection; and (3) vaccine availability in enough doses to cover the whole population. Engaging in a debate on trade-offs without first meeting those conditions is giving credit to the idea of vaccine passports, which I believe we should not do.

Requiring proof of vaccination to move around can be endorsed only if everyone has the same access to the vaccine and the document proving vaccination.

Sharifah: I have four key concerns about vaccine passports. First, as others have said, they are likely to lead to discrimination against groups who, for whatever reason, cannot take up the vaccine. This will moreover disproportionately impact marginalized groups (such as refugees; Black, Indigenous, and other people of color; and people who are living in poverty). Second, because there are several vaccines on the market, there is a risk that passports will create hierarchies, which damage national vaccination drives because people will rationally demand vaccines that have the most benefit to them. This is really bad for health systems. Third, vaccine passports will invariably involve private companies that are already coming forward to issue these certificates. This is part of a longer tradition of the commodification of health (as opposed to thinking about health as a human right) and may include handing over data from populations into private hands. Ultimately, with commodification, we will lose the public health argument, which will invariably lead to fraud. Lastly, this will be seen as

compulsory vaccination by stealth, and this will play into the hands of anti-vaxxers. This may seem okay in the short run, but as this crisis has illustrated, trust is essential to collectively respond to crises—and so this may harm health systems in the long run.

Amy: My fear is that we are talking about passports before even making access universal. How can you penalize people for not being vaccinated if we have not made it possible for them to get a vaccine, whether in the United States or around the world? In addition, the potential for a real, brutal kind of global apartheid is obvious, and truly immoral, particularly when we have all of the tools we need to do this differently and make vaccines available to everyone around the world.

The United States is also distinctive for how much power we give private market actors. If we see requirements for vaccination, they are more likely to come from the private sector, places like universities and employers, and of course that raises major accountability questions. I'm also worried that in the United States we're skating over the very real histories of abuse and neglect that have given many people reason to want more information and time, and we're trying to push everyone into a vaccine, creating a backlash.

It's hard to see how mandates could be legitimate if we have not built the programs needed to give everyone access. That said, I think these issues are complex.

JA: *The discussions I've seen comparing possible COVID-19 vaccine passports and international vaccination cards (for example, for yellow fever) all seem a bit superficial. There are other, perhaps more important, historical examples—and concerns—that should be considered.*

Amy: This pandemic has highlighted something fundamentally tragic about the US civil liberties tradition. Here, it's easier to argue that you have a right to *not* wear a mask or take a vaccine than it is to argue that you have a right to access to testing, vaccines, and health care. So we should be careful

about playing into that history, about suggesting that measures to protect all of us are somehow unjustified, or that the government is always a threat. Of course, health and rights advocates have worked hard against punitive public health approaches like mandatory testing—think of the HIV era—and in general, history suggests that punitive approaches are deployed mostly against the poor and marginalized, and that they just don't work very well. They also clearly will amplify real inequities here in the United States, given who has access to the vaccines and who is hesitant. We do have some new dynamics with white evangelicals and Republicans expressing hesitancy, part of the legacy of Trump and the nihilistic politics of the Republican Party—but here, too, I think mandates are likely to build resentment and that other approaches should be tried first.

Fatima: For me, inclusion, nondiscrimination, and dignity are the key rights issues in this passport debate. However, I think we should differentiate between someone refusing to take a vaccine (an antivaxxer) and someone who is unable to access one. The UN Human Rights Council, WHO, and scientists should lead these discussions. But I'm not optimistic. These passports are pernicious vaccine nationalism version 3 (version 1 was the bilateral buy-up by richer nations, and version 2 was the limited manufacturing deals for some markets only). It will block off large parts of the world from others.

Jockey: I agree it is a complex issue, but I can't quite see any circumstances today where vaccine passports can be useful and deployed in ways that do not exacerbate discrimination and inequalities. It is a trade-off between individual and collective rights in fighting against COVID-19. Balancing between the two is challenging. Models in the countries with tight restrictions and the ones with compromise measures have pros and cons.

