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Conceptualizing the Social Determinants of Mental Health Within an International Human Rights Framework: A Focus on Housing and Employment

KAY WILSON

Abstract

The social determinants of health and international human rights law share many overlapping concerns and goals in promoting human well-being. However, so far they have been developing largely in silos, resulting in calls for greater interdisciplinary collaboration. The purpose of this paper is to explore how the social determinants of health—specifically mental health—can fit within international human rights law conceptually and practically. I argue that the social determinants of mental health and international human rights law are mutually reinforcing. Both are necessary to realize the right to the highest attainable standard of health and its incorporation into domestic law and policy. International human rights law provides an indispensable universal and legally binding framework to realize both the right to health and the social determinants. Likewise, the social determinants enrich and expand international human rights law and challenge it to go further in responding to inequality, power imbalances, and the lifelong impact of adverse childhood experiences (especially in light of the early onset of mental ill-health). I use housing and employment as examples of how to deepen this conceptual and practical relationship.

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Introduction

The social determinants of health and mental health draw attention to the way in which structural social and systemic factors—such as the distribution of power, resources, and money—and the daily social and environmental conditions in which people live impact their health, mental health, and lifespan.[1] While there are many different models of the social determinants of health and mental health, they generally include life circumstances such as poverty, education, unemployment, work stress, violence, adverse childhood experiences, housing insecurity, neighborhood, and environmental factors.[2] (Henceforth, I will refer the social determinants of health and mental health in general as "the social determinants"; and if I am referring to a specific social determinant, I will simply name it—e.g., housing). While access to medical care is itself an important social determinant, the social determinants go well beyond the health sector to reach almost every aspect of life.[3] Indeed, there is interest in many subsets of social determinants, including the commercial, political, economic, historical, cultural, and legal determinants.[4]

The social determinants were originally intended to be developed within the framework of international human rights law, although this did not eventuate.[5] Therefore, over the past 20 to 30 years the bodies of scholarship around the social determinants and around international human rights law have been developing in parallel, passing each other like "ships in the night."[6] While many of the major reports on the social determinants give a nod to human rights values, they engage with human rights only briefly and superficially and have been criticized for not being developed within an international human rights framework.[7] In fact, many epidemiology and public health experts still often prefer the language of "ethics" and health equity over human rights and the scientific basis of the social determinants.[8] Similarly, while the human rights literature often mentions the social determinants, it tends to focus on the right to health, health systems, and the more limited "underlying determinants of health" necessary to support health, such as safe water, sanitation, and nutrition.[9] (For the purposes of this paper, I use the term "social determinants of health" rather than the "underlying determinants of health" to recognize that all determinants are in fact moderated by society.) Separate disciplinary silos, a lack of exploration of common ground for interdisciplinary cooperation, and a lack of interdisciplinary interest and expertise have led Yvette Maker and Bernadette McSherry to recently call for greater collaboration between the social determinants and human rights fields.[10] Others have looked to create a conceptual public mental health framework that combines the social determinants, health and human rights, and the social model of disability to guide law and policy development.[11]

Against this backdrop, the purpose of this paper is to further navigate and deepen the relationship between the social determinants of mental health and international human rights law with the aim of promoting better conceptual, legal, and practical integration between the two. I begin by exploring how the social determinants can fit within international human rights law, including through the realization of the right to health, and how the two fields can enhance each other. I then explore the relationship between the social determinants and human rights in greater detail in relation to two important social determinants—housing and employment—to begin building an integrated conceptual literature. I argue that human rights and the social determinants of mental health are mutually reinforcing and provide a bridge between the world of science and the world of law and policymaking.

Why focus on mental health?

While physical health, mental health, and well-being are all closely intertwined, for the purposes of this paper I have decided to focus on mental health because mental ill-health has a high prevalence, affecting 970 million people worldwide.[12] It is the leading cause of years lived with disability.[13] It can (unlike most physical conditions) result in detention in hospital and coercive treatment; and often, treatments have debilitating and permanent side effects or may not be effective.[14] Given that psychiatric treatment can often lead to poor outcomes and the overuse of coercion in the mental health system, which many people report as damaging, greater exploration of social and legal approaches to prevent mental ill-health (including the aggravation of existing mental health conditions) and the promotion of well-being is warranted.

Within mental health and human rights discourse following the entry into force of the Convention on the Rights of Persons with Disabilities in 2008, the focus has been on civil and political rights, particularly the abolition of mental health laws that authorize the use of involuntary detention and psychiatric treatment.[15] While debates about the future of mental health law are ongoing and have resulted in what some commentators have called an "impasse," the narrow focus on abolishing involuntary detention and psychiatric treatment can have the effect of overshadowing the potential of the convention as a whole to secure the right to the highest attainable standard of mental health and how human rights can be a driver of wider social transformation.[16] Arguably, focusing on citizenship and nondiscrimination has drawn attention away from the indivisibility of rights and the importance of persons with mental ill-health (the vast majority who will never experience coercion) being able to claim and enjoy their socioeconomic rights and right to mental flourishing.[17] Further, recent reviews, such as the Wessely Report in the United Kingdom, have concluded that it may not be possible to avoid mental health crises or reduce coercion in psychiatry without paying attention to social determinants such as discrimination and housing.[18] Indeed, addressing the social determinants and understanding how they relate to coercive systems of psychiatric treatment is reflected in recent recommendations for mental health law reform and a revision of psychiatry that involves shifting away from a purely individualist and biomedical understanding of mental ill-health to a social model.[19]

However, I note that the social determinants of health and *mental* health are currently conceptualized as being almost identical.[20] Indeed, until the last five to ten years, the social determinants of mental health were simply incorporated into the social determinants of health, rather than being conceived of separately.[21] Nevertheless, the same social and environmental stressors are detrimental to both physical and mental health, with the effects usually being evident in a person's mental health before later becoming manifest in their physical health.[22] That said, Handerer and colleagues have found that the social determinants of mental health are often considered to be more indirect and mediated by psychological factors (e.g., bullying and relationships), whereas the social determinants of health are sometimes regarded as being more direct and physical (e.g., exposure to toxic chemicals).[23]

Bringing together the social determinants of mental health and human rights: Why and how?

The social determinants and international human rights law are not without their critics.

International human rights law has been criticized for being overly legalistic and individualistic and for failing to address growing inequality.[24] Similarly, the social determinants have been criticized as being too broad and not taking into account the ability of individuals to create their own niches.[25] Nevertheless, both approaches can do much to improve each other and potentially overcome at least *some* of these limitations.

How human rights enriches the social determinants

The benefits of using an international human rights framework for the social determinants have been extolled in detail in the health and human rights literature, so I will only briefly reiterate them. The key strength of international human rights law is that all states that are members of the United Nations have ratified at least one of the nine key conventions, and 80% have ratified four or more conventions, giving this body of law widely accepted moral force, legitimacy, and universal reach.[26] In addition, there are regional human rights systems for Europe, Africa, and the Americas, and human rights have been incorporated into many domestic constitutions (although for the purposes of this paper I will focus on the international system). Human rights are also universal in the sense that they apply to all persons simply by virtue of being human, even if all people do not yet universally enjoy their human rights.[27]

International human rights law transforms diffuse claims made in the social determinants literature based on "ethics" and "justice" into *legally binding* obligations on states according to well-developed and widely accepted principles—for example, the indivisibility and interdependence of all human rights; processes to balance competing rights and rights holders; ways to deal with evidence, uncertainty, and resource constraints; the inclusion of marginalized and vulnerable groups; and community consultation and participation.[28] International human rights law recognizes that human rights are inherently political and a source of struggle, as opposed to the social determinants literature, which treats advances in health equity as a purely technical or bureaucratic task that has failed to gain widespread implementation.[29]

As noted by a former Special Rapporteur on the right to health, Paul Hunt, and his colleague Gunilla Backman:

> *There are numerous health movements and approaches, including health equity, primary health care, social determinants, and so on. All are very important. But it is misconceived to regard human rights as yet another approach with the same status as the others. Unlike ethics, the right to the highest attainable standard of health is not optional and, unlike ethics, it recurs throughout all other approaches. The right to the highest attainable standard of health is the only perspective that is both underpinned by universally recognized moral values and reinforced by legal obligations.*[30]

Thus, international human rights law creates a framework to shape clear norms and standards through existing treaties that can be used for advocacy and for guiding states in law and policy development. Such standards and norms allow international bodies to monitor and measure compliance and implementation by setting benchmarks, conducting impact assessments, and requiring continuous improvement.[31] Therefore, international human rights law contains many processes for accountability—judicially and through various international institutions and forums—including accountability for governments' non-responses to human rights problems.[32] There is rhetorical power in individuals and groups being able to conceive of themselves as rights bearers with entitlements rather than wishes.[33] Human rights-based approaches to health can empower health workers and their communities to claim their health-related rights as something that they are *owed* and to frame problems and injustices as human rights violations requiring state action.[34] In addition, human rights frameworks are supported by established civil society organizations experienced in grassroots advocacy which are essential for the realization of health gains.[35]

In particular, the broad definition of the right to health articulated in the Universal Declaration of Human Rights links health with an adequate standard of living and reinforces the social determinants.[36] This is further supported by the International Covenant on Economic, Social and Cultural Rights in which the right to health in article 12 includes the "improvement of all aspects of environmental and occupational hygiene" and the prevention of occupational diseases. Similarly, the Committee on Economic, Social and Cultural Rights recognizes that "the right to health is closely related to and dependent upon the realization of other human rights … including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement."[37] While the social determinants correspond with all human rights, some rights in the covenant of particular significance for mental health are the right to an adequate standard of living; the right to social security, protection, and assistance for families; the right to education; the right to housing; and the right to employment.[38] Therefore, state action on the social determinants is a precondition for realizing the right to health and mental health. It also includes the realization of civil and political rights such as the prevention of violence and discrimination.[39]

Accordingly, conceptualizing the social determinants within a human rights framework strengthens both approaches.

How the social determinants enrich human rights

Likewise, the social determinants fit nicely within international human rights law. Arguably, the biggest contribution of the social determinants to international human rights law is that the social determinants raise the stakes of human rights so that injustice is not merely a matter of moral outrage but a matter of life and death that is visible in patterns across populations and measurable for individuals in clinical social determinants assessments. That is, human rights violations have real health and mental health consequences. Further, the social determinants demonstrate that those violations do not have to be large one-off events but can also be cumulative in both type and quantity, so that many smaller human rights violations and their impact on human dignity can add up over a lifetime to damage a person's health, mental health, and longevity. [40] They can also be intergenerational.[41]

In particular, the treatment of children and young people—due to their vulnerability and developing brains, nervous, and immune systems—can have serious effects on lifelong mental health and well-being; indeed, two-thirds of mental disorders occur before the age of 24 years.[42] Adverse childhood experiences can be broadly defined as "inconsistent, stressful, threatening, hurtful, traumatic, or neglectful social interchanges experienced by fetuses, infants, children, or adolescents."[43] They can include poverty, hunger, abuse, neglect, family dysfunction, having a parent with a mental ill-health such as postnatal depression, discrimination, maltreatment, and bullying.[44] Thus, the social determinants underscore the importance of taking a life-course approach and increase the urgency of realizing the human rights of children and families and in creating stable and nurturing environments.[45]

The social determinants provide the scientific evidence to demonstrate that the whole international human rights framework, including non-health rights, is actually integral to mental health. Thus, the social determinants reinforce the importance of social, economic, and cultural rights as "true" human rights and the effects of the wider psychosocial context on health and mental health so that states' human rights obligations are not limited to individualized treatments and the availability of psychotropic medications.[46] The social determinants help demonstrate the interrelationship and indivisibility of rights and how civil and political rights and socioeconomic rights are dependent on each other (discussed further below). Persons with mental ill-health are disproportionately affected by many social determinants, having significantly lower education, higher unemployment, higher homelessness, and greater involvement with the criminal justice system than the rest of the population.[47] However, action on the social determinants will also have wider benefits in improving the mental health of all persons, including those without psychosocial disabilities.[48]

The social determinants place an emphasis on understanding the *causes* of poor health and mental health and *prevention*, primary care, and early intervention, helping to move away from a narrow understanding of health focused on tertiary and crisis interventions such as medical treatment.[49] As noted by former Special Rapporteur on the right to health Dainius Pūras:

> *There exists an almost universal commitment to pay for hospitals and medications instead of building a society in which everyone can thrive. Regrettably, prevention and promotion are forgotten components of mental health action.*[50]

Social determinants research also challenges narrow human rights conceptions of equality and discrimination by demonstrating how health, mental health, and longevity are distributed within societies along "social gradients" where health, mental health, and longevity gradually deteriorate from those at the top of the social hierarchy to those at the bottom.[51] Because the social gradient is steeper in more unequal societies, it is not enough to just address the poverty and powerlessness of those at the bottom—instead, there must be a focus on how *relative* wealth makes a difference to the health, mental health, and well-being of whole populations.[52] Thus, the social determinants draw attention to the way social power structures impact health and mental health, going beyond human rights concerns about "minimum floors" being respected to the need for wealth redistribution.[53] In particular, social determinants research has revealed the health and mental health impact of the dismantling of the welfare state and of austerity measures on human rights. As Michael Marmot and colleagues note, the rollback of the state in Britain—as demonstrated by a reduction in public expenditure from 42% of GDP to 35% between 2010 and 2020—has been regressive, with serious and measurable consequences for health and social inequity and unexpected increases in mortality among those most affected by the cuts.[54]

The social determinants also highlight the health and mental health effects of the failure of international human rights cooperation in relation to the sharing of resources between richer and poor countries.[55] Rather than replicating broken, under-resourced, and coercive mental health systems, addressing the social determinants to prevent mental ill-health and promote well-being can be a cost-effective and efficient use of mental health resources in high-, medium-, and low-income countries to help realize the right to the highest attainable health and mental health.[56]

Further, social determinants research draws attention not just to the mitigation of socially determined risk factors for poor health and mental health outcomes but also to the enhancement of resilience factors that are necessary to build positive mental health and well-being. The emphasis on positive factors enriches human rights by creating a focus that goes beyond preventing harm and looks at actions the state can take beyond the "minimum core" to enable mental flourishing. While there have been many specific social determinants programs designed to target particular determinants—for instance, improving education for poor and disadvantaged families—these do not always move from pilot to large-scale rollouts.[57] A human rights approach provides a way of creating a scientifically backed and morally grounded international legal framework where social determinants and human rights can be incorporated and embedded into all domestic laws and policies as a whole-of-society intervention.[58]

Even though the social determinants and international human rights law probably cannot overcome neoliberalism without a radical change to the social and international world order, the social determinants complement, further develop, and extend the relationship between mental health and human rights. Together, they create an impetus toward reducing inequality, increasing wealth redistribution, and strengthening the welfare state as necessary to prevent mental ill-health and promote well-being.

Below, I take a deeper look at how human rights and the social determinants fit together in relation to two examples: housing and employment.

Housing

While the right to housing is included in a number of human rights instruments at the international, regional, and constitutional level, the most well-known and authoritative basis for the right is as part of the right to an adequate standard of living enshrined in article 11 of the International Covenant on Economic, Social and Cultural Rights.[59] Understanding of the right to housing has been further developed by the Committee on Economic, Social and Cultural Rights, the body responsible for monitoring the implementation of the treaty, in its General Comment 4.[60] The right to housing is more than a right to shelter; it includes "the right to live somewhere in security, peace and dignity."[61] According to the committee, the right to housing is made up of seven factors: (1) legal security of tenure (protection against forced eviction), (2) availability of services, materials, facilities, and infrastructure (e.g., water, energy, sanitation), (3) affordability (cost does not compromise the ability of people to meet other needs), (4) habitability (protection from the elements and physical safety), (5) accessibility (nondiscrimination and housing that caters to special needs), (6) location (near transport, education, employment, and essential services), and (7) cultural adequacy (respects cultural identity and diversity).[62] The committee takes a neutral position in relation to whether housing is owned by the state or private sectors, as long as states do whatever is necessary to fulfill the right in the shortest possible time.[63] While the committee recognizes that the right to housing is linked to disease, mortality, and morbidity, it does not explicitly recognize the mental health impact of poor or unaffordable housing and homelessness (discussed below).[64] Although the right to housing as formulated by the committee has been criticized as being limited by "sufficiency"-based on minimum standards, it has been enormously valuable as a rallying cry for social movements seeking to realize the right.[65] The committee's formulation has also been criticized as being too weak to respond to the financialization of housing and the lack of housing affordability as homes have increasingly become an investment rather than a place to live, hindering the progressive realization of this right.[66]

The history of mental asylums and ongoing institutionalization means that the right to housing is of particular importance to people with disability. Article 28 (right to an adequate standard of living) of the Convention on the Rights of Persons with Disabilities requires state parties to ensure that people with disability have access to public housing programs without discrimination. Similarly, article 19 requires that people with disability be given support to live independently and with persons of their own choosing. In countries such as the United States, homelessness is strongly linked to mental ill-health and is used by authorities to gain public support to justify involuntary detention and treatment.[67] "Housing First" programs that allow persons with mental health and drug abuse problems to obtain housing without onerous conditions around treatment are often regarded as the gold standard, although they are not without their challenges, and people often need to seek treatment to remain housed over the long-term.[68] That said, studies indicate that housing programs are more successful if they also provide access to a range of mental health and social support services; arguably, such services are part of housing accessibility.[69]

The effects of poor housing and housing instability on physical health—including respiratory conditions due to poor air quality, cognitive delays due to exposure to neurotoxins, and accidents and injuries due to structural defects—are well documented.[70] In addition, the social determinants of mental health reinforce the right to housing by illustrating the bidirectional relationship between housing and mental ill-health. That is, persons who experience housing insecurity are more likely to suffer mental ill-health, and persons with mental ill-health are more likely to suffer from housing insecurity.[71] The social determinants enrich the right to housing by drawing attention to the psychological impacts of homelessness, housing insecurity, overcrowding, and poor housing quality in contributing to and aggravating mental ill-health. For instance, persons with housing affordability problems have worse mental health than those who do not.[72] Further, the social determinants highlight the adverse and *cumulative* mental health effects of the stress created by *prolonged* housing disadvantage, insecurity, and unaffordability.[73] In addition, living in substandard housing (whether as an owner or renter) is closely linked to depression and housing unaffordability stress.[74]

Social determinants research also illustrates the connection between housing, neighborhoods, and poor mental health, with areas that lack maintenance, social cohesion, and safety associated with increases in depression.[75] Therefore, the right to housing, a socioeconomic right, is intimately connected with exposure to neighborhoods with greater violence and higher crime rates and the right to security of the person, a civil and political right.[76] Further, social determinants research indicates how unaffordable housing is connected to adverse childhood experiences, with domestic violence being a major cause of homelessness and housing instability for victims.[77] Similarly, early childhood trauma is a risk factor for homelessness, housing instability, and mental ill-health among young adults.[78] The research also indicates that access to publicly subsidized housing (despite the neutrality of General Comment 4) and living in areas with built green spaces are positively associated with mental health.[79]

Employment

The relationship between employment, employment conditions, and workers' health, mental health, and well-being has long been a central concern of international human rights law. The United Nations Charter provides that the United Nations shall promote international stability and well-being through "higher standards of living, full employment, and conditions of economic and social progress and development."[80] The Universal Declaration of Human Rights also provides a number of work-related rights, including choice of employment, fair pay and conditions, protections from unemployment, limits on work hours, rights to leisure, nondiscrimination in the workplace, and the right to form trade unions.[81] The International Covenant on Economic, Social and Cultural Rights provides for fair remuneration and just and favorable conditions such as continuous improvement in workplace health and safety (which would also include protection from mental health injuries).[82] The Sustainable Development Goals also recognize "economic growth, full and productive employment and decent work for all," although the focus on economic growth has been criticized as prioritizing neoliberalism and overshadowing workers' rights.[83] The International Labour Organization, a specialist branch of the United Nations focused on monitoring and improving employment conditions, has developed a "decent work" agenda and numerous "soft law" instruments setting employment standards on matters such as working hours, fair pay, job security, and occupational health and safety.[84] In addition, the International Labour Organization's social protection floors link worker protection and social security, including for sickness and unemployment.[85] Further, the Convention on the Rights of Persons with Disabilities requires that people with disability have equal rights to safe and healthy work.[86] These rights ensure that workers, often with little bargaining power, are selling only their labor, not the health and integrity of their bodies and minds—or, at worst, their lives.