Yap: In West and Central Africa, we are just starting to vaccinate a tiny part of the population, and the idea of a vaccine passport is quite far away—and also useless because few countries are still in lock-

down, so there's no need to get any certificate to be allowed to live a normal life. The question will be different, of course, with regard to traveling. WHO should lead the discussion and ensure that no one is left behind. Until everyone has access to the vaccine, no one should have a passport. Otherwise, it is a culture of privilege.

ET: *I would like to come back to other inequities or forms of discrimination you see that are exacerbated in this COVID-19 vaccine access crisis.*

Judith: COVID-19 vaccine access inequalities also risk exacerbating health inequalities more broadly through the severe impact of COVID-19 and COVID-19 responses on health systems and social determinants of health in countries or among communities with low access. Vaccine inequalities risk further exacerbating other forms of inequality, including economic inequalities that have been driven by COVID-19, with profound human rights implications.

Sharifah: I would point to three specific areas of inequity, and where barriers to universal health coverage are overlapping with those to ensuring access to COVID-19 vaccines:

1. *User fees*

Many countries are attempting to recoup some of the costs of purchasing vaccines by imposing user fees. For example, Egypt has announced that it will charge US\$12 for the vaccine, which is likely to deter the poorest people, who have been severely affected by the crisis. India has introduced a dual-track system in which patients in private hospitals pay, while those in state hospitals do not. While this may seem equitable, in practice it means that richer people are getting to the front of the queue. *Free at the point of access* means that the vaccine is provided solely according to need, regardless of ability to pay. It has even been suggested that giving small incentives (such as *negative* user fees) for the poorest people would incentivize people to vaccinate their children. I am also sympathetic to broader

support for people to receive their vaccinations at work if possible and for paid sick leave to recover, especially for those in precarious jobs.

2. *Technological barriers to access*

Even where the vaccine is offered free of charge, other obstacles are excluding vulnerable people. For example, many countries are relying on technologies in order to vaccinate their populations. In India, people need to use apps, such as the Co-WIN 2.0 portal and the Aarogya Setu app to access the vaccine, and Uganda and South Africa are using digital ID systems for vaccination. Despite rapid digitization across the developing world, many older people, as well as poor people and migrants, lack access to technology and national ID systems and may therefore be excluded by these policies. Nondiscriminatory distribution entails priority based solely on clinical need, not knowledge of or familiarity with technology.

3. *Discrimination*

Some countries, such as Kenya, have proposed that private companies be able to buy vaccine supplies to vaccinate their employees and relatives. Kenya has also prioritized diplomats over health workers, and Indonesia has suggested that the more “productive” members of society be vaccinated first. Such policies reproduce the logic of commodification, as vaccines are given to more affluent or “productive” members of society at the expense of those who may need them the most. It is essential to ensure that vulnerable and hard-to-reach populations are prioritized and that intersectional characteristics are given consideration over and above this. Transparency is essential here. Phrases such as “officials with strategic importance” in national policies risk being abused into allowing wide groups of people—who are not particularly vulnerable—to benefit. Clear guidance helps avoid such loopholes.

Akshaya: At Human Rights Watch, one area we are monitoring is the systematic exclusion of certain populations—for example, the exclusion of Pales-

tinians under occupation from Israel’s vaccination program. Sometimes there is progress: countries like Lebanon and South Africa have backtracked after officials initially claimed that refugees and undocumented migrants would be excluded from their vaccination programs.

We’re also focused on the importance of inclusive and accessible outreach to marginalized populations and the extra hurdles that some may face in accessing vaccine registration systems. In some states in the United States and in some countries in Europe where vaccine rollout is further along, we’ve seen residents denied vaccine access because they lack valid identity documents. In the United States, our researchers have also documented the impact that the digital divide has had for older people’s access to the vaccine.

Reveka: Like Akshaya, I would highlight discrimination around refugees and migrants, where, for example, people are packed in different camps all across Europe (more specifically, in Greece) and in the Palestinian territories. Of course, there is already a big discussion related to the situation of prisoners in the United States and in many other countries.

But on the Palestinian territories and Israel: as COVID-19 spreads through the West Bank and Gaza, Palestinians remain unprotected while Israel, with a large availability of vaccine doses, carries out its fast-paced vaccination campaign and is now pursuing herd immunity, without any visible intention to significantly contribute to the improvement of vaccination rates in the Palestinian territories. As of mid-March, less than 2% of Palestinians had been vaccinated in the West Bank and Gaza—an alarmingly small number in light of the third wave of the deadly pandemic.

And if I may say one final thing about vaccine passports: we need to push back!

We cannot just accept the introduction as a fait accompli. And if journals like *HHRJ* don’t push back and offer clarity on the conditions for introduction, then who will? I am aware that it may be a lost battle if some countries decide to introduce them. At the national level, the introduction of pass-

ports cannot be done unless the whole population has access, and only then should be led by human rights associations in collaboration with health experts. Internationally, clearly WHO would lead this discussion, but again: we need to push back!

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BOOK REVIEW

Global LGBTI Rights: Between Homonationalism, Homoromanticism, and Homocapitalism

KAVERI QURESHI

Out of Time: The Queer Politics of Postcoloniality, Rahul Rao, Oxford University Press, 2020

I teach a course in health and human rights at the University of Edinburgh. LGBTI rights are an important focus within the course. As highlighted by the Global Commission on HIV and the Law and the Lancet Commission on the Legal Determinants of Health, punitive laws, discriminatory and brutal policing, and denial of access to justice are fueling the HIV epidemic in marginalized, criminalized groups. But after reading Rahul Rao's *Out of Time: The Queer Politics of Postcoloniality*, my teaching will never be the same. Two slides from my PowerPoint deck now strike me as particularly naïve. In the first, I show a map from ILGA—the International Lesbian, Gay, Bisexual, Trans and Intersex Association—depicting sexual orientation laws in the world. The map is color coded, with states that criminalize same-sex relations with death sentences or imprisonment depicted in shades of red, states that have decriminalized or never criminalized such relations shown in amber, and states that recognize same-sex marriages, partnerships, and adoption or parenting rights depicted in green. In the next slide, titled “sodomy laws and colonialism,” I show a long list of countries, former British colonies, with anti-sodomy laws criminalizing “unnatural” sexual acts under section 377 of the penal code or related formulations.

My message was to highlight the prevalence of homophobic laws but also, mindful of critiques of human rights discourse functioning globally as a discourse of cultural superiority, to stress that these do not reflect the inherent preferences of those countries but were first laid down by Western colonial governments. However, Rao's book calls out the oversimplicity of this message, arguing that we need to be critical not just of the consequences of treating LGBTI rights as a barometer of civilizational superiority—“homonationalism,” as framed by Jasbir Puar—but also of the perils of what Rao calls “homoromanticism”: the treatment of pre-colonial worlds as warmly inclusive of diverse sexual orientations and gender identifications, and the reluctance to apprehend postcolonial elites for their own role in cementing homophobic institutional frameworks.¹

Rao's argument begins with these ILGA maps. As he observes, the maps mobilize the competitive spirit of international relations, “applauding states that move in the direction of progress and shaming those that do not” (p. 38). However, “where value disagreements are at stake—when one state's ‘progress’ is another's ‘moral decay’—the motivational potential of such advocacy is less straightforward” (p. 38). Global advocacy efforts to entreat states toward progress in LGBTI rights may backfire, causing states to enact anti-homosexuality laws, particularly when top-down global queer activism has raised the anti-imperialist hackles of a conservative government, as in the case of Uganda, the focus of chapters 2, 3, and 5. In 2009, an anti-homosexuality bill was introduced in Uganda's Parliament, adding to the existing criminalization of

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homosexuality by creating a range of new offenses related to the practice and “promotion” of homosexuality out of a desire to protect the traditional family and culture. The bill proposed the new crime of “aggravated homosexuality,” carrying the death penalty. Parliamentarians presented homosexuality as un-African and imported. Advocacy efforts rejoined that the impetus for strengthening anti-queer laws originally imposed by British colonial authorities came from US evangelical Christians. Thus, homophobia was presented as imported, “romanticis[ing] the indigenous precolonial as a spacetime of unmitigated tolerance” (p. 45) while leaving unexplained the embrace of colonial laws and promulgation of new laws by the postcolonial elite.