These employment rights are, however, reinforced and expanded on by the social determinants, which demonstrate how unemployment and working conditions can impact workers' health and mental health. This is not just in relation to workplace accidents but in relation to how daily working conditions can impact long-term health, mental health, and well-being outcomes. Social determinants research has identified a number of psychosocial hazards that contribute to physical health conditions such as heart disease, high blood pressure, high cholesterol, diabetes, cancer, and mental health conditions such as anxiety, depression, and posttraumatic stress disorder.[87] Long-term unemployment in particular has been linked to serious mental ill-health and suicide, underlining the importance of employment rights in protecting people from unemployment—and the *fear* of unemployment—caused by job insecurity.[88] Psychosocial hazards such as excessive workloads (especially with low levels of control), effort-reward imbalance, bullying, harassment and discrimination, vicarious trauma, and insecure work illustrate how mental ill-health can often be caused by human rights violations.[89] However, social determinants research, by revealing the social gradient within the workplace hierarchy, also extends human rights by highlighting the need to address extreme power imbalances and structural and systemic factors in addition to simply improving work conditions.[90] Further, the social determinants show how human rights interrelate and how different violations can compound. For instance, unemployment and low incomes have effects on child development, housing, education, food, social networks, social equality, and mental health, creating poverty traps and cycles of disadvantage.

Conclusion

While the social determinants and health and human rights have long had similar concerns and goals, they have tended to develop along different trajectories, with only limited and often begrudging integration. However, there is growing recognition of the benefits of interdisciplinary collaboration and conceptual alignment. In this paper, I have focused on the social determinants of mental health to argue that the social determinants fit well within an international human rights framework and that both perspectives are mutually reinforcing. While both approaches are not without critics, international human rights law and the right to the highest attainable standard of health contribute a well-established moral and legally binding framework that is universally accepted to structure advocacy, guide law and policy development, monitor and set goals for implementation, and establish accountability. There is power in claiming rights as entitlements rather than relying on ethical arguments.

Further, as observed by Lisa Montel the social determinants and human rights correspond so closely that "when we talk about the social determinants of health, we are talking about human rights."[91] Conversely, as demonstrated by the examples of housing and employment, the social determinants not only coalesce with international human rights law but enhance and extend how those rights are conceptualized, in addition to reinforcing the indivisibility of different rights. The social determinants provide the scientific evidence and raison d'être to support human rights claims. The social determinants challenge human rights to be more ambitious than the "minimum core" and to aim higher than sufficiency by shining a light on the health and mental health consequences of unequal power structures and hierarchies, providing a compelling justification for wealth and power redistribution. The social determinants reorient international human rights law and the right to health and mental health toward prevention and early intervention and toward creating a society in which all people can thrive, rather than relying on medication and individualized medical treatment as the dominant social response to mental ill-health and disease. In addition, the social determinants underscore the urgency of addressing the human rights of children (and the families who support them) in taking a life-course approach. Thus, the social determinants and health and human rights are mutually reinforcing and enriching, and the relationship between them is worthy of future exploration and conceptualization.

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From Choice to Justice: Disrupting the Binary Political Logics of Assisted Reproduction

LEIFA MAYERS

Abstract

Reproductive rights and reproductive justice paradigms have long been viewed as incompatible, largely because of their divergent orientations to the notion of choice. According to this oppositional framing, reproductive rights approaches have centered the right of (white, middle-class, heterosexual) women to choose not to have children while reproductive justice organizing has focused on gendered, racialized, and classed obstacles to control over whether and how to have and raise children. Amid increasing examination of assisted reproductive technologies (ARTs) vis-à-vis human rights principles, I see an opportunity to narrow the perceived gap between the politics of rights and justice. Human rights organizations and scholars are recognizing the stratification of medical infertility rates and ART access, and human rights courts are articulating the right to assisted reproduction as part of a fundamental right to reproductive health. In reframing the opportunity to choose assisted reproduction as a justice issue, I seek to unsettle the traditional bifurcation of these political logics.

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Introduction

In 1994, 12 US-based Black women developed the theoretical and activist concept of reproductive justice in order to produce a more thorough account and recognition of "our full reproductive and sexual human rights."[1] Reproductive justice theory and praxis moves beyond the binaristic framework of reproductive rights—and, most notably, mainstream reproductive rights organizations' focus on abortion politics—to embrace an intersectional, human rights-based perspective.[2] Rather than discard the rights framework, reproductive justice understands reproductive rights as embedded within overlapping systems of racism, sexism, classism, colonialism, xenophobia, ableism, heterosexism, and cissexism. The three core tenets of the reproductive justice movement respond to these limitations: "(1) the right to have a child under the conditions of one's choosing; (2) the right not to have a child using birth control, abortion, or abstinence; and (3) the right to parent children in safe and healthy environments free from violence by individuals or the state."[3]

However, reproductive justice is often positioned in opposition to the reproductive rights or choice paradigm. The rhetoric of reproductive choice, which emerged in response to anti-abortion forces, has been roundly critiqued for its basis in the lived experiences of mostly white, middle-class women who, presumably, have access to multiple reproductive choices.[4] In both abortion and assisted reproduction contexts, rhetorics of choice have occluded the structural inequities that stratify access according to race, class, and geopolitics and reify embedded logics of racism, sexism, colonialism, and ableism.

The reproductive justice critique of assisted reproduction

Assisted reproduction has become a site of contestation for reproductive rights and justice approaches. A number of scholars argue that assisted reproductive technologies (ARTs) increasingly operate coercively within a system that discourages reproduction among low-income women of color.[5] Historically and currently, reproductive technologies—including various forms of birth control and forced sterilization—have been used to limit the reproduction of Black, Indigenous, and people of color in the Global North, as well as those otherwise deemed genetically "unfit." Additionally, all pregnant people are increasingly pressured to accept individualized reproductive interventions such as prenatal testing, selective abortion, and behavioral modification during pregnancy.[6] Thus, the development of reproductive technologies simultaneously represents increased choice for those who can afford ART procedures and coercive possibilities for many who cannot.

Disability and reproductive justice activists observe that the combined use of assisted reproductive and genetic selection technologies enable the de-selection of disability-linked characteristics, which reinforces both ableist discrimination and the regulation of reproduction.[7] However, others recognize how the rhetoric of prenatal testing and selective abortion of a fetus with potential disability as eugenics colludes with state control of individual reproductive bodies—a hallmark of eugenics itself.[8] Further, an overly simplistic critique of genetic selection technologies may ignore the financial hardship endured by individuals and families while distracting from broader ableist structures.[9]

LGBTQ rights to assisted reproduction have frequently been framed as antithetical to reproductive justice.[10] According to Marcin Smietana and colleagues, there exists a fundamental assumption that ART necessarily exchanges the reproductive choice of a privileged few (i.e., presumably wealthy intended LGBTQ parents in the Global North) for the injustice of many others (i.e., reproductive laborers and those without access to ART).[11] This assumption positions the interests of LGBTQ people in assisted reproduction against those of reproductive justice, writ large.

While assisted reproductive services are persistently organized around reproductive heterosexuality and LGBTQ people are not the primary users of ART, they have become centerpieces in debates about its ethics and accessibility. For example, gay men's pursuit of egg donation and surrogacy arrangements has come to symbolize the wealth stratification between the recipients and producers of reproductive material and labor.[12] Further, the inclusion of some LGBTQ people in fertility markets and biomedical services is juxtaposed with the exclusion of many poor women and women of color from basic reproductive and preventative health care.[13]

These conversations, among others, suggest that the interfaces of ART and (in)justice are infinitely complex. However, I contend that assisted reproduction is not necessarily antithetical to reproductive justice. Rather, especially given the burgeoning fertility industry and increasing global usage of ARTs, there is a need for sustained engagement with the social, legal, and economic implications of specific technologies and their surrounding arrangements of power.[14] If we direct our gaze only to the distribution of choice and its enactment by individual actors, it is more difficult to see the conditions of possibility for reproductive options (or lack thereof).[15]

As Laura Mamo and Eli Alston-Stepnitz point out, it is possible to attend to the inequities that structure health care provision and the fertility industry while also resisting the logic that the inclusion of some necessitates the exclusion of others.[16] For example, the recognition that state law and health insurance policies stratify access to assisted reproduction along the lines of class, race, sexuality, and gender identity and, therefore, disproportionately impact poor people, LGBTQ people, people of color, and people living in the Global South does not preclude activist and scholarly attention to similar disparities in access to health care more generally. Further, it is possible to support increased inclusion in reproduction and family-making for LGBTQ people and others who are systematically marginalized from these social arrangements while also seeking accountability to the providers of biomaterial and reproductive labor and interrogating the coercive potentialities of reproductive technologies.[17]

It is from this departure point—the recognition that reproductive justice may be used to simultaneously support and problematize inclusions that align with traditional notions of reproductive choice—that I turn to the potential convergence points of reproductive justice and rights paradigms. LGBTQ-centered assisted reproduction advocacy has been justifiably critiqued for its singular focus on the reproductive options afforded to white, middle-class patient-consumers. However, recent US and international legal developments point toward the expanded understanding of ART as a reproductive justice issue. In the international human rights literature, there is increasing attention to the ways in which "infertility" and the need for ART cleave to lines of race, class, and geopolitics. Simultaneously, international human rights courts and agencies have recognized the rights to family-making and use of ART as components of the right to health. While the pursuit of a human right to assisted reproduction may appear to advance a broader reproductive justice agenda, I caution that such an approach may further entrench disparities in access to medical infertility treatments in the Global South and reify biogenetic normativity—thereby devaluing adoptive families and excluding informal caretaking relationships from social and legal recognition.

Toward a reproductive justice approach to assisted reproduction

Contemporary human rights literature and scholarship increasingly acknowledge global disparities in ART access. The overall provision of ART services does not nearly meet demand; an estimated 20% of the need for ART treatment is fulfilled each year.[18] Despite lengthy histories of in vitro fertilization (IVF) in many countries of the Global South, access disparities between the Global North and Global South persist; ART utilization rates range from over 5,000 cycles per million population in the Middle East (Israel) to 129 cycles per million population in Latin America.[19] Affordability is the best predictor of treatment and is impacted by cost, insurance coverage, and government subsidization.[20] IVF is most expensive in the United States, as ART costs are highly correlated with overall health care costs.[21] However, relative ART costs are highest in low-resource countries, where the cost of one IVF cycle is more than half of the average annual income.[22] The subsidization of ART treatment varies considerably across countries, from no public financing in at least eight countries to "full" reimbursement (i.e., at least 81% of the cost of one or more cycles) in at least nine countries.[23] The number of publicly funded cycles also varies, from one to unlimited.[24] In countries with generous reimbursement for ART treatment, the utilization rates are five times greater than in other countries of the Global North.[25]

Human rights-based accounts of medical infertility have also begun to include analyses of the impact of poverty, racism, and concomitant structural factors such as unsafe abortions and inadequate health care—particularly in the Global South. There is now ample evidence that medical infertility disproportionately impacts people living in the Global South due to its correlation with poverty, lack of adequate health care, sexually transmitted infections (STIs) and infectious diseases, forced sterilization, and unsafe abortion procedures.[26] Researchers estimate that up to 30% of people in some countries in Sub-Saharan Africa are medically infertile.[27]

Against this backdrop, regional human rights courts are increasingly recognizing access to assisted reproduction as part of a human right to start a family or become a parent. For example, the Inter-American Court of Human Rights has determined that the Supreme Court of Costa Rica's 2000 prohibition of IVF violated the human rights to private and family life; found and raise a family; and nondiscrimination on the basis of disability, financial means, or gender.[28] Similarly, the European Court of Human Rights has held that the right to personal autonomy encompasses decision-making "to become and not to become a parent"—including through IVF treatment—and is protected under the private and family life provisions of article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms.[29]

Several national entities have also recognized a right to assisted reproduction as consistent with the rights to health care or to form a family. In 2009, Portugal's National Health Service began integrating medically assisted reproductive services into its public hospital system subsequent to the passage of Law 32/2006, which interprets the provision of these services as consistent with the Portuguese constitutional principles of universal access and free health care.[30] In 2012, the Brazilian Unified Health System recognized the right to start a family as a human right, and the Brazilian government initiated a universal ART program within the National Health System.[31] Argentina and Uruguay also recognize the right to found a family as a human right and have enacted policies that provide universal access to ARTs.[32]

These legislative and judicial projects reflect an internationally recognized right to reproductive health, part of a larger fundamental human right to health, as well as principles of nondiscrimination, equality, and privacy.[33] There is a fairly extensive history of recognizing reproductive rights as human rights, stretching back to 1968 when the Final Act of the Tehran Conference on Human Rights declared that "parents have a basic human right to decide freely and responsibly on the number and spacing of children and a right to adequate education and information in this respect."[34] Since then, the Convention on the Elimination of All Forms of Discrimination Against Women and other instruments have upheld rights to family planning, infertility resources, bodily autonomy and reproductive decision-making, sexuality education, nondiscrimination in access to health care, and pregnancy and childbirth services.[35]

Given this robust foundation, there may be an opportunity to expand the human right to health, and reproductive health and decision-making more specifically, to include a right to assisted reproduction. However, I argue that a reproductive justice framework demands greater attention to the structural inequalities that condition access to ARTs and related reproductive health services and families' legal and social legitimacy. In the next section, I take up two issues that would be insufficiently addressed, at best, by a fundamental right to assisted reproduction: (1) how the separation of ART and infertility discourses further entrenches the global stratification of services by obfuscating continuities across geopolitical contexts while furthering technological exceptionalism, and (2) how the pursuit of a human right to ART may reify the biogeneticism that continues to dominate family law and devalues other family forms—particularly those that feature nonbiological ties.

Assisted reproduction and infertility

With few exceptions, assisted reproduction and infertility have been viewed as separate issues, and attention to infertility has taken on different characteristics based on geopolitical context.[36] Efforts to present and address the scope and human rights impacts of infertility largely leave intact the prevailing biomedical definition of infertility, situate structural causes of medical infertility—such as gender-based violence, environmental toxins, and subpar reproductive health education and care—in the Global South, and include ART access as an afterthought.[37] Meanwhile, many national ART policies in the Global North presume both heterosexuality and medical infertility, often denying access or funding to single people or same-sex couples.[38] Although ART services in the Global North cater mostly to heterosexual patient-consumers, critical scholarship tends to position LGBTQ individuals as the primary benefactors of both national and transnational ART procedures and accompanying gamete transfer and surrogacy arrangements.

Heterosexuality is presumed when discussing the causes, consequences, and treatment of infertility in human rights literature, which focuses on the Global South. The World Health Organization's definition of infertility as a medical condition assigned when a clinical pregnancy does not occur after 12 months of regular, unprotected intercourse maintains the centrality of heterosexuality and the separation between issues of infertility and assisted reproduction.[39] Although a 2023 research paper sponsored by the Office of the United Nations High Commissioner for Human Rights proposes a reconceptualization of infertility to encompass social and structural causes, the remainder of the paper focuses on the causes and consequences of preventable infertility (i.e., medical conditions of infertility the likelihood of which may be reduced through social and structural changes).[40] Thus, while connections are made between social and medical dimensions of infertility, the biomedical focus remains intact.

Heterosexuality is also central to human rights cases challenging IVF prohibitions, predominantly in the Global North. Only heterosexual couples have brought successful challenges in regional human rights courts to laws that either completely ban IVF or restrict the procedure to infertile couples.[41] Laws and policies that prohibit, restrict, or deny funding for IVF to those who cannot prove medical infertility (i.e., lesbians and single women) have withstood international human rights challenges, although several have been altered through national legal and legislative processes.[42] It is also noteworthy that each case in the European Court of Human Rights and Inter-American Court of Human Rights has featured disability as an organizing conceptual framework. Most prominently, and in keeping with the World Health Organization's definition, denial of medical intervention for the disease of infertility constitutes discrimination on the basis of disability. In one case, *Costa and Pavan v. Italy*, a heterosexual couple was found to have a right to access both IVF and genetic selection procedures in order to select an embryo that did not carry the disease of cystic fibrosis.[43]

This heterocentricity reflects both the material and symbolic effects of (neo)colonialism and racialized imperialism: (1) the conditions of poverty, environmental racism, and inadequate health care produce higher rates of medical (i.e., heterosexual) infertility in the Global South, and (2) in the neocolonial imaginary, the ongoing conditions of racism and coloniality—e.g., poverty—are routinely used to other those living in the Global South. By dislocating structural causes of medical infertility, including health care inequalities, to the Global South and creating the expectation of access to IVF (which becomes synonymous with ART) only for those in the Global North, the human rights literature, human rights case law, and scholarship fail to grapple with structural arrangements of power in the Global North and render expansive reproductive assistance unimaginable for (LGBTQ) people in the Global South.

I contend that the gaps that exist across human rights and scholarly literature on infertility and ART may be addressed using a reproductive justice paradigm that unsettles medical infertility as a necessary prerequisite to reproductive assistance. Some argue that treatment for the disease of infertility should be universally accessible.[44] However, this argument neither extends to family composition-related or anatomical infertility, which is disproportionately experienced by LGBTQ and single people, nor suggests that access to ART—which is the most expensive, technologically complex, and rare category of assisted reproductive treatment—should be expanded.[45]

As Laura Briggs notes, both assisted reproduction and infertility are shaped by economics and racial politics.[46] A growing group of people facing family composition-related infertility is going into debt to finance ART services, while low-income people, people of color, and people living in the Global South are more likely to experience infertility due to environmental factors, underlying medical conditions, and lack of access to health care.[47] Taking this one step further, I argue that structural and medical infertility cannot be disentangled from one another or issues of reproductive justice. While ART is framed as a choice when financially attainable, it is an increasingly necessary treatment for all forms of infertility due to environmental toxins, poverty, and barriers to health care.