Chapter 2 addresses this latter problematic through a detailed dissection of the transnational actors and processes implicated in the Ugandan anti-homosexuality bill. Rao traces the recent politicization of homosexuality in Uganda to the late 1990s, a time when the Anglican Church was rocked by a series of ordinations of non-celibate homosexuals as priests and bishops and turned to the Anglican Communion in the Global South for a more conservative support base. Yet Ugandan clergy were no mere pawns in a displaced Western “culture war” (p. 45). Indeed, Ugandan clergy explicitly refused the imperial attitude of Western bishops, rejecting homosexuality as their own, independent, reasoned theological conclusion. As Rao argues, recognition of the position that Ugandan elites could be simultaneously decolonial *and* homophobic “demands a more complex moral reaction than has typically been forthcoming from either liberal Episcopalians or their secular LGBTI allies” (p. 69).

Chapter 3 returns to the romanticization of the indigenous precolonial. It has been tempting for queer activists to rejoin claims that homosexuality is a Western import by scouring the archive for a usable history of precolonial same-sex relations. Rao suggests that such efforts are hamstrung not only by anachronism—the impossibility of reading back our global categories of gender and sexuality into the past—but by an “incuriosity about the pos-

sibility that non-normative desire might also have been stigmatized in the precolonial past, even if in ways that were distinct and less institutionalized than those introduced by colonial modernity” (p. 19). Chapter 3 digs deeply into the historical figure of Mwangi II, the last precolonial ruler of the Buganda kingdom, who according to the colonial archives engaged in “sodomy” with his courtiers. Between 1885 and 1886, some of these courtiers converted to Christianity and refused to indulge in Mwangi’s “unnatural” desires, angering Mwangi so much that he executed them. The “Uganda martyrs,” as they came to be known, were later canonized by the Catholic Church. This gave rise to an annual pilgrimage, in the outskirts of Kampala, to the site of their execution. The sheer visibility of this founding myth of Christianity in Uganda is intriguing: when a precolonial king’s same-sex intimacies and proclivities are so public, how can anyone claim that same-sex intimacy is alien to Ugandan culture? Yet the archive does not secure homophobia as a Western import. Indeed, some Ugandan historians claim that homosexuality was abhorred by the Baganda, although this is impossible to untangle from their efforts to rehabilitate Mwangi as an anticolonial figure, skepticism of the colonial archive, and denial of any non-normativity.

Chapter 4 explores British LGBTI activists’ justification of their leading role in the struggle to decriminalize homosexuality in the Global South as a form of atonement for the colonial-era sodomy laws. For Rao, this deployment is more than a little disingenuous, for British elites have been very willing to offer atonement for the homophobic laws laid down by earlier colonial administrations but have not been willing to do so, for example, for slavery. Further, the modes through which British actors have sought to discharge this obligation to undo the legacies of colonialism has exposed them to charges of neo-colonialism. Uganda is again a germane example, as the country’s aid dependency made it a particular target for international LGBTI advocacy. When the anti-homosexuality bill was passed into law in 2013, condemnation from donor states, Bretton Woods institutions, and the United Nations system was immediate. A number

of donors signaled their intention to delay, redirect, or cancel aid, and the World Bank followed through with the deferral of a US\$90 million loan to Uganda. In Chapter 5, Rao terms this “homocapitalism”: the World Bank’s endorsement of rosy futures of economic growth and productivity for states that embrace LGBT rights. Arguably, this may be more significant than homonationalism in certain contexts, the weapon of choice wielded by a global LGBTI liberalism, succeeding to convince through the consensual carrot of neoliberal reason where the stick of chastisement has raised certain anti-imperialist hackles. But clearly, there are deep dangers of collusion here, absolving the World Bank and other agents of global capital of “complicity in the production of the material conditions in which homophobic moral panics thrive” (p. 140). From now on, I will be teaching Rao’s political economic analysis of homophobia, which allows us to “account for social antipathy towards figures read as queer, without lapsing into orientalist accounts of a timeless and irredeemable ‘African’ homophobia” (p. 162). It also proposes a different response to homophobia than that focused on the human rights tactic of chastisement: a fight for global economic justice, to alleviate the precarity that has fed moral panics.

The necessity of queer investment in anticapitalist struggles is developed in chapter 6 through an excavation of the social mobilization that culminated in the 2014 decision by the Indian Supreme Court in *National Legal Services Authority (NALSA) v. Union of India*. This ruling recognized trans persons as a category of “backward” citizens, a category historically understood principally in terms of low caste, who are entitled to constitutional guarantees of affirmative action. Whereas homocapitalism seeks upward mobility by producing queer people as model capitalist subjects, “the Indian trans movement’s desire for backward caste status makes common cause with those relegated to the very bottom of the social hierarchy” (p. 175). Rao shows us that global LGBTI advocacy must mobilize rights-based approaches in less top-down and self-serving ways and be more attentive to the complexly negotiated, radical politics of local queer

activist mobilizations such as those of India’s trans communities, with their commitment to “the annihilation of all forms of hierarchy” (p. 211).

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BOOK REVIEW

Dissident Blood: Using Critical Feminist Study to Advance the Health and Human Rights of Menstruators

CAITLIN R. WILLIAMS, ASHLEY HUFF, AND BENJAMIN MASON MEIER

The Palgrave Handbook of Critical Menstruation Studies, edited by Chris Bobel, Inga Winkler, Breanne Fahs, Katie Ann Hasson, Elizabeth Arveda Kissling, and Tomi-Ann Roberts (Palgrave Macmillan, 2020)

Half of humanity has personal experience with menstruation, spending approximately half of their lives managing their menstruation, yet it is only recently that “menstrual health” has received more than passing attention in health policy.¹ The emerging field of critical menstrual studies looks to change that, drawing on lived experience and critical scholarship to frame menstrual health as a human rights concern over the life course. *The Palgrave Handbook of Critical Menstruation Studies* seeks to codify the field, exploring the meaning of menstruation to menstruators and examining menstrual health within diverse social and cultural contexts. The resulting *Handbook* is a tour de force, presenting work from 134 contributors across 72 chapters. As the global health community shifts its understanding of menstrual health from a sanitation issue to a human rights concern, Chris Bobel et al. provide a comprehensive interdisciplinary analysis to further rights-based approaches to menstrual health policy.

Historically, global health’s engagement with menstruation has been limited to menstrual hygiene management (MHM), which seeks to ensure that menstruators have access to safe and hygienic washroom facilities, menstrual products, and means to dispose of used products. MHM efforts have been framed around narrowing gender inequities in education by preventing menstruation-related school dropout. Such programs emerged in part from “decades of evidence indicating that educated girls contribute to healthier population outcomes.”² Thus, despite the inherently gendered nature of menstrual health, MHM has largely been conceptualized as a water, sanitation, and hygiene (WASH) concern underlying education, rather than a matter of sexual and reproductive health and rights.

While this conceptualization of MHM under the WASH sector was intended to depoliticize menstrual health—providing a path for progress in improving girls’ and adolescents’ access to menstrual products and safe and sanitary washroom facilities—this strategy has served instead to marginalize it. The vast majority of sanitation programs ignore menstrual hygiene, focusing instead on hand washing and latrine design, with neither the United Nations’ nor the World Health Organization’s WASH programs promoting menstrual health as a part of their sanitation agendas. Given this neglect of the specific needs of menstru-

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ators, the *Handbook* skillfully demonstrates how MHM's narrow focus ignores critical dimensions of menstrual health.³

The *Handbook* defines a new field of critical menstruation studies by examining (1) what new lines of inquiry, including research questions and social justice engagements, are possible when menstrual health and politics are considered across the lifespan and (2) what knowledge is gained when menstruation emerges as a dynamic category of analysis. By identifying menstruation as an analytic category upon which systems of power and knowledge are built, the field of critical menstruation studies seeks to uncover the consequences of such social constructions and the ways in which they shape understanding of menstruation and menstrual health. Building from previous scholarship, the *Handbook* represents a new landscape for menstrual knowledge that both reflects the current diversity of the field and invites further development.