Additionally, both infertility and ART access are overdetermined by race, class, family form, and geopolitics (i.e., (neo)colonial power relations). Historically, single, poor, and LGBTQ people, as well as people with HIV or disabilities, have been denied access to ART services.[48] Treatment and funding exclusions, some of which are justified by the absence of medical infertility among LGBTQ and single people, remain codified in many legal schemes.[49] Discrimination in ART settings is commonplace and undoubtedly underreported in the Global North and mostly unreported in the Global South.[50] Many people cannot afford the high costs of ART, and only 1% of those who express an interest in IVF are able to access it.[51] People of color and poor people living in the Global North are less likely to have health insurance and therefore more likely to be impacted by ART cost barriers.[52]

The bridging of assisted reproduction and infertility under a reproductive justice paradigm may expand access to ARTs while highlighting their continuity with other forms of reproductive care. As discussed above, while there is no enumerated international human right to assisted reproduction, international human rights bodies have advised state parties to provide universal "infertility" prevention, diagnosis, and treatment.[53] The de-hierarchization of medical and family- and social-structural infertility would enable ARTs to be viewed as a set of reproductive health tools that should be available across gender, sexuality, and geopolitical boundaries and under a variety of circumstances. If ARTs are viewed as one among a set of treatment options independent of medical indication, they are more likely to become financially accessible and receive more institutional, regulatory, and financial support. However, this move simultaneously risks the further medicalization of ARTs and diminished access for some LGBTQ and single people.

In order to more fully recognize infertility and ARTs as justice issues, infertility must be unmoored from its biomedical foundations. The American Society for Reproductive Medicine recently published a new definition of infertility that incorporates the "need for medical intervention"—including ARTs—to achieve pregnancy, either individually or with a partner.[54] While the definition still leaves heterosexual intercourse as the unnamed but presumed norm, it decenters the biomedical causes and thus disrupts the hierarchy of medical and structural forms of infertility. The society's definition supports, but does not guarantee, policy changes at the state level that would provide insurance coverage for LGBTQ and single people seeking ART services.[55] It appears to be a first step in decentering heterosexuality and complicating the assumptions that animate ART practices and scholarship.

The risk of collapsing these categories is that important forms of difference will be obscured. Stewart Marvel argues that combining different forms of infertility effaces the nuanced medical, social, and legal positions and needs of varied individuals and couples who seek reproductive assistance.[56] While these needs are vital, and Marvel's proposed four-category schema disrupts the normative relationship between heterosexuality and reproduction, I see alternative value in recognizing the commonalities across the different pursuits of ART services.[57] The detachment of infertility from medical etiology and diagnosis may highlight its social contributors such as poverty, environmental toxins, and racialized imperialism. After all, the medical diagnosis of infertility is neither precise nor inclusive; up to 30% of infertility diagnoses have no identified cause.[58] In turning away from a set of elusive biomedical explanations, the structural commonalities may be more visible.

Together, these moves would complicate the narrative of ART as antithetical to reproductive justice and expand its accessibility while maintaining the critical focus on the power gradients that reproductive material and labor traverse and reinforce. Upon the de-medicalization of infertility and symbolic—if not material—expansion of ART, it may be possible to queer our understanding of ART by unsettling its norms of heterosexual reproduction and biological kinship. Although unseating medical infertility as the necessary prerequisite to ARTs may make reproductive assistance more financially and legally accessible, it does little to destabilize the social and legal dominance of biological kinship or legitimize other modes of family-making. In the next section, I unpack the limitations of pursuing a right to assisted reproduction and explore queer-, justice-oriented alternatives.

Assisted reproduction and biogeneticism

A handful of scholars have critiqued the social and legal supremacy of the (nuclear) biological family and suggested that support for a right to assisted reproduction may unwittingly contribute to this "pervasive *biogeneticism*."[59] Indeed, the development of ARTs is anchored to the notion that the technologies may be used to assist "natural" reproduction (i.e., the procreation of children within a heterosexual relationship and with genetic ties to both parents).[60] Courts have upheld this vision, with the Inter-American Court of Human Rights determining that Costa Rica's IVF prohibition interfered with a heterosexual couple's "decision-making concerning the methods or practices they wished to attempt in order to procreate a biological child."[61]

Others point to the ways in which reproductive technologies both de-naturalize and reinforce the biological underpinnings of reproduction. In their imitation of sexual reproduction, ARTs may reify both the social and biogenetic normativities of the nuclear family. However, they also have the capacity to create new hybrid entanglements of the biological and technological.[62] Even when mimicking the biogenetic ties of the heterosexual nuclear family (i.e., genetic relationships between children and two parents), IVF introduces "a seemingly endless, and inevitably somewhat parodic, *sequelae* of quasi-, semi- or pseudo-biological forms of parenting."[63] With these possibilities comes an uncertainty about the technobiological origins—and, therefore, the naturalness—of any reproduction.[64]

Sarah Franklin highlights these new forms of "biological relativity," created through the familiar merging of technology and biology, as an opportunity to view all reproduction as "strange" and unsettle the normativity of (hetero)sexual reproduction.[65] Similarly, Marvel attends to the "polymorphous reproductivity of queer biokinship," by which multiple arrangements emerge from the convergence of the biotechnological and the familial.[66] The queer parent is someone whose entry into the domain of assisted reproduction bears no relationship to (in)fertility as it is conventionally understood, and whose partiality of biological ties (i.e., usually only to one parent) necessarily complicate traditional notions of biological kinship.[67] Marvel suggests that the centering of the queer family and biokinship may unsettle the presumed nexus of procreative heterosexuality and biological kinship, which forms the basis of US and European family law, while creating space for LGBTQ non-biokinships.[68]

I take up Franklin and Marvel's recognition of partial, and thus parodic, biological kinship to examine the possibilities for a queer-, justice-oriented human rights approach to assisted reproduction. A reproductive justice approach requires the pursuit of reproductive health care that is accessible to all and accounts for the racialized injustices that shape not only its accessibility and provision but also its differential impacts on individuals, families, and communities. In my approach, I also heed Michael Boucai's warning that the uptake of ARTs by LGBTQ people reinforces the biogeneticism that privileges biological parenthood and devalues adoptive and extra-legal kinship relations.

I believe that a right to comprehensive reproductive health care must be pursued in conjunction with the rights to family formation and equality. First, it is necessary to understand the division of human rights by type and character (positive versus negative). Whereas negative rights entail freedom from government intrusion (e.g., in family or private life), positive rights require affirmative government action. Additionally, civil and political rights constitute immediate obligations whereas economic, social, and cultural rights may be realized gradually.[69] Thus, while the rights to equality or privacy, including the right to establish a family, may be used to prevent interference with, or require equal access to, ART procedures such as IVF, they would not require the provision of health care. And while the right to health may be used to move states toward affirmative action, it will not result in the provision of immediate care beyond that which is deemed essential.[70]

If pursued within a right to health, ART procedures should be publicly funded and—in accordance with the equality principle—accessible to all. Indeed, at least six European and three non-European countries and territories provide "full" public funding, and many more provide partial funding (1%–80% of the cost of one or more cycles).[71] However, there are at least two concerns raised within a queer reproductive justice framework: (1) this financial support must not come at the expense of other health care provision, including basic reproductive health services, and (2) in order to undermine the common rationale that reproductive technologies are not medically necessary, it is imperative to both reframe health care as a means to well-being rather than solely a remedy for illness or pathology *and* counter the myth of normal or natural reproduction. These two concerns are intertwined and indicate the importance of a gradual and context-specific—rather than universal or unlimited—expansion of (IVF and non-IVF) ART access. The reframing of holistic well-being as the end goal of health care supports the integration and balancing of an array of reproductive health services with other forms of health care.

Importantly, the right to health does not encompass the social and legal dimensions of family formation and recognition. Further, although the right to health has been a successful avenue for addressing preventable medical infertility (e.g., treatment of STIs), it has not been the basis for a successful claim to ART.[72] Rather, both the Inter-American Court and the European Court of Human Rights have recognized decision-making as to whether or not to become a parent as a component of the right to privacy.[73] While most of these cases have involved interference with ART access, and all arguments have been grounded in regional human rights instruments, the European Court has indicated that there is a positive dimension to the right to privacy.[74] This suggests that there may be room to interpret article 10 of the International Covenant on Economic, Social and Cultural Rights—which provides for protection and assistance in the "establishment" of the family, among other family-based rights—as encompassing a positive right to reproductive assistance.[75]

It is necessary—and, I believe, possible—to pursue this right to family formation without prioritizing biological families. Rather than focus on the "right to procreate" or the right to "biological parenthood," we must reconceptualize the right to parent or found a family as inclusive of all forms of kinship, whether (quasi-)biological or not.[76] Here, it is useful to turn to Marvel's "polymorphous reproductivities of queer biokinship" and the recognition that (hetero)sexual procreation is one among many reproductive possibilities. Histories of LGBTQ family-making, as well as "othermothering" and other community caretaking forms, highlight the social if not legal possibilities for decoupling kinship and biology.[77]

Valuing all families, as advocated by many critical scholars over a number of decades, requires robust financial, legal, and material support for a variety of family forms, with a focus on substantive rather than formal caretaking relationships.[78] Legally, this would necessitate universal access to various types of parental recognition—ranging from second-parent and confirmatory adoption to intended parent provisions and functional parent doctrines.[79] These parental recognition schemes would legitimize families as they currently exist, including relationships between a child and more than two parents or caregivers.[80] Social and financial assistance must be provided so that existing families may adequately support children and other dependents, such that foster care and adoption become options rather than mechanisms of racialized social control.[81]

Conclusion

Although recent scholarship and human rights literature has begun to apply an intersectional lens in analyzing access to reproductive assistance, and specifically IVF, the separation of ART and infertility discourses according to a choice/justice binary persists. In particular, the continued biomedicalization of infertility and attention to ART politics and potentialities in the Global North situates the structural antecedents of infertility—e.g., gender-based violence, STIs, and unsafe abortions—in the Global South and obscures the range of options for (LGBTQ) reproduction. I argue that the separation of ARTs and infertility and biomedicalization of infertility must be addressed through a coordinated set of queer reproductive justice strategies. Upon recognizing the many forms of partial or pseudo-biological kinship enabled by ARTs and disproportionately enacted by queer caregivers, the norms of (hetero)sexual procreation and biological kinship may be subverted.

In addition to upending traditional reproductive expectations, these existing realities underscore the need for legal and social recognition of quasi- and non-biological kinship arrangements alike. The human rights to establish a family and to family life, as well as the reproductive justice tenet of having children under the conditions of one's choosing, provide that all family forms must be supported in their creation and ongoing well-being.[82] When paired with a positive right to reproductive health, these principles support the equitable provision of assisted reproductive services that accounts for specific histories of colonialism, racism, and LGBTQ marginalization. Thus, a reproductive justice approach to assisted reproduction must embrace the initial promise of a theory and praxis that accounts for co-constitutive elements of justice, human rights, and choice.

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The Spirit of Human Rights: Universal Health Coverage in Makueni County, Kenya

ESTHER KAMAU AND GILLIAN MACNAUGHTON

Abstract

In view of the United Nations' goal to achieve universal health coverage (UHC) by 2030, this paper investigates MakueniCare, the highly successful UHC program in Makueni County, Kenya, to reveal the spirit of human rights underlying it. Drawing on international, Kenyan, and Makueni County law and policy, as well as 30 interviews with government and civil society leaders in health care policy and programming at the national and county levels, we examine the human rights law and principles that underlie the adoption and implementation of MakueniCare. We first set out key human rights principles grounded in the International Covenant on Economic, Social and Cultural Rights and the 2010 Kenyan Constitution, and then describe the research design and methodology of the project. Then, we analyze the data collected to highlight the various ways in which the adoption and implementation of MakueniCare were influenced by human rights, particularly the right to health. We conclude with thoughts on how MakueniCare could be further improved from a human rights perspective.

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Introduction

Universal health coverage (UHC) has been promoted by the World Health Organization since 2005 and was adopted by the United Nations General Assembly in 2015 as target 3.8 of the Sustainable Development Goals (SDGs) to be achieved by 2030.[1] According to the World Health Organization:

> *Universal health coverage (UHC) means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.*[2]

Despite United Nations General Assembly and World Health Organization commitments to prioritize UHC, in 2021, 4.5 billion people were not fully covered for essential health services.[3]

Importantly, UHC is not equivalent to the right to health.[4] Indeed, "not all paths to universal health coverage are consistent with human rights."[5] First, the right to health includes but extends far beyond health care to include the underlying determinants of health, such as safe housing, decent work, nutritious food, potable water, sanitation, and a clean environment. Second, the right to health also includes process rights such as nondiscrimination, transparency in policymaking, participatory decision-making, and accountability, including the right to a remedy. Thus, UHC may be a component of the right to health, if it is implemented in a rights-based manner, but it is only one component of the broader right to health.[6]

While UHC is not necessarily rights based, human rights underlie the SDGs, including SDG target 3.8 on UHC. Indeed, the SDGs are grounded in the Charter of the United Nations, which aims to advance respect for human rights, as well as the Universal Declaration of Human Rights and international human rights treaties.[7] Thus, consistent with their international legal and political commitments, UN member countries must implement UHC in a human rights-based manner to achieve SDG target 3.8. Significantly, at the national level, the right to health has proven to be an important factor in driving action to achieve UHC in several countries, including Mexico and Turkey.[8]

Kenya has struggled to implement UHC since the country's independence in 1963.[9] A major step forward was the recognition of the right to health in the 2010 Kenyan Constitution, which simultaneously devolved significant authority to the 47 counties to implement UHC. Article 43(1)(a) of the 2010 Constitution states, "Every person has the right to the highest attainable standard of health, which includes the right to health care services, including reproductive health care."[10] Toward this end, in 2013, the national government eliminated user fees for primary health care, as well as for maternal care and under-five health care.[11] Devolution of health care to the county level resulted in a variety of approaches to implement UHC across the country. None was as successful as the UHC program in Makueni County, MakueniCare. In 2013, only 8.8% of the county population had health insurance, primarily covered under the National Hospital Insurance Fund; by 2018, 91% of the county was insured under MakueniCare.[12]

In this context, this paper examines the highly successful UHC program, MakueniCare, to reveal the extent to which human rights principles and the right to health underlie its adoption and implementation. Recent articles on health rights and UHC in Kenya have focused on several county programs—including those in Kwale, Nairobi, Kisumu, Nyeri, Machakos, and Isiolo Counties—but have not examined Makueni County.[13] Further, while several publications analyze MakueniCare, none of them have made human rights central to their inquiry.[14]

This paper is the second in a series of papers on MakueniCare that draws on (1) international, Kenyan, and Makueni County law and policy and (2) 30 interviews conducted in 2019 with leaders in health care policy and programming at the national and county level.[15] While the previous paper focused specifically on the political drivers for the adoption of MakueniCare, this one examines the spirit of human rights—specifically, the right to health—in the adoption and the implementation of MakueniCare. We begin by briefly setting out human rights principles grounded in the International Covenant on Economic, Social and Cultural Rights and the 2010 Kenyan Constitution, and then describe the research design and methodology for the project. Next, we analyze the data collected to highlight the various ways in which the spirit of human rights infused the adoption and implementation of MakueniCare. We conclude with thoughts on how MakueniCare could be improved from a human rights perspective.

Human rights law and principles

The spirit of human rights, particularly the right to health, provides a strong foundation for UHC by setting normative standards, principles for governance, and expectations of duty bearers and rights holders. In the case of Kenya, the human rights foundation is established in the International Covenant on Economic, Social and Cultural Rights, which Kenya joined by accession in 1972. Article 12 of the covenant provides in part that state parties must "recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[16] Further, "to achieve the full realization of this right," states must create "conditions which would assure to all medical service and medical attention in the event of sickness."[17] This obligation is spelled out more fully in General Comment 14 issued by the United Nations Committee on Economic, Social and Cultural Rights, which explains that the right to health includes the right to health facilities, goods, and services, including "the provision of equal and timely access to basic preventative, curative, rehabilitative health services and health education."[18]

Further, the right to health includes key human rights features, including the rights to transparent processes of health governance, participation of the population in political decisions relating to health, nondiscrimination and equality in decision-making and in access to health care, accountability of government officials as duty bearers, and access to remedies for rights holders.[19] Importantly, the International Covenant on Economic, Social and Cultural Rights recognizes that state parties may not be able to provide all elements of the right to health immediately; however, they must take steps to the maximum of available resources with a view to achieving progressively the right to health.[20]

Kenya incorporated the international right to health, including its key features, into its 2010 Constitution. Reflecting article 12 of the covenant, article 43 of the Kenyan 2010 Constitution states, "Every person has the right (a) to the highest attainable standard of health, which includes the right to health care services, including the right to reproductive health care." Further, the 2010 Constitution recognizes the human rights principles of governance and public service, including nondiscrimination, transparency, participation, and accountability, as well as the obligation to progressively realize in full the right to health.[21]

On the basis of these commitments in international and domestic law, this paper analyzes the circumstances of the adoption and implementation of MakueniCare to unveil the extent to which this UHC program reflects the spirit of human rights.

Research design and methodology

Makueni County made for an interesting case study on realizing SDG target 3.8 on UHC because it is an outlier in Kenya and in Sub-Saharan Africa due to its rapid success in expanding health insurance coverage. We used a case study research design and employed qualitative methods allowing the flexibility to probe multidimensional factors in a complex landscape of health care reform in Kenya.[22] We employed two main data collection techniques. First, we undertook document and archival research to develop an in-depth understanding of the political and policy framework guiding health policy from 2010 to 2021 in Kenya and in Makueni County.[23] We analyzed key national and county health policies, development plans, campaign manifestos, government gazettes, and media clippings. In the field, first author Kamau also reviewed county government internal memos, operational guidelines and budgets, and health facilities' inpatient and outpatient statistics. Second, in the summer of 2019, Kamau conducted 30 in-depth interviews with key informants, including three politicians, fourteen bureaucrats, and seven civil society representatives in Makueni, as well as six key health policy experts in Nairobi.

The interview data were manually transcribed, and all data (interview transcripts, documents, and field notes) were analyzed using ATLAS ti., a qualitative social science software using human rights principles as the framework for analysis. We employed several strategies to ensure rigor, including triangulating information from the multiple methods and sources, providing a rich and thick description of the findings, and debriefing with peers.[24] Research approval was received from the University of Massachusetts Boston (approval no. 2019115) and the National Commission for Science, Technology and Innovation in Kenya (reference no. NACOSTI/19/218221/31705).

Findings

The evidence showed that the following six key human rights principles provided a foundation for the adoption and implementation of MakueniCare: (1) the right to health care as a normative framework, (2) progressive realization of the right to health, (3) use of maximum available resources, (4) universality, equality, and nondiscrimination, (5) participation, transparency, and accountability, and (6) understanding of duty bearers and rights holders.

The right to health care as a normative framework

The 2010 constitutional provision that guarantees everyone the right to health created a foundation for the adoption of policies to realize UHC. Both the key informants and the documents reviewed connected the investment in the county's health sector and the establishment of MakueniCare to the 2010 constitutional guarantee of the right "to the highest attainable standard of health, which includes the right to health care services."[25] For example, James Kanyange, the county director of health commodities and technology, claimed:

> [T]*he governor mentioned in his manifesto that he'll ensure that the population gets the highest attainable standard of health as is dictated in our Constitution; so every year we have been getting some amount of budgetary allocation.*

Similarly, Peter Owiti, executive director of Wote Youth Development Project, a county nongovernmental organization (NGO), asserted:

> *The Constitution says that every citizen has a right to the highest level of health care. So that was a drive in itself, that it was a constitutional mandate for people to have the highest level of health care. So, if you combine the* [global UHC] *wave plus the Constitution, then automatically the county government made it one of its pillar projects.*

Further, the 2016 *MakueniCare Implementation Guidelines* cite the constitutional guarantee of the right to health as a key impetus for the county government's commitment to enhance access to health services. The guidelines state that "[t]he Department of Health [in] Makueni is committed towards improving access to health care to all citizens as a means of realising the Right to Health enshrined in the constitution of Kenya 2010 as well as the long-term development blueprints including the Makueni County Vision 2025."[26] In sum, the record shows that the constitutional right to health played an important role in influencing the adoption of MakueniCare.

Progressive realization of the right to health

Following devolution in 2013, the Makueni County government began to progressively realize the right to health. Key informants and policy documents revealed that, like many other counties, Makueni inherited a dysfunctional health care system from the national government at the start of devolution. The evidence further indicated that during the first three years, from 2013 to 2016, the county invested substantially in strengthening the health care system to increase access to both primary and secondary care. To this end, the county increased the number of health care workers, improved access to quality essential drugs, and expanded and equipped health facilities, all of which contributed to a more efficient service delivery system.[27] This set the stage for the subsequent adoption of a county health insurance program in 2016. In the words of Governor Kibutha Kibwana, a key lesson from Makueni is that

> *Universal health coverage is possible, but you must make sure that the basis for it exists—so that you don't have a hollow universal health coverage system in terms of you have no facilities, you have no doctors, you have no budget for medicine. It is almost like a checklist so that by the time you think you are considerably ready, tick the following … So that's very vital, and that's why we were lucky to have, first of all, just worked on the essentials. And then when we now came to the decision that we could have the universal health care and let the people contribute to their own insurance coverage, the facilities, health workers and the money for drugs and the systems for how you get the drugs to them and so on are in place … By the time we started, because of the focus on health, we had already prepared quite a bit …* [T]*here was deliberate work to prepare ourselves.*

Similarly, Andrew Mulwa, Makueni County minister of health, explained that upon devolution, the county worked to invest in the health system to ensure increased access to both primary and secondary care, and the next logical step was to resolve the issue of financial protection. He recounted:

> *So, we asked ourselves, now that the primary component seems to be fairly sorted and everyone feels happy, how can we have a mechanism of taking care of financial protection of the citizens in the secondary level of care?*

To this end, in early 2016, the county government launched a six-month pilot program that covered the cost of health services for residents 65 years and older.[28] Then, in October 2016, the county government established the Makueni Universal Health Care Programme, known as MakueniCare, to provide health insurance to all households that pay an annual premium of Ksh 500 (US$5).[29] The Ksh 500 annual premium for MakueniCare is much lower than the Ksh 6,000 (US$60) annual premium for the National Hospital Insurance Fund. Moreover, residents over the age of 65 are exempt from the Ksh 500 premium.[30]

MakueniCare pools members' contributions together with a county government contribution derived from its annual allocation from the national government general tax revenue.[31] Table 1 shows the county government's allocations to MakueniCare from its inception in 2016 to 2020.

Significantly, following devolution, the Makueni County government progressively realized the right to health by first building the health care infrastructure, then launching a pilot health care financing scheme for people aged 65 and older, subsequently establishing a health care financing system for all county residents, and then annually increasing funding for health care. According to the World Health Organization, 91% of the 188,000 households had registered for MakueniCare by the end of 2018.[32]

Maximum available resources

The right to health calls for governments to use the maximum of available resources toward progressively realizing the right to the full extent.[33] The Makueni County government took significant steps to do so, including (1) adopting measures to curb corruption, (2) putting in place procedures to minimize waste in spending, and (3) prioritizing health care in the county budget.

A key change brought about by devolution was the provision for the equitable sharing of at least 15% of the revenue raised nationally to all 47 counties, thereby substantially increasing the Makueni County budget.[34] In this context, Makueni implemented

TABLE 1. County government allocations to MakueniCare, 2016–2020

Year	2016/2017	2017/2018	2018/2019	2019/2020
Amount in US$	2 million	2.5 million	3.0 million	3.5 million

Source: P. Muasya, "Inside Makueni's Universal Health Care Programme," The Standard (August 13, 2018), https://www.standardmedia.co.ke/health/article/2001291782/inside-makueni-s-universal-health-care-programme; Key informant interviews, June-August 2019.

several measures to build a culture of integrity despite the country context characterized by endemic corruption. First, key informants reported that the county leadership took action against corrupt officials. The Honorable Jackson Mbalu, member of the County Assembly and chair of the Health Committee, noted:

> *Makueni has succeeded because the governor is keen in fighting corruption … Because the minute you open a crack of corruption, everybody down there will follow you. So that's what Kenya needs, leaders who are very true to what they say … leaders who will toe the line. Anybody who is involved in corrupt dealing is sacked. So, it has to start from the top …* [E]*ven if the executive officer who is hired by Governor Kibwana himself becomes corrupt, he will be sacked … If you're corrupt, you'll be sacked and that's very good. Because even chief officers know, everybody knows, if we catch you with corruption, you'll be sacked, and there is no question about Governor Kibwana. He won't allow it … And he has sacked several ministers before.*

A second measure taken to stop corruption was hiring an external consultant to vet bills of quantities for county government-funded projects to ensure that prices are not inflated. Key informants underscored that most corruption in government stems from procurement. They explained that before a tender for a new construction project is advertised, the Ministry of Public Works first develops bills of quantities. To ensure that these are not inflated, the Makueni County government engages an external quantity consultant to evaluate and approve all the bills of quantities before they go through the tendering process. Patrick Kibwana, Makueni County's chief officer of health, explained:

> [M]*ost of the bills of quantities in the country are usually inflated. But … we have hired an external consultant quantity surveyor who reviews the bills of quantities from our public work and makes sure that there's no money hidden there for any public servant.*

A third measure taken to curb corruption was the installation of project management committees (PMCs) composed of two members from the county government and three members from the community. Key informants explained that PMCs ensure that construction projects are completed to the required standard and that material and equipment procured are delivered in the right quality and quantity. Several key informants spoke about the role played by the PMCs in reducing opportunities for corruption and ensuring value for money. For instance, Jopha Kitonga, a county health administrator, related:

> *Another unique thing is that all the projects in Makueni County are manned by PMCs. Project contractors cannot be paid if the PMC has not approved. The PMC has to ascertain that this is the building that was constructed, or that toilet was constructed properly, or these are the materials or equipment that were delivered, and they are of the right quantities and quality. When you do that, then you avoid a situation where people say money has been stolen, or you've paid for it, but it has not been constructed. No payment can be made, not unless the PMC has signed.*

The use of PMCs was also commended by NGO leaders. For example, Joseph Mbalu, regional programs coordinator for the Red Cross, shared:

> *For Makueni it has been a system-wide sort of thing. So, for example, the entire procurement process, the nightmare of corruption for Kenyans, it is run a bit differently. For example, health center X in Kilome or somewhere has a local committee from the village cluster, and if they're supposed to procure a CT scan, a table, and a bed for the maternity wing, the supplier does not get paid until that committee on the ground signs off on the delivery. So that promotes efficiencies because in the other few counties that I've been, I'll not mention them, the only person who signs off is the person in charge or the manager … But in Makueni, you have members of that community, people who will use that hospital, not employees who will be there for a time.*

The fourth measure that the county government took to curb corruption was open contracting—that is, opening the procurement process for scrutiny by all. As Governor Kibwana explained:

> [H]*ere in Makueni, we are transitioning into open contracting, which means that the entire process is open to everybody, and it is online so you can see who has bid, you can see how much, you can see what has happened, you can see who was sitting on the committees. All that information is now available to everybody. So, those are the kind of innovations that we are making so that it's harder to do a lot of rent seeking.*

Media reports indicated that the Makueni County government's implementation of Kenya's procurement laws has curbed corruption.[35] Indeed, the media is full of praise about Makueni's zero corruption as reflected in its clean audit reports by the Office of the Auditor-General, being one of only two counties in Kenya to get a passing score.[36] Meanwhile, media reports are awash with reports of corruption in the other counties and in the national government.[37]

Key informants stressed that in addition to curbing corruption, reducing inefficiencies was an important factor in Makueni's success in the health sector. Joseph Mbalu, regional programs coordinator for the Red Cross, stated:

> [A] *key lesson from the Makueni experience is the efficiencies within the system. And I'm not pointing fingers at any other saying somebody else is inefficient but looking at Makueni … the non-corruption, the level of efficiencies that have been developed in the bigger system* [county wide], *are things to learn about. That it is not possible to have a good universal cover or a health care system inside a system that is corrupt, or where there are a lot of leakages. So that is the other thing to learn about Makueni and the universal cover.*

Members of the County Assembly also pointed to the measures taken to enhance the efficient use of public funds in Makueni in order to make UHC attainable. For instance, the Honorable Jackson Mbalu, County Assembly member, noted:

> *They* [the county executive] *also use the money prudently, that's why you see like the mother and child hospital, which people expect we used a lot of money and we only used Ksh 135 million. What does that tell you? It tells you there is prudent use of resources. Anything is attainable as long as corruption is cut back because you give the same money to anybody else and see how much they will bring!*

An NGO leader shared that Makueni does more with less, which is the main difference between Makueni and the other counties. He stated:

> *For instance, early last year the governor was able to launch a mother-child hospital with around 230-bed capacity. It is something that wowed the whole nation because the governor was able to construct it with only Ksh 133 million. I have stayed in other counties. I have been in Narok, I've been in Siaya, Homabay, Nairobi, and I've seen what those people do sometimes with Ksh 100 million. It makes you wonder. I was reading a news article about Narok County that they were able to do an expansion of a 10-bed maternity wing,* [on] *which they spent Ksh 250 million. And then I come to Makueni, and I find the governor has done a 230-bed capacity* [maternity hospital] *with Ksh 133 million, fully equipped, and I just can't understand … So what magic are they doing so that they can be able to provide free health services to their communities?*

Finally, key informants also shared that from the onset of devolution, Makueni prioritized health care by allocating at least 30% of its county budget to the health sector. For example, Bill Olwenda, project manager of the Partnership for Primary Care, a public-private partnership in Makueni County, stated:

> *Makueni county allocates not less than 30% of its budget to health. Not that there has been a lot of advocacy efforts towards that—it's a conscious decision which the county has sat down from both executive and the County Assembly, and they have said this is what we want. But in other counties, you look at the budgetary allocations and you even do not know where to start the dialogue from. That is key.*

Media clippings and Makueni County government reports aligned with the perspectives of key informants.[38] For example, the *Standard Digital* reported that "so far, the county [Makueni] has managed to keep its budget allocation to health above 30 per cent."[39] Similarly, Mohammed and colleagues reported that since 2013, the county allocated more than 30% of its annual budget to the health sector, which was invested in strengthening the health system.[40] In sum, the evidence revealed that devolution enabled the county government to take measures to curb corruption, reduce government wastage, and prioritize the health sector in budgeting, which were all fundamental to the county's ability to maximize available resources and successfully adopt and implement MakueniCare.

Universality, equality, and nondiscrimination

In building the health care system and establishing MakueniCare, the county government's goal was to advance the right to health by providing universal, equal, and nondiscriminatory access to health care. Key informants noted that after taking substantial steps to increase access to primary and secondary health care services at the onset of devolution, the county government realized that out-of-pocket payments at the time of service continued to be a major barrier to health care access for those living in poverty. MakueniCare was the county government's effort to ensure universal and equal access to health care services. The Honorable Jackson Mbalu, a member of the County Assembly, stated:

> *The majority* [of residents] *could not afford health care because of payment and most of them are living below a dollar a day … Most of them are quite poor. So that's why the idea came up of finding where they can chip in. You know like, now if you pay Ksh 500 per family, that's quite cheap. And also, we have the elderly scheme, which treats them for free. Most of those people were just being left to suffer because they have no income, and they are not able.*

Similarly, another government official, Joseph Mulei, acting medical officer of health, Makueni Sub-County, reflected on the county government's commitment to universal access to health services:

> [F]*rom my own observation, the governor really wanted to see that his people could access health care services in a way that is affordable to them, and that is how the idea came in. Because basically any household can afford Ksh 500 per year, and once they pay that money, any service provided within the county is free for the next one year—name any service, whether it is major operations, drugs, anything for one year for that household. And actually, from my own observation, it has really increased the patient flow. In all health facilities, demand for health services has tremendously increased.*

Likewise, the 2016 *MakueniCare Implementation Guidelines* state that out-of-pocket payments had been posing a barrier to access health care, especially for people living in poverty. To this end, a key reason for starting MakueniCare was that access to quality public health care services in Makueni "should not be impeded by the cost patients have to pay."[41] Further, media reports indicated that MakueniCare was a measure "to cushion people from unwarranted suffering and inability to access quality healthcare."[42]

Promoting equality and nondiscrimination was also a key consideration in the establishment of the seniors' scheme and MakueniCare. Key informants explained that the governor's campaign slogan was *O kila nyumba oo kalila*, which directly translates to "every household a glass of milk," and loosely means that his administration will make every effort to ensure equity and fairness in the distribution of county resources to all residents. Indeed, article 174(g) of the 2010 Constitution says that a key objective of devolution was "to ensure equitable sharing of national and local resources throughout Kenya."[43]

Key informants noted that investment in the health sector and the eventual adoption of MakueniCare was an opportunity for the governor to fulfill his campaign promise of ensuring that all residents benefit equally from county resources. For example, Joseph Mulei, acting medical officer of health, Makueni Sub-County, stated:

> *When the governor was running for his second term, his slogan was, "oo kila nyumba oo kalila" … that is, every household a glass of milk, symbolizing sharing of the county cake. And you know, in terms of health, if they can make it affordable, everybody would be able to access it such that we can say, every household a glass of health.*

In sum, in establishing MakueniCare, the county government aimed to provide universal, equal, and nondiscriminatory access to improved county health services to all Makueni residents.

Transparency, participation, and accountability

The human rights principles of transparency, participation, and accountability also played important roles in the success of MakueniCare. Key informants and the documents reviewed linked the prioritization of the health sector and the establishment of MakueniCare to a new public participation system. Key informants related that soon after devolution, Makueni put in place a robust public participation system that allowed residents to meaningfully participate in planning and budgeting processes right from the village level. This enhanced transparency because people knew what was planned and budgeted for, which enabled residents to hold the government accountable to implement the plan and the budget.

Key informants believed that participatory planning and budgeting processes created space for the needs and priorities of even those in remote villages to shape development and resulted in the prioritization of the health sector and the adoption of MakueniCare. As Peter Owiti, executive director of Wote Youth Development Project, a county-level NGO, stated:

> *When we got into devolved government, there was a requirement by law that public participation is one of the mandatory requirements in the budgeting process. In that respect, you find that when people went to start budgeting at the ward level, then most of the money was being allocated either to building the facilities or providing medical services. So that's how it originated …* [I]*t was the community that was demanding health as priority number one.*

Another NGO leader in Makueni County stated:

> [The public officials] *felt that the greatest importance is to ensure that you respond to the immediate need of the communities. And in this case, the information that was gathered across the county during the public participations was: health is very critical and on top of all the priorities. It was health followed by water and then followed by livelihood—that is, improving the agriculture, livestock, fisheries and all those other departments. So, health was given a priority.*

The *Makueni County 2019 Annual Report* aligns with the perspectives of key informants, stating that in the annual public participation forums, residents had prioritized the provision of health care.[44]

Key informants also related that the robust public participation structures in Makueni empowered residents to hold leaders accountable, which in turn resulted in more responsible and people-oriented leadership. Jackson Mbalu, a member of the County Assembly, noted:

> *When devolution came, people were empowered to be heard, empowered to participate in what they need … I cannot introduce anything which the people have not prioritized in the budget, and the citizens know that. So, when I start, I tell them, "What you said is what I am following up on." When I come here I ask* [the executive], *"Why didn't you follow what my people said?" … That is the way. If you don't do that, you will be chucked off. So, when I'm following up for my people, it shows that I'm very serious … It's my job on the line and that is how it should be because I am offering oversight, and I am doing legislative work, which is beneficial to my people.*

Further, informants explained that the fact that health workers are now employed by the county government has made them more accountable to patients, who may report health workers to their elected representatives—members of the County Assembly––who report to the governor. Jackson Mbalu explained:

> *Before devolution … the hospitals were in a very bad state, run by people who do not have the responsibility of answering to the local people. Now they are answerable; the personnel are answerable to the people here. If you mistreat somebody in a dispensary, it will reach me. I'll want to know from the chief officer of health, "Why have you mistreated so-and-so?" And it becomes a big issue. So it's not the way it used to be. Before, people were not responsible; today it is different.*

Simon Kavisi, unit head of health records and information at the Department of Health, provided a health worker's perspective:

> *The citizens have really benefited. They really worship devolution because the leaders have gotten closer to them, because when they are harassed by the civil servants, they can report to the member of the County Assembly, then phones go ringing up to the governor, then we see big cars coming to do fact finding and see where the problem is, and the problem is solved … When you are a health worker in the facility, the governor's number is on the board, the minister's number is on the board … So, when a patient is wronged in the slightest way, they call the numbers provided. For example, when the doctors are late. So, the civil servants are forced to write a letter explaining why there was a complaint.*

In sum, the evidence showed that participatory planning and budgeting empowered residents to influence development planning and budget allocation, enhanced transparency, and enabled residents to hold the government accountable to implement development plans and budgets. In addition, having elected county executive officers and legislators so close to the people improved (democratic) accountability, resulting in improved service delivery at the county level.

Duty bearers and rights holders

Key informants also linked the adoption and successful implementation of MakueniCare to the election of Governor Kibwana, a human rights activist and constitutional scholar who has advanced degrees in constitutional law and international human rights law and was previously an associate professor and dean of the Faculty of Law at the University of Nairobi. As a national expert on human rights, he had advocated for the reforms that led to Kenya's 2010 Constitution, including the Bill of Rights. His subsequent election as governor of Makueni allowed him to implement the Constitution at the county level, including the right to health, that he had championed at the national level. Key informants noted the governor's lifelong advocacy on behalf of the human rights of marginalized populations, as well as his commitment to advancing Makueni residents' rights. Indeed, in the governor's campaign manifesto, he committed specifically to advancing the right to the highest attainable standard of health, as recognized in the Constitution.