The *Handbook* is organized into six thematic sections: menstruation as fundamental, menstruation as embodied, menstruation as rationale, menstruation as structural, menstruation as material, and menstruation as narrative. These overlapping themes function as distinct nodes of inquiry, where contributors explore menstruation (from menarche to menopause) and its meaning (both personal and societal). Each section concludes with a “transnational engagement” that is framed as either a dialogue between multiple authors or a collection of distinct responses to a shared set of questions. The *Handbook* thereby takes an inclusive approach to “studies” in the field, with contributions of empirical research, theoretic essays, first-person narratives, notes from the field, poetry, and visual art. This editorial decision further situates the *Handbook* within critical feminist studies, which has long emphasized the ways in which expertise coexists inside and outside of academic spaces. The juxtaposition of diverse contributions and contributors effectively articulates the tensions and liminalities between those who menstruate and those who conduct menstrual research (not necessarily mutually exclusive categories)—reflexively considering the

sociopolitical environments they inhabit.

Bringing together these contributions, the *Handbook* foregrounds the central importance of dignity in advancing the menstrual health agenda, framing human rights as foundational to the field. Menstruation impacts a wide range of human rights, from the right to education to the right to participation in cultural life, and promoting the individual dignity of menstruators ensures that their right to exercise meaningful agency is protected under international law. Rather than focusing solely on researchers' and professionals' interpretations of menstruation, the *Handbook* encourages policy makers and program managers to center the experiences of menstruators themselves in crafting a rights-based approach to menstrual health. As seen in the focus on humanitarian settings in chapter 45, early United Nations responses to humanitarian crises conceived of menstrual health needs as encompassing only MHM products; however, sustained rights-based advocacy has pushed humanitarian health initiatives to think more expansively about menstruation, influencing international programs, policies, and guidance. Building from such efforts, the World Health Organization's *Inter-Agency Field Manual on Reproductive Health in Humanitarian Settings* now goes beyond product distribution to discuss the relationship between inadequate sanitation options for menstruators and gender-based violence, poor hygiene, and increased school absences. It emphasizes the educational and physiological impacts of poor menstrual health, highlighting the need for menstrual health to be understood as a multilayered human rights issue, not solely a sanitation concern. In re-envisioning menstruation as part of the sexual and reproductive health and rights agenda, various chapters of the *Handbook* recognize how governments and agencies could be better positioned to address the full range of menstruators' needs.

Looking ahead in advancing the human rights of menstruators, broader and deeper scholarship on the significance of menstruation among marginalized communities is needed. The *Handbook* provides a glimmer of the richness of experience that lies just beyond the boundaries of mainstream

menstrual studies, drawing on firsthand accounts of menstruation among marginalized populations—people who are homeless, incarcerated, transgender, living with disabilities, and from low castes. Yet, while these personal accounts capture a range of experiences, moving past mere documentation of stigma, such perspectives are missing from later sections on policy and advocacy. The policy and advocacy agendas highlighted in the *Handbook* largely reflect the priorities of mainstream second-wave feminism—achieving parity with an imagined (white, heterosexual, middle-class) male reference—rather than the more transgressive and disruptive futures envisioned by subaltern analyses. While policies that, for example, reduce the cost of menstrual hygiene products are an important step toward gender parity, they fail to institutionalize the more transformative changes for which newer generations of activists are advocating. This limitation in the *Handbook* raises an imperative in the field to mainstream intersectional analysis on sexual and reproductive health and rights in the development of menstrual health policy. With human rights demanding special attention to vulnerable populations, the dearth of scholarship on marginal experiences of menstruation contributes to the neglect of these groups' rights in menstruation-related policy, programming, and practice.