The governor's commitment to human rights is widely recognized. Indeed, he was honored in 2018 by the Kenya Human Rights Commission "for his outstanding performance, reformist agenda and fight for human rights in the country" that dates back from the 1990s and for his "implementation of a model public participation system" in Makueni County.[45]

Consistent with the governor's commitment to human rights, key informants attributed the increased investment in the health sector and the establishment of MakueniCare to his appointment of executives who were both social change-minded and knowledgeable about the health sector in Makueni. Patrick Kibwana, the Makueni County chief officer of health, noted that it was one thing to have resources that came with devolution and yet another to apply the resources appropriately for the benefit of the residents. He continued:

> *Now we have an opportunity to do the things that we thought the national government was not doing and put a smile on somebody's face. So, essentially the difference would be leadership. It is very, very key. Even as resources are availed, if the leadership is wrong, then definitely those resources would be misapplied.*

Further, NGO leaders noted that unlike in other counties, in Makueni County all ministries were headed by professionals. They noted that hiring professionals as opposed to political allies ensured that Makueni ministries were run competently. They also pointed out that having a medical doctor head the Department of Health made it easier for the department to make the right judgment in investing capital and human resources.

Complementary to the governor's commitment to advancing the right to the highest attainable standard of health and his appointment of professionals with knowledge of and experience in the local community, Makueni residents knew and claimed their human rights set out in the 2010 Constitution. Key informants believed that the robust public participation system in the county was crucial to prioritizing the right to health care, leading to increased budget allocations and investment in the health care system. Further, because residents knew and approved the plan and the budget, they could hold service providers accountable by following up with their representatives if plans were not implemented. In sum, duty bearers carried out their duties, and rights holders held their leaders accountable.

Conclusion

This case study revealed that human rights, particularly the right to health, provided an important foundation for MakueniCare. International and Kenyan constitutional law recognize the right to health care, which encouraged both the county government and residents to achieve UHC and provided a legitimate rationale for prioritizing UHC in the budget. Further, human rights principles—namely, progressive realization; maximum available resources; universality, equality, and nondiscrimination; transparency, participation, and accountability; and the understanding of rights holders of their rights and duty bearers of their obligations—guided the adoption and implementation of MakueniCare.

Still, MakueniCare could align more closely with the right to health care for all. Registration in MakueniCare has always been voluntary. Initially, the program did not require a grace period after registration. Because residents could access benefits immediately after registration, many residents waited until they fell sick to enroll. In 2020, a grace period was instituted to provide incentives for healthier residents to register and thereby address adverse selection and promote sustainability of the health insurance pooling mechanism. The current design of MakueniCare could be further improved by enacting an individual mandate requiring the registration of all households, which would further enlarge the pool and move toward universality. From a human rights perspective, however, fully financing MakueniCare through general tax revenue would make health care truly universal since access would not depend on residents' ability to understand, register, and pay for health insurance. An insurance scheme like MakueniCare that requires people to sign up and pay will often exclude the most marginalized.[46] Moreover, under the current scheme, all households, rich or poor, pay the same premium; it would be more equitable if funded through progressive general tax revenues so that residents could pay according to their ability to do so.

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PERSPECTIVE

Roadblocks to Cancer Care in the Occupied Palestinian Territories

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Introduction

The occupied Palestinian territories, as referred to in international humanitarian law since 1967, comprise 6,220 square kilometers divided into three regions: the Gaza Strip (360 square kilometers), the West Bank, and East Jerusalem (together, 5,860 square kilometers).[1] The occupied Palestinian territories have a population of approximately five million people—and 44% are children under 18 years, double the percentage in the United States (21.7%).[2] Population density for the whole region is 892 people per square kilometer, making it one of the world's most densely populated areas.[3] For context, Palestine is similar in area to the US state of Delaware, but with five times Delaware's population.[4]

The existing health care system comprises fragmented services that have evolved across generations and various governing regimes. The main providers of health services include the Ministry of Health, the United Nations Relief and Works Agency for Palestine Refugees, nongovernmental organizations, and the private medical sector. The Ministry of Health is regarded as the primary provider.[5] However, in the West Bank, the division of the region into areas A, B, and C limits the ministry's ability to serve Palestinians in Area C, which makes up 60% of the West Bank and remains under full Israeli control.[6] This fragmented health care system is unable to meet people's needs during the best of times.[7] Because it relies heavily on external actors, patients' care is placed at the mercy of third parties.[8] This deliberate "de-development" and lack of independence hinders the system's ability to develop autonomously, contributing to what Yazid Barhoush and Joseph Amon describe as a form of medical apartheid.[9]

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Cancer remains among the top leading causes of death in Palestine.[10] According to the International Agency for Research on Cancer, breast cancer is the most common cancer in the country. Although its cancer incidence rates are comparable to those of other Arab nations in the region and significantly lower than in Israel, Palestine has a higher mortality rate compared to most neighboring countries.[11] Despite the Palestinian Cancer Registry being almost 25 years old, the reported statistics are still elementary and cases are underreported, which could indicate that prevalence is higher than what is documented.[12]

In this paper, we describe the landscape of cancer care in Palestine, focusing on factors that perpetuate violations of Palestinian cancer patients' fundamental right to health and how these violations were exacerbated after October 7, 2023.

Cancer care in Palestine

Cancer care in Palestine is divided primarily into two branches: governmental and nongovernmental. Treatment occurs at small oncology units within hospitals in the West Bank and Gaza, none of which have specialized pathology laboratories or advanced diagnostic facilities. While surgery and chemotherapy services are generally accessible, radiotherapy services are absent. The Augusta-Victoria Hospital Cancer Care Center in East Jerusalem stands as the main and only comprehensive cancer center in Palestine. Advanced hematology and bone marrow transplantation are still unavailable. Patients needing hematopoietic cell transplants for leukemia and other blood cancers must seek referrals to neighboring countries.[13]

Although one-third of cancers can be prevented by controlling known risk factors, cancer care in Palestine remains focused on treatment, with limited emphasis on screening and prevention.[14] There are no effective national programs addressing preventable cancers, including lung, colon, tobacco-related, or cervical cancer in Palestine.[15] The only active screening program is for mammography. Since 2009, there have been efforts to establish a population-based mammographic screening initiative in the occupied Palestinian territories, but it remains opportunistic and not well-targeted. In 2021, just 2% of women in the target group for mammographic screening received a mammogram.[16]

According to the United Nations Population Fund, even before the 2023 war began, Gaza, in particular, had seen significant deterioration in living conditions, health care access, and basic infrastructure. Its hospitals regularly suffer from equipment and medicine shortages that prevent the detection of cancers at early stages where treatment is more successful and prognoses more optimistic. For example, Augusta-Victoria Hospital data indicate that more than 60% of breast cancer cases are detected at stage III or later—almost double the percentage in the United States (33%).[17]

The lack of screening and diagnostic capacity leaves little room for effective treatment and long-term survival in cancer patients. For example, the five-year breast cancer survival rate among Palestinian women in Gaza and the West Bank is estimated to be as low as 40%; in most other countries with access to screening technology, the survival rate is nearly 90%.[18]

Pre-war challenges and limitations

Referrals

For patients in the West Bank and Gaza, the lack of tools for cancer diagnosis and treatment makes it necessary to seek care outside of the territory.[19] In 2021, the majority of referrals (48%) were to nongovernmental hospitals in the West Bank, followed by 38% to hospitals in East Jerusalem. Referrals to Israeli hospitals accounted for 5%, as did those to nongovernmental hospitals within the Gaza Strip. The remaining 4% were to hospitals in other countries, mainly Jordan, Egypt, and Turkey.[20] Gaza's hospitals in particular face significant challenges in delivering treatment for cancer patients, primarily stemming from chronic shortages of medicines and a lack of essential medical equipment; certain specialized surgeries are simply unavailable. In 2018, many key chemotherapy drugs remained at less than one month's supply.[21]

Seeking treatment outside Gaza requires obtaining an Israeli medical permit. This process involves receiving a physician referral and a Ministry of Health approval, as well as submitting a request to Israeli authorities. A similar permit process is required for any companion, including the parents of young children.[22] Patients leaving Gaza must cross the Erez checkpoint, where they undergo permit checks, body and luggage searches, and the possibility of interrogation, arrest, or detention. As outlined in the World Health Organization's 2022 timeline for Gaza patient referrals, applying for a permit is a lengthy and unpredictable process that can take several months (Table 1). After getting the permit, crossing the checkpoint—even in urgent cases—can take up to seven hours.[23]

In 2022, 20,295 permit applications were issued for Palestinian patients in Gaza. Most (35%) were cancer patients. Of the 20,295 permit applications, 33% were delayed or denied. Nearly one-third (29%) of the patients applying for a permit were minor children who needed a companion, but 62% of companion permit applications were delayed or denied, and 25% had to proceed to treatment without their companion.[24] The vast majority of unsuccessful patient permit applications do not receive any explanation of the reason for denial or delay.[25] A survival analysis conducted by the World Health Organization for Gaza patients referred for cancer therapy from 2008 to 2017 revealed that delays or denials of permits increased the likelihood of death from cancer by 1.5 times.[26]

Patients in the West Bank seeking treatment in East Jerusalem or Israel go through a similar process that includes obtaining Israeli permits and crossing checkpoints. In early 2023, 565 movement barriers in the West Bank were documented. These include Israeli checkpoints, roadblocks, earth walls, and trenches.[27]

Lack of equipment and facilities

Those seeking to build or equip a health care facility must get permission for these materials from Israeli authorities. Permits are frequently delayed or denied.[28] In 2021, for example, the Palestinian Authority submitted to Israel 120 requests to import X-ray machines and spare parts for imaging equipment into the Gaza Strip. Of these applications, 83 (69%) were denied, 6 (5%) were canceled, 1 (1%) was delayed for further study, and 30 (25%) were approved an average of 58 days after request submission. Similarly, of 13 requests submitted for the entry of oxygen generators and related installation or spare parts, 9 (69%) were denied.[29]

Although Israel's stated concerns about theft of radioactive materials for nonmedical use have never materialized, Israel unilaterally blocks radiotherapy machines entering the West Bank and Gaza.[30] This means that the two linear accelerators in East Jerusalem must serve all Palestinian oncologic needs. Thus, Palestinians have an access rate of one machine per 1,000,000 inhabitants; for comparison, the United States has an access rate approximately 11 times higher.[31]

Financial challenges

The Palestinian economy has witnessed a significant deterioration and accelerated "de-development" characterized by poor public investment, infrastructural deterioration, and a deepened dependence on Israel.[32] Although nearly half (47%) of the 2022 Ministry of Health budget for disease treatment was utilized for cancer treatment, since September 2021, the main Palestinian cancer cen-

TABLE 1. World Health Organization timeline for Gaza patient referrals in 2022

Type of case	Medical decision	Medical approval	Financial approval	Appointment date	Permit process	Total time from referral to permit
Regular cases	2–7 days	3–4 days	7–20 days	14–60 days	7–30 days	33–121 days
Urgent cases	1 day	1–3 days	1–3 days	2–3 days	1 day	6–11 days

Source: World Health Organization, *Timeline for Gaza patient referrals: 2022* (2022), https://www.emro.who.int/images/stories/palestine/WHO_infographic_timeline_for_gaza_patient_referrals_2022.pdf?ua=1.

ter has been forced to turn away nearly 500 cancer patients due to its inability to afford expensive chemotherapeutic drugs and other cancer treatments.[33] The economic crisis led the Palestinian Authority to default on US$72 million in loans intended to support cancer treatment for Palestinian patients.[34]

Political instability

Before October 2023, 100 cancer patients traveled daily from Gaza to the West Bank and Jerusalem for radiotherapy, chemotherapy, or surgery. When checkpoints close, these patients are deprived of access to hospitals and necessary treatment. The Israeli authorities' five-day closure of the Erez checkpoint in May 2023, for example, meant that nearly 500 patients missed scheduled treatments. Many had to reapply for permits, leading to further delays.[35]

The Israeli occupation also harms Palestinian health care workers, facilities, and patients.[36] In 2022, 187 attacks on health care workers and facilities were documented. These attacks affected operations at nine health care facilities, injured 105 health care workers, and obstructed, damaged, or otherwise impeded 108 ambulances.[37] We cannot know the impacts of these incidents on cancer care, as some individuals whose treatment is disrupted or prevented may simply decide not to seek further care in the face of violence.

Consequences of the current war in Gaza

In 2007, Israeli authorities initiated a land, sea, and air blockade on Gaza, isolating Gaza's residents from the rest of the world.[38] Since then, multiple acts of oppression and aggression have been inflicted on Palestinians in Gaza.[39] However, the current war has been unprecedented in its scale. Following the Hamas attack on October 7, 2023, which resulted in the deaths of 1,200 Israelis, and the subsequent Israeli military invasion, over 41,500 people in Gaza have been killed in Israeli attacks, nearly 100,000 have been wounded, and thousands remain missing under the rubble of destroyed buildings. More than 1.9 million people have been displaced.[40] Only 10 of Gaza's 36 hospitals remain partially operational, hundreds of health care workers have been killed, and at least 26 such workers have reportedly been kidnapped by the Israeli military.[41]

Cancer patients in Gaza urgently need basic health care services—a situation further complicated by restrictions on essential medical supplies, including chemotherapy drugs. The Turkish-Palestinian Friendship Hospital, the sole facility in Gaza specializing in treating cancer, has closed because of frequent Israeli attacks and a lack of fuel and medical supplies. The deaths of at least 12 cancer patients were documented 10 days following its closure.[42] Despite some international efforts to evacuate cancer patients, of Gaza's estimated 10,000 cancer patients, approximately 3,800 have been granted permission to leave. However, in reality, only around 600 have been evacuated since the start of the war.[43]

The way forward

Despite the enormity of the obstacles facing cancer care in Palestine, we as physicians and scientists must work to mitigate the dreadful consequences. We join with many other health professionals to urge the global medical community to demand a humanitarian ceasefire to protect innocent lives. Concurrently, we must advocate grand-scale humanitarian aid, launch fundraising campaigns to restore health infrastructure in Gaza, and facilitate the transfer of cancer patients to safer hospitals for continued treatment with a guarantee of return when appropriate. Establishing accessible cancer care in Palestine necessitates a robust referral system for timely access and a long-term commitment to the protection of health care professionals and facilities. Most crucially, we must foster autonomy by building sustainable health care capacity and ensuring that health care in the occupied Palestinian territories has an independent budget dedicated to supporting cancer patients.

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HHR Health and Human Rights

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The Digital Transformation and the Right to Health of Young Adults in Bangladesh and Colombia: A Community-Engaged Study

DIGITAL HEALTH AND RIGHTS PROJECT CONSORTIUM

Abstract

In her 2023 report to the United Nations Human Rights Council on digital innovation, technology, and the right to health, the Special Rapporteur on the right to health underscored the positive impact of the digital transformation on young people, but also noted serious concerns, calling for greater efforts to consult and engage with youth and civil society. In our study, early-career researchers from Bangladesh and Colombia collaborated within a broader international research and advocacy project to investigate how diverse young adults experience digital health and to invite their recommendations and collaborative advocacy. Researchers held focus group discussions and interviews with young adults aged 18–30 (in Bangladesh, predominantly men; in Colombia, people living with HIV, gay men, and transgender women). In both countries, young adults said the digital turn had transformed their access to sexual and reproductive health and HIV information, highlighting both the positive role of young social media influencers and the harms caused by misinformation, lack of confidentiality, and widespread stigma. They called for greater government efforts to develop digital health, including through social media platforms. We find that transnational collaborations like this one offer the potential to generate actionable insights and inform the development of rights-based digital governance.

The Digital Health and Rights Project Consortium includes the BRAC University James P. Grant School of Public Health, Bangladesh, the Global Network of People Living with HIV (GNP+), Netherlands, KELIN, Kenya, Privacy International, United Kingdom, Restless Development, STOPAIDS, United Kingdom, the Universidad de los Andes, Colombia, and the University of Warwick, and is hosted by the University of Warwick, United Kingdom.

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Introduction

The digital transformation of health—including the integration of technologies and tools for health data management, telemedicine, artificial intelligence (AI)-driven diagnosis, mobile phone apps, and more into health systems—offers resource-constrained governments new ways to fulfill the right to the highest attainable standard of health. Yet related evidence of threats to privacy and autonomy, along with other harms, is accumulating.[1] Social media platforms are increasingly used to share sexual and reproductive health (SRH) information and for HIV prevention.[2] Systematic reviews have found that social media interventions are effective tools for the HIV response.[3] At the same time, the rapid growth and consolidation of power in social media sites, and the related spread of misinformation, have made these spaces challenging to regulate.[4]

The World Health Organization (WHO) defines digital health as "a broad umbrella term encompassing eHealth as well as developing areas such as the use of advanced computing sciences (in the fields of 'big data', genomics and artificial intelligence, for example)."[5] To address and develop digital health globally, in 2021, the World Health Assembly adopted a *Global Strategy on Digital Health 2020–2025*, which commits states to strengthening digital governance that upholds human rights, among other goals.[6] The *Global AIDS Strategy 2021–2026* also calls for intensified efforts to use digital spaces to reach people living with HIV and key populations (defined by WHO as gay men and other men who have sex with men [MSM], sex workers, people who use drugs, and transgender people).[7]

To strengthen the governance of digital health, United Nations (UN) agencies have promulgated new guidelines. These include guidance on the ethics and governance of AI; guidance on ethics and rights in the governance of technologies in the HIV response; and guidance on SRH and AI, to name a few.[8] In her 2023 report to the UN Human Rights Council, the Special Rapporteur on the right to health, Tlaleng Mofokeng, proposed the first normative framework for digital innovation, digital technologies, and the right to health, grounded in human rights standards.[9] This framework affirms that digital technologies "should improve the availability, accessibility, acceptability and quality of health services for all," highlighting the need to attend to opportunities for and threats to SRH in particular, and calling for governance to be grounded in the human rights principles of nondiscrimination, accountability, and privacy (see Table 1).[10] In particular, it emphasizes the right to participation in calling on states to "develop a regulatory environment with the participation of users," including young people.[11]

Globally, over a third of internet users are between 25 and 34 years old.[12] However, a review of national digital health strategies finds little evidence of either youth participation or attention to their specific needs.[13] The same is true of global health policy: while young people are often online and often the targets of digital health interventions, they are frequently left out of consultations, design, and policymaking, according to the first major review of global governance of digital health led by the Lancet and Financial Times Commission on Governing Health Futures 2030.[14]

Likewise—and perhaps relatedly—while an estimated 60% of the world's population uses social media, the UN guidance on ethics and rights noted above, and the WHO *Global Strategy on Digital Health*, do not address social media as a venue for digital health governance. To be fair, doing so is not a small challenge, particularly in relation to SRH. Most member states have little direct influence over powerful social media companies. Meta has three billion active users on Facebook, and many more on Instagram and WhatsApp—numbers that dwarf the populations of Bangladesh and Colombia combined.[15] The net worth of Meta's co-founder, Mark Zuckerberg, is estimated to be US$184.6 billion, roughly half the gross domestic product of Colombia.[16] Setting aside the power and influence of these agencies, managing SRH misinformation on social media raises complex challenges, given the need to protect the rights to freedom of expression and to quality health information in diverse social and legal standards on sexually explicit language and imagery.

To take on such challenges may require new thinking and collaboration. César Garavito-Rodríguez calls the digital transformation a threat to human rights that will require collaborative research and advocacy across national borders.[17] Mark Goodale similarly proposes that rights advocates set aside claims to universality in favor of "translocal" alliances that cross boundaries of community or nation to confront shared challenges.[18] We have argued elsewhere that the digital transformation of health will require new collaborations and new approaches to knowledge production and advocacy that center the voices of advocates in low- and middle-income countries.[19]

To understand the experiences of young adults with the digital transformation of health, and establish a platform through which they might collaborate to promote their recommendations, we established an international consortium that has conducted collaborative research across diverse contexts through three related studies. Below, we briefly outline our consortium's approach, and then provide background on the study in Bangladesh and Colombia, before sharing our methods and findings.

Digital Health and Rights Project Consortium

The Digital Health and Rights Project Consortium (hereafter, Digital Health and Rights Project) includes human rights lawyers, social scientists, health advocates, and global and national networks of people living with HIV in 10 countries. Our research aims to draw on the lived experience of people living with and affected by HIV with documenting abuses (such as health sector discrimination and criminalization) and with effective local and transnational mobilization for policy impact.[20]

The co-founders of the Digital Health and Rights Project include civil society leaders engaged with the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria, who, together with social scientists, identified the need for policy recommendations about technology and health that could inform global health governance. We agreed to use participatory and community-engaged approaches to build capacity in national institutions to engage on the issues over the long term.

The project focused initially on Ghana, Kenya, and Vietnam, based on consultation by the Glob-

Table 1. Digital innovation, digital technologies, and the right to health

The 2023 report by the UN Special Rapporteur on the right to health draws on the normative framework provided by human rights law and consultations with member states, civil society, and experts to analyze emergent issues in the digital transformation of health that impact the right to health.	
Availability	Availability of health facilities, goods, and services supported by digital innovation and technologies
Accessibility	Accessibility of health facilities, goods, and services supported by digital innovation and technologies, understood as including • nondiscrimination • physical accessibility • economic accessibility • information accessibility
Acceptability	Digital technologies and the (cultural, linguistic, gendered, and generational) acceptability of health facilities, goods, and services
Quality	Digital technologies and the quality of digital health facilities, goods, and services
Sexual and reproductive health and rights	Digital innovation and technologies and the right to SRH; importance of addressing • expanded access to SRH care through digital technologies • surveillance • intrusive data collection • bodily autonomy
Right to privacy	Digital innovation, digital technologies, and privacy
Good practices	Global, regional, and national digital health governance
Participation	Importance of a participatory approach to digital health governance, including • transparency • accountability • access to remedy for harms

al Network of People Living with HIV (GNP+), a consortium member, with national networks. In 2021, with support from the Open Society University Network (OSUN), the Digital Health and Rights Project invited BRAC University and Universidad de los Andes to join, adding Bangladesh and Colombia to the list of focus countries. These five countries were thus selected by actors in each country based on their own interest to engage. Fortuitously, the five countries also represented five different geographic regions (West Africa, East Africa, Southeast Asia, South Asia, and Latin America, respectively), informing collective recommendations for global governance.

In all five countries, the project focuses on young adults either living with or affected by HIV, including key populations, and on training and mentoring young researchers and advocates in national institutions who use the research findings to engage in advocacy. To date, the Digital Health and Rights Project has undertaken three studies, including the one presented in this paper, which are interlinked as follows:

1. *Botnar One*. The first study, conducted in Ghana, Kenya, and Vietnam and funded by Fondation Botnar, was undertaken in 2021–2022 and applied a transnational participatory action research approach.[21] National researchers from study populations collaboratively led processes of training, consultation, data-gathering, and validation of findings in each country.[22] Based on focus group discussions with 174 young adults, as well as digital ethnography on social media accounts and key informant interviews, the Botnar One study team found that young adults relied heavily on social media for health information. Participants described learning from, or becoming themselves, social media health champions; they also disclosed online harms, issues with misinformation, and concerns about data protection. They called for more training on digital rights and a voice in governance. These findings and methods informed the next two studies.
2. *Botnar Two*. In 2022–2024, a second grant from Fondation Botnar funded Kenyan human rights group KELIN to lead an effort to support the Special Rapporteur on the right to health in producing her report on digital technologies, digital innovation, and the right to health, described above. This work included a literature review led by the Geneva Graduate Institute, as well as youth and civil society consultations led by KELIN, GNP+, and STOPAIDS (a UK health advocacy network) with human rights lawyers, health advocates, and young people in Africa, Asia, Europe, and Latin America. The civil society networks co-authored submissions to the Special Rapporteur and disseminated the final report and its recommendations in a series of public events.
3. *OSUN*. The third study, funded by OSUN, is presented in this paper. It was conducted during 2021–2023 by researchers from BRAC University in Bangladesh and Universidad de los Andes in Colombia and guided by a principal investigator from the Geneva Graduate Institute. The OSUN study began six months after Botnar One and included strong collaboration between the Bangladesh and Colombia researchers within the frame of the overall Digital Health and Rights Project. The objective of this study was to understand how young adults experience the benefits and risks of the digital transformation of health and to invite their recommendations for digital governance.

The first study, Botnar One, utilized a participatory action research approach, which required significant resources to complete.[23] For the third study, which had less funding and time available, the researchers decided to use a less intensive community-engaged research methodology.[24] They adapted the Botnar One research protocol, briefing community-led and youth-led organizations on it in local languages, and inviting advice on the study design. They rigorously reviewed the discussion question guides with community leaders to tailor questions to local contexts. The BRAC University team held a closing validation workshop with young people from the study in Dhaka. The Universidad de los Andes team and the principal investigator spent two weeks traveling to the offices of community-based organizations of people living with HIV and key populations in Bogotá and Medellín, which served to validate study findings and inform future research plans. Throughout, the BRAC and los Andes researchers participated in the larger consortium, which included researchers and groups engaged in the Botnar One and Two studies. Participation included weekly online research clinics that convened researchers from all of the study countries for training and experience-sharing; monthly calls with guest lecturers; and smaller working groups that planned public events. Further, the BRAC and Andes researchers presented on the OSUN study to the full Digital Health and Rights Project at an in-person meeting in Nairobi, Kenya, in 2022.

Civic engagement continued throughout and after the study. The BRAC team held two webinars in Bangla with national experts to discuss digital governance and SRH in Bangladesh.[25] The Colombian team held an in-person event to share and discuss findings with experts and community-based organizations of people living with HIV. After validation was complete, each national team provided microgrants to community-led organizations to support online advocacy and knowledge-sharing. The teams also shared the study findings at a workshop with UN and other stakeholders at the Brocher Foundation in Geneva, Switzerland, in 2023. Additionally, they participated in joint dissemination activities, including research presentations to the Global Fund, UNAIDS, and the Permanent Mission of Bangladesh in Geneva.[26] Because of this broader collaboration, we authored this paper collectively.

Before turning to the study methods, findings, and how these findings have been used in advocacy, we provide a brief overview of the two national contexts of Bangladesh and Colombia.

Bangladesh and Colombia

Bangladesh and Colombia are at first glance more different than they are similar. Bangladesh is a lower-middle-income country; Colombia is an upper-middle-income country. Over 90% of Bangladesh is Muslim; approximately 87% of Colombia is Christian (78% Catholic).[27] The countries have different languages, geographies, and histories.

However, as two low- and middle-income countries contending with the digital transformation, Bangladesh and Colombia share common challenges. First, both have rapidly growing young populations, who are increasingly online. Twenty-six percent of Colombia's population is between 14 and 28 years of age, and close to 80% own a mobile phone.[28] Likewise, in Bangladesh, an estimated 28% of the population is between 15 and 29 years; mobile phone ownership exceeds the size of the population.[29] In Bangladesh, the digital divide is gendered: less than a quarter of young women use internet, while the rate among young men is more than double, at 56%.[30] Nonetheless, in both countries, the digital turn offers the promise of efficiently reaching young people with SRH and HIV information and services.

Both Bangladesh and Colombia need to meet this challenge, as they have significant gaps in accurate SRH knowledge among young people.[31] In Bangladesh, Subas Biswas and colleagues find that a lack of knowledge and strict taboos on discussing sexual health are linked to risky sexual behaviors.[32] In Colombia, the leading national center for SRH, Profamilia, finds that poor implementation of education policies is one of the determinants of high adolescent pregnancy rates.[33]

Relatedly, both countries also face concentrated HIV epidemics among young key populations. Stigma and punitive laws create challenges to reaching these populations with information and services. HIV prevalence in Bangladesh has steadily increased since 1990, particularly among MSM and people who use drugs.[34] The criminalization of same-sex relationships, and related homophobic violence, may contribute to driving this population underground.

Colombia also has a concentrated epidemic, with growing numbers of AIDS-related deaths and high rates of HIV among transgender people.[35] Close to 30% of people living with HIV report experiencing either discrimination or denial of medical services in Colombia.[36] While same-sex sexual behavior is not illegal in Colombia, transgender women do confront epidemic rates of violence, and this has been shown to create considerable cultural barriers to accessing health services.[37]

Thus, in both countries, reaching young adults—and in particular, young key populations—with health information and services is critically needed. The digital transformation offers a means to circumvent the social barriers created by taboos, stigma, and violence. To do so will require targeted efforts.

In her report to the UN Human Rights Council, Mofokeng highlights the progress in many countries in developing digital health governance that upholds human rights. Such progress is evident in Bangladesh and Colombia, as the BRAC and los Andes researchers found in a comparative review.[38] They identified efforts in both countries to strengthen digital governance and data protection.[39] They also found gaps, including a lack of specific attention to SRH rights, youth needs, and data protection, as well as a lack of youth participation and consultation in digital health governance. In both countries, researchers found some uncertainty regarding limitations on the utilization and sharing of personal health data with third parties.[40]

As these efforts to strengthen digital governance and digital governance continue in Bangladesh, Colombia, and global health agencies, what do young adults in Bangladesh and Colombia experience as working and not working for them in the digital transformation of health? And if they were consulted, what insights would they offer? These are the questions we sought to answer in this study.

Methodology

Study population

The OSUN study population in Bangladesh and Colombia was intentionally identified in ways that were seen as consistent with and as extending the study population in the Botnar One study in Ghana, Kenya, and Vietnam. The age range had been earlier identified by the Botnar One study team as consisting of young adults between 18 and 30. Because the definition of "young person" varies among countries, the age range of 18–30 years was set across all five countries by the study team in the Digital Health and Rights Project based on consultation with global youth networks.

Within this common age group, each national team identified a focus population that fitted its own research expertise and future advocacy plans. In the Botnar One study in Ghana, Kenya, and Vietnam, researchers at the Ghana National Association of Persons Living with HIV opted to focus on young people living with HIV; the Vietnam Network of People living with HIV focused on young people living with HIV and key populations; and KELIN focused on young women in Kenya, given its ongoing work on SRH.

In the OSUN study, the BRAC team decided to focus on young men in Bangladesh, both to build on the team's prior research on young men and SRH and to complement the Kenya team's focus on young women.[41] The los Andes team focused on people living with HIV, MSM, and transgender people in Colombia.

In both Bangladesh and Colombia, national researchers used purposive snowball sampling, recruiting through established networks of student health advocates (in Bangladesh) and peer-led networks of people living with HIV, MSM, and transgender people (in Colombia). In Colombia, los Andes researchers advertised on social media platforms. In Bangladesh, given strict taboos and related security risks, the research team decided not to advertise the study publicly, instead recruiting through established networks.

Research methods

Research was conducted between April and September 2022 in Colombia, and between July and December 2022 in Bangladesh. The qualitative research design centered on focus group discussions and in-depth interviews with the study population, supplemented by digital ethnography on social media accounts and by key informant interviews, as follows:

- *Focus group discussions (FGDs) and in-depth interviews.* Researchers held FGDs with young adults in at least two cities in each country. The discussion guide explored where and how young adults obtain and share health information on mobile phones; their experience of the benefits and risks; their knowledge of digital health governance; and their recommendations for digital health development and policy. Researchers also held semi-structured one-on-one interviews with the study population to probe their experiences in more depth.

- *Digital ethnography.* To understand how young adults use social media to gather and share health information, researchers conducted participant observation on Facebook, YouTube, and Instagram, selecting those with active youth engagement on issues pertaining to HIV and SRH (based on numbers of likes and comments). The digital ethnography informed researchers' analysis of the FGDs.
- *Key informant interviews.* Researchers conducted semi-structured interviews with experts to gain insight into the current governance of digital health in each country. These included community leaders; leaders of health advocacy organizations and health tech companies; and human rights scholars. The interviews explored progress and challenges in national digital health governance in light of the emerging benefits and risks identified by FGD participants. The timing and location of interviews were scheduled at the convenience of respondents. Interviews ranged in length from 30 to 120 minutes. These interviews informed researchers' analysis of the recommendations by young adults.

Data analysis

All interviews were recorded in Bangla or Spanish, transcribed, and translated into English. A team of seven researchers from BRAC University, Universidad de los Andes, and the Geneva Graduate Institute analyzed transcripts on Dedoose. They utilized the codebook from the Botnar One study, reviewing and adding concepts identified based on an initial reading of the transcripts from Bangladesh and Colombia. A second coder reviewed each transcript, and differences were discussed in weekly online meetings to reach agreement. The draft findings were then presented to study participants for discussion as noted above.

Ethical considerations

Ethical concerns included the risk of public exposure for study participants given the above-noted stigmatization of sexual activity (in Bangladesh), and sexual orientation, gender identity, and HIV status (in both countries). In Bangladesh, there was additional risk that either researchers' or participants' views might be interpreted as critical of the government. Ethical approval was sought and obtained from ethics review boards in Bangladesh, Colombia and Switzerland, with details provided at the end of this paper.

While participants were recruited through established networks of people living with HIV, MSM, and transgender people, we did not ask individual participants to identify their sexual orientation or HIV status; some did volunteer this information. All participants were anonymized using codes. All participants provided written informed consent. Data were stored on locked, secured drives and shared using only encrypted sites.

Results

In total, 118 individuals were interviewed—60 in Bangladesh and 58 in Colombia (see Table 2):

- *FGD participants in Bangladesh.* BRAC researchers held eight FGDs in Bangladesh (three FGDs in Manikganj, three in Bagerhat, and two in Dhaka) with 49 participants. Given the BRAC team's focus on young men, most study participants were male and between the ages of 18 and 24, apart from a few young women who joined in Bagerhat to share their perceptions of their male partners' SRH practices. Most participants were university students, with a few development workers, nurses, and businesspeople. Researchers held one FGD with a support group of gay male, non-binary, and transgender young adults in Dhaka; for security, this was held online.

- *FGD participants in Colombia.* The los Andes team conducted four FGDs in Medellín and one in Bogotá, with 26 participants. Participants included 24 men and two non-binary people. Despite ongoing efforts, the recruitment of women below 30 years of age proved challenging. Leaders of support groups of women living with HIV attributed the low response rate to pervasive HIV-related stigma and slut-shaming. The Colombian FGDs included students and professionals, including administrators, auditors, architects, instructors, and several unemployed people; many identified as AIDS activists. Most FGDs took place in the offices of nongovernmental organizations. One FGD was held online at request of the community organization supporting mobilization.
- *In-depth interviews.* In Bangladesh, researchers conducted four in-depth interviews: one with a project officer from a nongovernmental organization, one with an Ayurvedic medical practitioner, and two with students. In Colombia, to address the gap in female recruitment, researchers conducted a group interview with nine women living with HIV over 30, and a small-group interview with five transgender women over 30 in Bogotá, three of whom identified as sex workers.
- *Key informant interviews.* In Bangladesh, researchers conducted seven key informant interviews with editors, digital health professionals, health service providers, and legal scholars (see Table 3). In Colombia, researchers conducted 18 key informant interviews with digital health experts, health rights advocates, online editors, health service providers, civil society directors, community leaders, human rights experts, and transwomen community leaders living with HIV.

Results

Availability, accessibility, acceptability, and quality

Study participants in both countries expressed enthusiasm for the use of digital spaces, including community-developed mobile health apps, to access SRH information, but said that Google and social media were their main sources.

In Colombia, TeCuidamos, an HIV web platform supported by EnTerritorio, a state agency, and funded by the Global Fund, links users to HIV information and services such as tests and condoms. In Bogotá, an interviewee involved with TeCuidamos described conceiving the idea during

Table 2. Distribution of interview participants by gender and location

Country	District	Gender	Focus group discussions	Key informant interviews	In-depth interviews	Subtotal	Total
Bangladesh	Dhaka	Male	11	6	4	23	60
		Female	0	1	0		
		Chose not to disclose	1	0	0		
	Manikganj	Male	20	0	0	20	
		Female	0	0	0		
	Bagerhat	Male	9	0	0	17	
		Female	8	0	0		
Colombia	Medellín	Male	19	6	0	38	58
		Female	0	2	9		
		Trans woman	0	0	0		
		Non-binary	2	0	0		
	Bogotá	Male	5	7	0	20	
		Female	0	3			
		Trans woman	0	0	5		
		Non-binary	0	0	0		

the COVID-19 pandemic:

> *I said, well, what is happening in the pandemic? How do you order food? Through an app. How do you order a cab? Through an app. In other words, all these through an app.*

Bangladeshi participants similarly identified several locally developed apps as valuable sources of Bangla-language health information and services.