Building from the successes of the *Handbook* and responding to calls for the decolonization of global health, future editions would be strengthened by including a broader range of contributions from researchers and advocates working in the Global South. While the editors acknowledge this limitation, it is an important one that obscures vibrant feminist advocacy throughout the world. For example, despite extensive critical feminist scholarship and praxis around menstruation in Latin America, the *Handbook* includes only a single chapter on the region, describing the evolution of the femcare industry in the Americas (inclusive of the United States). This is a crucial missed opportunity, as Latin American activists have often used rights-based framings to advance policy agendas—as seen in the promotion of laws addressing gender inequality and “period poverty” (the inability to

afford menstrual hygiene products) by distributing free menstrual hygiene products in schools (for example, in the state of Michoacán, Mexico) and exempting these products from value-added tax (for example, in Colombia). Proposed legislation in Argentina seeks to extend this human rights framing, focusing on vulnerable populations (with bill 1409-D-2019 seeking to guarantee free menstrual products through schools, universities, health facilities, homeless shelters, mental health institutions, and prisons) and climate justice (with bill 5749-D-2020 seeking to guarantee sustainable menstrual products, including reusable pads, menstrual cups, and absorbent undergarments, and require that menstruation-related policy and programming be construed in accordance with environmental protection standards).⁴ The inclusion of such perspectives would avoid any misconceptions that contestation over the meaning and impact of menstruation is “owned” by the West rather than an ongoing part of the human experience across both place and time.

Despite these limitations, *The Palgrave Handbook of Critical Menstruation Studies* provides a central academic foundation for future progress, exploring menstrual studies in a range of formats, creating spaces for transnational discussion, and consolidating scholarship dedicated to menstruation. As menstruation gains necessary attention in global health, this timely scholarship provides a springboard for launching a broader rights-based agenda to advance menstrual health.

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BOOK REVIEW

Decolonizing Public Health Requires an Epistemic Reformation

BRAM WISPELWEY

Epidemic Illusions: On the Coloniality of Global Public Health, by Eugene Richardson, MIT Press, 2020

Physician-philosopher-revolutionary Frantz Fanon begins his chapter “Medicine and Colonialism” with the ideal setup for Eugene Richardson’s *Epidemic Illusions: On the Coloniality of Global Public Health*: “Introduced into Algeria at the same time as racialism and humiliation, Western medical science, being part of the oppressive system, has always provoked in the native an ambivalent attitude.” Western medical science’s role in subjugation is precisely what Richardson, an anthropologist and infectious disease physician, seeks to unpack as an insufficiently explored driver of the “disproportionate amounts of suffering and death from infectious diseases in the Global South.”

The method with which he does so—a “carnavalesque” unveiling and rupturing of the discursive, analytic, and implementation norms used in epidemics—is what makes the book, in its networked reliance on existing social science theory, so striking and revelatory. While Richardson primarily takes his case studies from Ebola and HIV, the book’s release in the midst of a once-in-a-century pandemic provides an urgent timeliness to supplement its assured timelessness. *Epidemic Illusions*’ core lessons are more vividly imbibed by mentally substituting COVID-19 whenever possible—in fact, the book’s self-described carnivalesque styling practically begs it to be utilized this way, ensuring its ongoing relevance for this and the next epi/pandemic.

In the book’s introduction, fellow physician-anthropologist Paul Farmer compares Richardson to Marxist philosopher Antonio Gramsci, rightly suggesting imminent exposure to a thinker who can effectively reveal hitherto obscured knowledge. Akin to Gramsci’s unveiling of cultural hegemony as an explanation for the lack of a socialist revolution to date in Europe, Richardson explicates coloniality—“the matrix of power relations that persistently manifests transnationally and intersubjectively despite a former colony’s achievement of nationhood”—in order to clarify how global public health not only fails to mitigate but in fact propagates massive health inequities and suffering in the world.