However, many participants in both countries said that Google searches and social media had become equally—if not more—important spaces for accessing youth-friendly health information. They emphasized that the anonymity afforded by these digital spaces enables the avoidance of slut-shaming, transphobia, homophobia, and HIV-related stigma by health care workers. In Manikganj, Bangladesh, MNK-FGD1-D04, a 19-year-old male student, said, "If I go to the central hospital with a sexual problem, I don't think they will examine it carefully. They would not even look at me." On social media sites, by contrast, he said, "I feel my confidentiality is maintained. It's a blessing." In Bogotá, BOG-KII-I, a 33-year-old transgender sex worker, said:

> *Sometimes out of fear, or fear of going to an establishment where you are going to be treated badly, where you are going to be discriminated against, where you are going to be violated—you are like, "Oh, no, I better ask by WhatsApp."*

Thus, study participants in both countries said that trusted content creators on social media had become important sources of information and personal advice. In Colombia, men recruited through networks of MSM living with HIV referenced peer-led social media accounts such as Más Que

Table 3. Key informant interviews by gender, age, and occupation

ID number	Gender	Age	Employment
Bangladesh			
DHK-KII-A	Male	29	Legal coordinator and trainer
DHK-KII-B	Male	26	Health technology brand manager
DHK-KII-C	Male	35	Fact-checking editor
DHK-KII-D	Male	34	CEO of health technology company
DHK-KII-E	Male	47	Director of medical services
DHK-KII-F	Male	33	Academic law expert
DHK-KII-G	Female	25	Founder of health site
Colombia			
BOG-KII-A	Female	Over 40	Coordinator of a digital intervention
BOG-KII-B	Male	Over 40	HIV activist
BOG-KII-C	Female	28	Coordinator of digital intervention
BOG-KII-D	Female	Over 30	HIV activist
BOG-KII-E	Female	Over 30	Coordinator of a digital intervention
MED-KII-A1	Female	25	SHR podcast
MED-KII-A2	Male	26	SHR podcast
MED-KII-B	Male	Over 40	Lawyer and HIV activist
MED-KII-C	Female	Over 40	Coordinator of a digital intervention
MED-KII-D	Male	27	HIV activist and YouTuber
MED-KII-E	Male	29	HIV activist and Instagrammer
MED-KII-F	Male	32	HIV activist
MED-KII-G	Male	Over 50	Coordinator of NGO defending people's right to health
MED-KII-H	Female	Over 30	Woman living with HIV
MED-KII-I	Female	Over 30	Woman living with HIV
MED-KII-J	Male	Over 40	HIV activist
MED-KII-K	Transgender woman	30	Sex worker and activist
MED-KII-L	Transgender woman	26	Transgender woman living with HIV

Tres Letras and RASA. In Bangladesh, participants praised Tasnim Jara, a medical student who shares health information in Bangla through YouTube videos. Such intermediaries make SRH information not only available and accessible but acceptable to young adults by making the information and advice less stigmatizing and youth-friendly.

Study participants also described how free access to social media platforms had empowered them to become content creators themselves on HIV and SRH ("micro-influencers") to inform peers, combat stigma, and, in some cases, generate extra income from donations. In Medellín, MED-KII-D, a 27-year-old TikToker and YouTuber living with HIV, recalled:

> *On the 4th day [after HIV] diagnosis, I got up and I said "no more" … I am going to make money out of this diagnosis. And then from there it came out—my YouTube channel.*

Unsurprisingly, the reliance on web searches and social media was linked to concerns about misinformation. In Dhaka, DHK-IDI-4, a 19-year-old male student, provided a checklist of steps he follows to evaluate health information on Facebook:

> *I look at [content quality] first, ok? Then, [number of] views come as part of the Facebook algorithm, ok? And mostly, I read the comments. How many negative comments are there, which is good, and which is bad. I look at these things.*

Stigma on social media

Given the persistent stigmas and taboos described above, participants expressed anxieties about their online engagement. Some felt that community-led social media groups were hostile to them. In Medellín, cisgender women living with HIV described joining WhatsApp groups for people living with HIV but then leaving these groups after finding the exchanges to be dominated by young gay men who used sexist language. Likewise, transgender sex workers interviewed in Bogotá described WhatsApp groups as important for psychosocial support but said that some community members had encountered transphobic verbal abuse in such groups.

In Bogotá, BOG-FGD5-F, a 26-year-old unemployed man, described how HIV status is used to verbally attack MSM on social media:

> *If I know John Doe's diagnosis, then I go and put it on Facebook, or I put it [on] Grindr … his reputation goes down, because: "Ah yeah, the [homophobic slur] has HIV."*

In Bangladesh, a BRAC researcher conducting digital ethnography on Facebook identified Bangla-language accounts that actively promote the targeted harassment and slut-shaming of young women online.

Some Bangladeshi participants worried that even clicking "like" on an informative post about SRH might inadvertently expose the user as sexually active to others in the community. In Manikganj, MNK-FGD1-D02, a 19-year-old male student, suggested:

> *If I react to a post on a Facebook page which provides information on sexual health, advertisements on sexual health awareness will automatically go to one of my younger brothers [who is on my friends list]. Then he would say, "Brother has liked this type of page. Maybe he has sexual problems."*

MNK-FGD1-D03, a 24-year-old male student in the same focus group, agreed:

> *If I like that page [on SRH on Facebook], my friend or senior brother will not know with what intention I liked that page. I don't want others to know about my problems.*

The increasing need for access to mobile phones for the health system also was seen as creating new risks of privacy breaches. In Medellín, MED-FGD3-D, a 21-year-old non-binary student, recalled how their HIV diagnosis was sent electronically to their parents without the patient's permission, describing this as a confidentiality lapse in the health system. In Medellín, a female activist in her thirties living with HIV said that many women living with HIV may have to share smartphones with other family members, and face concerns about protecting medical confidentiality from the family when making medical appointments.

Participant recommendations

BRAC and Andes researchers asked FGD participants to share policy recommendations for the development and governance of digital health. Overall, participants called on government to do more to promote access to SRH information online, address misinformation, ensure digital inclusion, and address privacy and data protections. Participants in both countries were overall enthusiastic about digital health—but understood this as largely referring to web platforms and social media.

In Bangladesh, many of the young male FGD participants affirmed a strong interest in seeing the government promote digital health and share SRH information online in accessible and youth-friendly language. They called for more online information portals, workshops, and educational videos. DHK-FGD1-D01, a 22-year-old male student in Dhaka, imagined an online database, "so that if we need help … we can seek help from there, as [it is] not available in our families." MNK-FGD3-D15, a 20-year-old male student in Manikganj, said that online SRH resources were needed to "dismantle awkwardness, … and [young people] should be encouraged to denounce the taboo around [SRH]." Another FGD participant commented that he had heard of many health programs for young women but few for young men.

Bangladeshi FGD participants further urged public health agencies to engage more effectively with social networks and social media to reach young people with health information. DHK-FGD1-02, a 20-year-old male student in Dhaka, recommended that health officials leverage networks of male friends to reach their peers. He said:

> *If [young men] know about this information, they can tell their friends, "There is information about this here. Search here. Go here. There you will receive the proper knowledge."*

In Dhaka, DHK-FGD2-D02, a 20-year-old male student, proposed that health authorities partner with social media influencers interested in health, such as Tasnim Jara:

> *If one or two of her videos were pinned on the page of DGHS [Directorate General of Health Services], or renowned faces like her in Bangladesh, whom everyone knows, whose videos people watch, whom they follow; if videos of two or three of them could be pinned above the page or featured on the sides, then I think people would engage more.*

Others in the same focus group agreed with this participant, echoing his call to partner with Tasnim Jara.

Bangladeshi FGD participants also urged the government to do more to regulate health mis- and disinformation on social media. Some noted that the government has engaged in sweeping actions to suppress information classed as violating the Cybersecurity Law and asked why similar efforts have not tackled health misinformation.

However, BRAC researchers interviewed legal and civil society experts in Bangladesh who were understandably cautious about the complex legal challenges this would raise. In considering this challenge, DHK-KII-F, a legal scholar, posited a hypothetical case in which one lawyer alleges that SRH information is vulgar and should be suppressed, while another claims that it is educational, concluding:

> *The judge will be in conflict. In whose favor will the judge give [the] verdict? So you see the problem? So those who were drafting the law, I mean there's a lot lacking … If the laws are not properly defined, you cannot get proper justice … I would say we need a [Sexual and Reproductive Health and Rights] Act.*

Other experts on digital health in Bangladesh shared similar concerns that any government effort to regulate health misinformation could lead to censorship. Some proposed alternative solutions, such as a licensing system to award credentials to reliable online health information providers; or a multistakeholder civil society, academic, and government panel to review cases of alleged health misinformation. However, all agreed with the young FGD participants that more needed to be done. DHK-KII-D, the CEO of a local digital health company, warned that if the government fails to act, future harms or deaths resulting from health misinformation online would undermine public trust in the digital health industry.

Colombian study participants expressed concerns about the need to address the financial barriers to digital inclusion for people living with HIV, in order to ensure their access to health information and services. MED-KII-G, a 50-year-old male HIV activist in Medellín, commented that clinics have subsidized transportation costs for clinic visits, and he recommended that these subsidies be used today to finance digital access:

> *Telemedicine … should be a progressive, incremental gain, even financed in some circumstances. For example, if you are not going to pay transportation to a user and that user does not have connectivity, then you subsidize connectivity, just as you subsidize transportation, yes? Pay them at least a data plan of 20,000 pesos [approx. US$5] per month.*

Several transgender study participants raised concerns about the lack of recognition of gender identity change in Colombia's eHealth systems and urged patient databases to recognize these changes. As a good practice, one transgender sex worker recommended Yana, a Latin American mental health app that offers non-binary gender categories and pronouns.

In Colombia, FGD participants emphasized the need for greater efforts to protect privacy, which may reflect the fact that most of these study participants were living with HIV or from key populations. Colombian FGD recommendations included calls to better regulate Facebook to limit the sale of health information to third parties, and more stringent regulation of health data privacy in the formal health system. Participants in Colombia raised concerns about data on their online activities being used in court cases on intentional HIV transmission. In Bangladesh, experts we interviewed also recommended the reform of data protection laws to treat personal health data as sensitive and restricted. At the same time, participants' views on privacy were complex; many participants in both countries expressed resignation that their information online would be sold without their consent but wanted more transparency on where and how their information would be used.

Overall, FGD participants in both countries described themselves as reliant on their phones and comfortable with the digital transformation of health. However, when asked how their data are managed, who has access to these data, and how they are protected, most had little to no information. In Medellín, a 30-year-old male social media director, MED-FGD3-B, echoed the views of others we interviewed when he said:

> *Because of my [occupation] as a team leader, I am aware of the rights that my employees or collaborators have regarding their health issues, but I don't know how the health care companies or the Ministry of Health or the government protect my data, for example. I have no idea.*

In Bangladesh, most study participants described themselves as lacking basic knowledge about existing data or digital governance. In Bagerhat, BGT-FGD2-D08, a 26-year-old unemployed man, called for more public education on the existing laws.

Discussion

Overall, the study reaffirms the robustness of Special Rapporteur Mofokeng's normative framework, which interprets core elements of the right to health in the context of the digital transformation. While the study is limited by a gender imbalance among participants, its findings resonate with findings from our concurrent participatory action research study in Ghana, Kenya, and Vietnam on the same questions, which did include more young women. In both cases, it emerges that the growth of social media and access to mobile phones extends the availability, acceptability, and accessibility of health information and services, while creating additional challenges for rights-based digital health governance.

In particular, our findings point to a gap between the existing norms of digital health governance, which focus narrowly on eHealth and mHealth interventions within the control of national health ministries, and the broader real-world context in which young adults access health information. Young adults in Bangladesh and Colombia report that their experience of digital health is mediated by privately-owned web search platforms and social media accounts that are largely beyond the control of authorities of either country. In both Bangladesh and Colombia, two quite different contexts with very disparate religious and cultural norms, we found young adults strongly preferring young social media content creators over credentialed health experts because of the ability of the former to communicate in youth-friendly, non-stigmatizing, and nonjudgmental language.

While this study population was made up largely of young men, with smaller numbers of cisgender and transgender women and non-binary people, this finding is consistent with results from the Botnar One study in Kenya, Ghana, and Vietnam, which did engage young women in larger numbers; there, too, young adults reported heavy reliance on Google and social media for health information and peer support.[42]

The findings also emphasize an observation from the Special Rapporteur's report: that the rise of social media offers special opportunities for promoting SRH information to marginalized groups, such as young MSM and young transgender people, who may otherwise avoid formal health settings to avoid stigma. This shift to social media as a source of health information, however, exposes marginalized young adults to new risks of misinformation and stigma.

Thus, in the context of the right to health, the lack of regulation of social media content creators on health may facilitate free expression, enhancing the *availability*, *accessibility*, and *acceptability* of SRH information for young adults; still, this shift creates significant threats to the *quality* of health information. To address this challenge, study participants urged their governments to develop new approaches—namely, to partner with social media influencers to train and credential them, and thus reach young adults with reliable information. We strongly encourage states to consider this recommendation. Such partnerships, including training and official accreditation, could enhance the credibility, standing, and effectiveness of social media influencers and micro-influencers working in the public interest and enable health officials to reach otherwise hard-to-reach young adults. Governments should also seriously consider the practical proposal from key informants of forming multi-stakeholder panels with human rights, health, and civil society experts to collaborate and address health misinformation.

Other recommendations from young people in the study are practical, sensible measures that merit further discussion, such as the recommendation to provide subsidies to cover airtime and mobile phone costs to facilitate access to health information and services. The call by transgender women for gender-diverse eHealth platforms, if taken up, could help Colombian health officials reach transgender people with health information and services and help bring down rapidly escalating HIV rates in this key population. In both countries, governments could also expand the impact of existing data protection standards by promulgating digital governance and data protection rights more widely to ensure that young adults know their rights and where to turn if their rights are violated. All these measures could help improve public trust in digital health.

This study has highlighted some ways that listening to young people can shed light on real-world challenges, generating practical solutions. It also shows the potential of what Goodale calls "translocal" research and advocacy.[43] Youth and civil society consultation and participation in the study both enriches the findings and recommendations and has effectively helped shape "upstream" norms through the Digital Health and Rights Project's support to the mandate of the Special Rapporteur.

Learning from this and the previous studies, we have now formed a larger participatory action research consortium, with community advisory teams of 12 diverse young people in each of the focus countries in our study, including some former study participants, HIV activists, and digital rights activists who are collaborating with national research teams to dive deeper into the issues and advocate globally and locally. They are also contributing to collaborative work with WHO to analyze national digital health strategies and how these should address gender, equity, and rights.

UN agencies and donors should support the growth of similar participatory and community-engaged approaches with technical guidance and capacity-building resources and should include more youth and civil society representation in digital health strategy and policymaking processes. We see an important role for UN platforms to establish new norms for rights-based digital governance that consult young people about the challenges they face with the digital transformation, and to mobilize action.

Contributors

The following members of the Digital Health and Rights Project contributed to this paper:

- Md. Tanzirul Alam (BRAC University) contributed to data-gathering.
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- Sara L. M. Davis (University of Warwick) contributed to study design, literature review, data-gathering, analysis, project administration, writing, review, and editing.
- Afrida Faiza (BRAC University) contributed to literature review, data-gathering, and analysis.
- Catalina González-Uribe (Universidad de los Andes) contributed to study design, project administration, review, and editing.
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PERSPECTIVE

Pushing Back: Civil Society Strategies to Address Punitive Anti-LGBTQI Laws in Uganda, Ghana, and Kenya

NINA SUN, MEGAN MCLEMORE, AND JOSEPH J. AMON

Introduction

Since 1990, 54 countries have decriminalized private same-sex sexual acts between adults.[1] However, in 61 countries, such acts remain criminalized. Penalties can be severe, including capital punishment, life sentences, forced labor, and corporal punishment, such as flogging. Even where same-sex relations are not explicitly criminalized within a country's legal framework, laws pertaining to public morality can serve as tools for authorities to prosecute, persecute, and intimidate LGBTQI individuals.

The criminalization of same-sex sexual relations infringes on a wide range of human rights, including the rights to privacy, nondiscrimination, and equal protection under the law.[2] The criminalization of same-sex sexual relations has also long been recognized as interfering with other rights, such as the rights to security of the person, to housing, to work, to education, and to health.[3]

In the last five years, progress toward achieving the United Nations Sustainable Development Goal of ending AIDS by 2030 has slowed rather than accelerated.[4] While there have been notable reductions in new HIV infections in Sub-Saharan Africa, incidence in some regions, such as in Eastern Europe and Central Asia and in the Middle East and North Africa, has continued to rise.[5] This increase is disproportionately borne by key populations, such as sex workers, gay men and other men who have sex with men (MSM), people who inject drugs, and the sexual partners of individuals in these groups.[6]

The criminalization of same-sex sexual relations, sex work, drug possession and use, and HIV exposure, non-disclosure, and transmission has been shown to impede access to HIV services and increase

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HIV risk.[7] Countries that criminalize key populations have been found to lag in progress toward HIV testing and treatment targets, while greater advances have been made by countries that provide legal protections against discrimination and gender-based violence.[8]

Despite acknowledgment that the criminalization of sexual identity and expression is not only a rights violation but also detrimental to public health, new anti-LGBTQI laws—including laws that punish same-sex relations, gender diversity, and freedom of expression—have been proposed in recent years across a range of national settings. In 2022, for example, Hungary passed a law prohibiting the dissemination of content that "promotes" homosexuality and gender change.[9] In Pakistan, in May 2023, a court struck down sections of the 2018 Transgender Persons Act, deeming sections related to gender identity "un-Islamic."[10] Indonesia's newly revised Criminal Code prohibits all consensual sexual relations outside of marriage, effectively criminalizing homosexuality.[11]

In Uganda, Ghana, and Kenya, repressive criminal laws targeting the LGBTQI community have been introduced, and political and cultural hostility against this community has intensified.[12] Making matters worse, the introduction of these laws is occurring in an environment where funding for the HIV response, especially for key populations and civil society organizations, is decreasing and—with a new US administration coming to power in 2025—likely to decrease further.

Since 2017, the Global Fund has been financing programs to remove human rights-related barriers to access HIV, tuberculosis, and malaria services through the Breaking Down Barriers initiative. This funding supports evidence-based, rights-focused interventions, including ones that promote nondiscriminatory, people-centered care, reduce stigma and discrimination, enhance legal literacy, and increase access to justice.[13]

In 2022–2023, the Global Fund commissioned evaluations of programs addressing rights-related barriers in 20 countries.[14] As a part of the evaluation, key informant interviews with government officials and civil society implementing partners examined the impact of the introduction of anti-LGBTQI bills and laws. Follow-up interviews in 2024 further explored the strategies used by stakeholders to challenge anti-LGBTQI legislation, focusing on three countries—Uganda, Ghana, and Kenya—that offer a comparison of the challenges faced and the responses implemented in the context of newly proposed laws and policies impacting LGBTQI+ communities.