Because public health is “an apparatus of coloniality,” Richardson argues in the book’s opening, it “*manages* (as a profession) and *maintains* (as an academic enterprise) global health inequity.” Where others turn their attention to the obvious perpetrators in a pandemic (for example, the US government during the first year of COVID-19), or highlight poor communication from health scientists and politicians’ poor listening to said scientists, Richardson’s critical attention is directed at those often lauded as benign experts, if not protagonists, in a quest to expand the core rights to health and well-being.² He contends that it is

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these experts who, usually unwittingly, maintain coloniality by failing to understand, in Foucault's words, "what what they do does."³

And "what what they do does" is, often enough, lend epistemological currency to status quo positions that shield the extractive logics and practices of those in power. After all, what has a stronger claim to truth, in the liberal mind, than scientific facts? To illustrate how this currency is generated, Richardson discusses the use of the term "superspreader" in a World Health Organization report. Rather than focus on, say, the corrupt mining companies and other practitioners of predatory accumulation that provided the social and material conditions for Ebola's spread, health experts at the World Health Organization provide cover for the structural causes of health inequity by transferring terminological responsibility to the very people suffering from coloniality's ongoing depredations. The implications are consequential: the "superspreader" framing informs the report's argument for designing infection control programs that target these 20% of infected individuals rather than the conditions that put them at risk for infection. While this approach is as political as one that targets multinational corporations, epidemiology's popular status as an "apolitical" science shields us from this recognition, insidiously perpetuating coloniality in the process.

Enhancing the potency of such analyses, the book's case studies become clever redescriptions (Richardson's Twitter handle is @Real_Ironist), designed to creatively illuminate, rather than dryly explicate, coloniality. As a philosophical pragmatist, Richardson's refusal to grant legitimacy to any inherent or objective truth might seem like a blow to human rights discourse, but his ironist approach in fact strengthens arguments for the right to health. Because most hegemonic truth claims are steeped in coloniality and thus structured to create a hierarchy of rights and privileges, Richardson's irony serves to expose their often racist, patriarchal, classist, or colonial underpinnings. What has come to seem objective and natural to public health experts in the Global North is anything but, and Richardson's mission is to formulate new strategies

to make this epistemic violence legible.

COVID-19 has magnified these issues, compounding the "conditions of global apartheid" with a new vaccine injustice that has seen fewer than 10% of vaccinations to date in the low-income and lower-middle-income countries that make up nearly half of the world's population.⁴ The country leading the rich-world vaccination race, Israel, has done so in part by striking a special deal with Pfizer, in which the country paid twice as much as the European Union per dose and agreed to provide the company with extensive data in return for a robust early vaccine supply.⁵ While the medical and lay presses stumbled over themselves to highlight Israel's success and glean early insights on the vaccine's real-world effectiveness, the territory occupied by Israel for more than half a century—the Gaza Strip and the West Bank—has received a modest number of vaccines to date, mostly from Russia, China, and COVAX, and is currently experiencing a deadly surge in cases.⁶

Public health and medical publishers at times play an important role in epistemic violence by platforming and mainstreaming the denial of Palestinian health rights as something defensible or, even more perniciously, as the responsibility of the occupied and oppressed.⁷ This practice has resurfaced with Israel's refusal to provide equal vaccination to Palestinians under occupation, despite the state's obligation as an occupying power under the Fourth Geneva Convention to adopt "preventive measures necessary to combat the spread of contagious diseases and epidemics" to "the fullest extent of the means available to it."⁸ One suspects that Richardson might have the ironic tools necessary to express and make palpable the full weight of the epistemic violence that such publications perpetuate. In the meantime, all of the public health experts and journalists dutifully quoting Israel's vaccination percentages should, for the sake of accuracy, add five million unvaccinated Palestinians to the denominator.

In tackling similarly heavy topics, Richardson's prose remains light, clever, and concise, making for a quick read that is also ripe for revisiting. He is acutely aware of how his positionality as

“a white upper-middle-class male settler-colonist privilege-exerciser” influences his experiences and knowledge, bringing a welcome self-awareness to his writing. And ultimately, he pulls off something especially difficult for any intellectual, whether traditional or organic: a genuinely counterhegemonic philosophy and politics, choosing to join forces with the subaltern in seeking an epistemic reformation and decolonial praxis. By exposing the epistemic battleground that exists in our own academic realm, Richardson ultimately provides the hopeful message that each of us can similarly add “grist for the mill of decoloniality” by challenging the powerful interests that have hegemonized our knowledge and norms.

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