Uganda

Background

In May 2023, Uganda's Anti-Homosexuality Act (AHA) went into force, becoming one of the most draconian and restrictive anti-LGBTQI laws globally.[15] The AHA was passed by the Ugandan Parliament despite laws on the books that already penalized consensual same-sex sexual relations.[16] Specifically, the AHA introduced life sentences for acts of homosexuality, and the death penalty for "aggravated homosexuality." The law prohibits "promoting" homosexuality, which includes operating an organization "which promotes or encourages homosexuality" or the "observance or normalization" of it. This includes providing financial support for such organizations, a provision that could limit bi- and multilateral aid for the HIV response. The law also includes other provisions, including a duty to report persons for the "offense" of homosexuality and prohibitions against renting spaces to LGBTQI persons. The 2023 AHA comes after years of threats to strengthen penalties for consensual same-sex sexual relations in Uganda, and pushback from Ugandan human rights activists, journalists, religious leaders, academics, and lawyers; international human rights organizations; and donor countries to Uganda such as the United States.[17]

Impact and civil society response

The Uganda Breaking Down Barriers progress assessment found that the passage of the AHA significantly impacted program implementers working with LGBTQI communities, who now faced legal threats and security concerns.[18] In response, donors and implementing organizations worked together to design and deliver a range of measures to improve safety and security for LGBTQI organizations and individuals. The assessment also found that access to justice activities, such as the implementation of paralegal and legal aid programs, were critical to addressing risks and barriers to the uptake of HIV services. Peer paralegals were found to play an important role in supporting community needs, though the assessment found that resourcing and staffing support for these interventions were inadequate. Moreover, while these services have scaled up geographically since 2021, demand for legal aid and mediation has exceeded supply. For example, the Human Rights Awareness and Promotion Forum, a Ugandan human rights advocacy organization, saw its caseload triple after the passage of the AHA, with increased cases of police abuse, eviction, and harassment. The organization also reported major disruptions of its operations, with security concerns limiting the ability of peer paralegals to work outside of urban areas. Lawyers are now having to travel to those areas in place of paralegals because they face less risk of arrest and harassment. The combination of increased demand and greater security risk puts a strain on already limited resources.

After the law's passage, civil society, government ministries, and United Nations agencies worked together to protect and promote access to HIV services for LGBTQI populations. For example, a coalition was formed that included civil society, government entities (including the Ministry of Health and the Ugandan AIDS Commission), and UNAIDS and other technical partners and donors. As part of this coalition, the AIDS Support Organization and other civil society implementers of HIV and human rights programs developed an "adaptation plan" with the goal of mitigating harm from the AHA and maintaining continuity of HIV services for the LGBTQI community.

Designed to operate at national, district, and local levels, key features of the adaptation plan included enhanced safety and security measures for drop-in centers that provide HIV prevention and treatment services to key populations. The coalition also proactively sought out and met with national, district, and local law enforcement officials to emphasize the importance of protecting access to HIV prevention and treatment to ensure that HIV-related public health objectives could be met. In some cases, implementers sought to relocate drop-in centers to locations with a lower visibility or where security was greater.

Ugandan civil society also challenged the law in the Ugandan court system. In December 2023, human rights lawyers, LGBTQI activists, and members of Parliament filed a case before the Ugandan Constitutional Court to challenge the law's constitutionality. In April 2024, the Constitutional Court invalidated sections of the law that it deemed inconsistent with the right to health and privacy, including the prohibition against renting to LGBTQI persons and the creation of a duty to report; however, it largely upheld the main components of the law.[19] In response, the coalition conducted outreach to staff at HIV clinics to explain the ruling and address concerns among providers concerned about running afoul of the law. The case was appealed to Uganda's Supreme Court in July 2024.[20]

More broadly, Ugandan civil society organizations continue to face significant challenges. Nonprofit registration in Uganda remains on precarious grounds, with the government deregistering groups that either work or have a history of working on human rights issues.[21] Within this environment, the government has further targeted nonprofits working on key population issues by creating obstacles to the renewal or maintenance of their nonprofit status, a challenge that remains ongoing.

Ghana

Background

On February 28, 2024, the Ghanian Parliament passed an anti-LGBTQI bill entitled the Human Sexual Rights and Family Values Act.[22] The bill was originally introduced in 2021, even though the country already had a law—section 104(1)(a) of the Ghanaian Penal Code—that criminalized consensual same-sex sexual relations, as part of its legacy of British colonialism.[23] According to the preexisting law, violations are misdemeanors punishable with up to three years' imprisonment. However, the new bill takes this further, targeting individuals for openly identifying as LGBTQI, and prohibiting the promotion, advocacy, and funding of LGBTQI-related activities. In the new bill, the punishment for engaging in "promotion" or "advocacy" activities is between five to ten years of imprisonment. Organizing a group, association, or society that works on LGBTQI issues is also illegal, with a sentence of three to five years. The bill prohibits same-sex marriage, prohibits the adoption and fostering of children by LGBTQI individuals, and includes a duty to report persons who violate any of the prohibited provisions to authorities.

Impact and civil society response

Even before the bill was passed by Parliament, its introduction increased stigma and discrimination and violence against LGBTQI individuals. The human rights group Rightify Ghana noted that the introduction of the bill worsened the climate for LGBTQI persons, including increases in harassment and violence against LGBTQI people.[24] Program implementers serving LGBTQI communities also reported that Parliament's passage of the law created a hostile environment for HIV prevention and outreach, with some organizations having to close offices due to safety issues. In addition, these organizations reported an increase in fear and apprehension on the part of MSM and other gender-nonconforming community members, with arrests and incidents of cyber bullying, and fear of engaging on e-platforms and social media.

In response to these threats, program implementers have had to adapt their programs by, for example, limiting meetings with LGBTQI communities to smaller groups and frequently changing locations. Program implementers reported shifting to virtual and digital outreach instead of in-person meetings and providing trainings to LGBTQI community members and organizations on how to identify and respond to threats and how to reduce vulnerability to extortion, harassment, and arrest. In this environment, infrastructure for legal literacy and peer paralegal programs already in place under the Breaking Down Barriers initiative was helpful to efforts to develop an effective response. For example, LGBTQI individuals noted the importance of relying on paralegals to disseminate "know your rights" information and to make referrals to legal resources. LGBTQI individuals also recognized the role of peer educators in referring them to safe locations for HIV and other health services. Partnerships with legal service providers such as pro bono lawyers, the Ghana Legal Aid Commission, and the Ghanaian Commission on Human Rights and Administrative Justice have also facilitated legal support, where needed, in cases of harassment, arrest, and violence against members of the LGBTQI community.

Ghanaian advocates have also been using the courts to challenge and delay the enactment of the bill. Three separate lawsuits have been filed disputing the constitutionality of the bill—one prior to its passage and two after. In July 2024, the Ghanaian Supreme Court dismissed one of the legal challenges, but as of October 2024, the two other legal challenges remained before the Supreme Court.[25] President Nana Akufo-Addo has thus far refused to sign the bill into law, citing constitutional challenges.

Kenya

Background

In April 2023, the Family Protection Bill was submitted by a member of the Kenyan Parliament to the National Assembly. Although Kenya's Penal Code already criminalizes same-sex sexual relations, the bill increased criminal penalties, including a provision for the death sentence in cases of "aggravated homosexuality." The bill also included provisions on "aiding and abetting" homosexuality and "conspiring" to commit homosexuality. A provision prohibiting the "promotion" of homosexuality penalized providing financial support for activities that "normalize" the prohibited conduct and operating an organization that "promotes" homosexuality.[26]

Impact and civil society response

The submission of the Family Protection Bill significantly heightened stigma and discrimination toward LGBTQI individuals, including in health centers.[27] Since the tabling of the bill, there has been an increase in attacks against LGBTQI individuals, incidents of gender-based violence, and evictions of individuals believed to be LGBTQI. In Mombasa and Kilifi Counties, drop-in centers had to close temporarily due to safety and security issues. Even prior to submission of the Family Protection Bill, individuals who identified as a part of LGBTQI communities reported that they faced harassment and discrimination resulting from backlash to a Supreme Court ruling that permitted the registration of the National Gay and Lesbian Human Rights Commission.

In response to the introduction of the bill, civil society and community-led advocates engaged in a campaign of public and private "shadow" diplomacy to encourage its rejection by lawmakers. MSM and transgender community leaders advocated for the legislature to drop the bill, pointing out the potential for negative consequences not only in the context of health but also in other key areas such as the economy and trade.[28]

Kenyan activists reported that interventions that sought to create an enabling environment for HIV-related activities, particularly legal support and access to justice programming, provided an important foundation for efforts to mobilize and respond to the Family Protection Bill. For example, activists cited the partnership formed by the Key Populations Consortium, the Gay and Lesbian Coalition of Kenya, and the National Gay and Lesbian Human Rights Commission as an important means of ensuring a more rapid response to incidents where community members experienced human rights violations.

As in Uganda and Ghana, safety and security were key concerns in Kenya, as was the need to address and respond to increased, and often intense, stigma and discrimination. Though the 2023 bill is currently shelved, program implementers felt that it was important to strengthen internal safety and security measures, including the protection of client data and the physical security of organizational offices.

Conclusion

Several key strategies in response to the introduction of repressive anti-LGBTQI legislation were seen across Uganda, Ghana, and Kenya, including (1) the creation of coalitions of civil society organizations, government, United Nations agencies, and donors to support vulnerable LGBTQI individuals and coordinate strategies for pushing back against repressive laws and their enforcement; (2) efforts to obtain increased funding for the safety and security of LGBTQI-led organizations and for the provision of legal support to community members and civil society organizations (as well as for legal challenges); and (3) the development of new approaches to reach vulnerable individuals, including through more targeted and smaller-scale outreach and the expansion of online resources. Based on our interviews with key stakeholders, the success of these strategies was variable and dependent on social and political contexts, such as election cycles and interparty politics. Strategies that may be effective in one country may be less so in another.

Investment by the Global Fund's Breaking Down Barriers initiative and others in the integration of access to justice programs into HIV service delivery has contributed to the training and availability of lawyers, peer paralegals, and legal literacy campaigns that has strengthened the ability of many vulnerable communities to respond to threatening legislation and to mitigate its impact and maintain access to health services for those most vulnerable.

However, much work remains to be done, and donors will need to continue to support LGBTQI organizations and individuals in addressing often rapidly changing conditions on the ground related to safety and security. This requires funding mechanisms, both core and project based, that are flexible and efficient in design and that allow implementers to repurpose existing funds, and access additional funding, where necessary. Sufficient emergency funds should be available to support people who may need relocation to safe housing and resources for food, clothing, and basic necessities. Investment in peer-to-peer learning among individuals facing similar circumstances may also be strategic to facilitate learning and the sharing of experiences among activists and advocates.

In addition, programmatic measures of success must adapt to reflect the reality of quickly changing local conditions. For example, reporting indicators should take into account that the achievement of target outputs and the expansion or scale-up of programs may not be possible as the legal environment shifts and funds are needed to address urgent security concerns.

Funding for responses to punitive laws and policies should be sustained for the long term. This includes ensuring that community and civil society organizations receive sufficient funding to develop their capacity to quickly respond and adapt to threats; and ensuring their ability to continue reducing barriers to health services. These are integral aspects to the core mandate of promoting the dignity and human rights of LGBTQI individuals.

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VIRTUAL ROUNDTABLE

Rights-Based Approaches to HIV, Tuberculosis, and Malaria

Nina Sun and Joseph J. Amon

Participants

All roundtable participants contributed to the Global Fund's Breaking Down Barriers program progress assessment, which occurred in 20 countries in 2023. They are identified by their country of residence.

Carmina (Mina) Aquino, Philippines
Joanne Csete, United States
Mikhail Golichenko, Canada
Kitty Grant, South Africa
Alexandrina Iovita, Switzerland
Karyn Kaplan, Thailand
Cécile Kazatchkine, France
Diederik Lohman, United States
Julie Mabilat, Germany
Sheilla Masasabi, Kenya
Megan McLemore, United States
Ria Ningsih, Indonesia
Florence Obua, Uganda
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Competing interests: None declared.

Nina and Joseph: *Thank you everyone for participating in this virtual roundtable on rights-based approaches to—and their impact on—HIV, tuberculosis (TB), and malaria, drawing on results from the recent evaluation of the Global Fund's Breaking Down Barriers initiative.*

Joseph: *Let me start with a big question for Alistair and Alexandrina—why is the Global Fund providing funding for rights-based interventions? Why is this important not just to each of you as human rights advocates but for the organization as a whole?*

Alexandrina: The Global Fund recognized some years ago that in order to end HIV, TB, and malaria, we must invest in rights-based responses: scaling up comprehensive human rights programs and supporting the establishment of enabling environments—that is, environments which ensure that health care is available without discrimination, that people's rights and dignity are respected, and that policies support access to prevention and treatment. By dismantling barriers to health services and addressing the inequities that leave people behind, we are creating resilient and sustainable systems for health and empowering people to claim their rights. Putting human rights at the heart of health responses is even more critical today given the global context of conflicts, climate-related disasters, pandemics, and pushback against human rights.

Alistair: I agree with Alexandrina completely, but I'll just add that we know that human rights-related barriers significantly reduce the effectiveness and impact of national responses to HIV, TB, and malaria. They make people more vulnerable to infections, they limit access to quality health services, and they drive poorer health outcomes. These barriers are further compounded by an aggressively growing pushback against gender equality and human rights in many countries around the world, evidenced by punitive and regressive policies and actions. Evidence shows that removing human rights-related barriers can powerfully accelerate progress toward ending AIDS, TB, and malaria, and has demonstrated that inaction against structural barriers will result in an increase in people living with or affected by the three diseases. So, quite literally, we can't do our job at the Global Fund without paying attention to human rights.

Nina: *When did the Global Fund begin this work? Can you describe the kinds of human rights interventions you support? How hard has it been to implement and scale up these interventions?*

Alexandrina: The Breaking Down Barriers (BDB) initiative was launched in 2017 in 20 countries. The initiative provides countries with matching funds to amplify Global Fund investments and with technical support to drive the development and implementation of country-owned national plans and comprehensive programs to address the injustices that continue to threaten progress against the three diseases. The interventions funded by BDB cover the following program areas:

- Eliminating stigma and discrimination in all settings
- Ensuring the nondiscriminatory provision of health care
- Promoting human rights-based law enforcement practices
- Expanding legal literacy ("know your rights")
- Increasing access to legal services and justice
- Improving laws, regulations, and policies
- Reducing gender discrimination, harmful gender norms, and violence against women and girls, in all their diversity
- Mobilizing communities for human rights advocacy
- Removing barriers to TB services in prison
- Advancing equity, rights, and gender equality for malaria responses.

Alistair: Since the BDB initiative started, we have observed big jumps in the scale of human rights programs being implemented, especially related to TB and malaria, where rights-based approaches were less common than with HIV. Programmatic funding increased from US$10.6 million in the 2014–2016 allocation period to $135 million between 2020 and 2022, leading to substantial progress in the scaling-up of programs.

Nina: *Let's turn now to some of the researchers who participated in the recent evaluation of the BDB initiative, which, full disclosure, I also participated in and which was led by my co-moderator. Let's start out with what people found most surprising or impressive. Rachel, do you want to go first?*

Rachel: I worked on the Ghana assessment and I was most surprised and impressed by the enthusiastic reception of the program, particularly the commitment shown by the Commission on Human Rights and Administrative Justice (CHRAJ) commissioner, who launched it as the first initiative of its kind in Ghana. The strong endorsement from CHRAJ, along with support from the Ghana Health Service, the Ghana AIDS Commission, and traditional and religious leaders, played a crucial role in the program's success.

Sheilla: I worked in Kenya, and what I found most surprising was that rights-based programs were able to scale up despite Kenya's challenging legal environment that had threatened to derail gains made. For example, legal literacy programs implemented by key population-led organizations were scaled up despite increased stigma and discrimination exacerbated by anti-LGBT protests and the draft Family Protection Bill, which sought to further criminalize same-sex sexual relationships. Most impressive was the sense of national ownership for reducing or removing human rights- and gender-related barriers to HIV, TB, and malaria services. This was clear from the adoption of the Kenya AIDS Strategic Framework (2020/2021–2024/2025), as well as the National Strategic Plan for Tuberculosis, Leprosy and Lung Health (2019–2023) and the Kenya Malaria Strategy (2019–2023), all of which have a strong emphasis on the removal of human rights- and gender-related barriers, such as addressing gender-based violence and providing post-violence care.

Juliette: I was particularly impressed by the work done in Côte d'Ivoire on changing the perceptions and gaining the support of police officers for men who have sex with men, transgender people, and sex workers. These populations are socially shunned in many countries, and efforts to challenge perceptions are often reduced to a narrative of "Western" values against "African" culture. The approach led by Alliance Côte d'Ivoire together with key population organizations helped create a safe space (during a three-day workshop called "Look In Look Out") where police officers and key populations could connect as human beings, share life stories and challenges, question their behaviors, and build bridges between them. Some key populations noted that this approach of sharing their life and struggles with a group of police officers had a "therapeutic" effect for them. This really blew me away; I had never seen police officers talk in the way they did about key populations and how this changed their perspectives and behaviors afterward in their interactions with sex workers, men who have sex with men, or transgender persons who would come into the police station for help.

Cécile: When conducting the assessment in Senegal, I was particularly impressed and inspired by the tireless work and dedication of peer educators. They are proud of their work because they know they save lives. Senegal put in place a strong network of mediators and peer educators throughout the country that has proved essential to improving access to care, decreasing stigma, and improving self-esteem. Another element that struck me is the importance of maintaining a culture of dialogue in Senegal. Despite what seems to be an increasingly polarized world, dialogues remain possible and, in countries like Senegal, can make a difference. Many stakeholders we met during the assessment talked about people's ability to listen and change their minds. They also described the importance of talking with local authorities and community leaders to secure HIV-related interventions, especially for key populations that face violence and discrimination within the broader community. That confirmed the importance of maintaining and supporting space and time for dialogues with multiple stakeholders, including at a very local level.

Joseph: *It's great to see both the way in which government commitment can advance programs and the way that civil society organizations can work to break down stigma and discrimination person-to-person, bringing people together to recognize that we have to see one another as people first. Let's hear from some researchers who have worked outside of Africa about some of their findings.*

Karyn: I have worked in Asia, especially Thailand, for many years, and for this project, I worked in Indonesia and Nepal. As always, I was most moved by the community advocates whom I met—whether a TB survivor, an HIV-positive transgender migrant worker, or a woman who uses drugs—and who are creatively pushing for change, locally or nationally, despite countless barriers and daily assaults on their dignity. Also, peer project workers, despite being lowest on the budgetary totem pole in terms of financial reimbursement for their work, are deeply motivated to achieve services and justice as equals in their society. This kind of brave and experience-driven leadership in challenging political and economic environments never ceases to amaze me. There is such a tremendous resistance to despair—even without resources, you can be sure these activists will persist. I was so grateful to meet them and to be profoundly inspired as an "unintended consequence" of my work on this project!

Diederik: In Ukraine, despite the challenges from Russia's full-scale invasion, we saw impressive progress over time in reducing HIV-related stigma and discrimination. Led by the organization 100% Life—formerly the Network of People Living with HIV—Ukraine is one of very few countries that has regularly conducted stigma index studies since 2010. This allowed us to examine trends over time: we found, across four stigma index studies, that most key variables show steady decreases over time. For example, exposure to gossip related to HIV status in the past 12 months dropped from 30% in 2010, to 25% in 2013, to 19% in 2016, to 8% in 2020. Fear of breaching of medical confidentiality similarly dropped steadily, from 34% in 2010 to 6% in 2020. While the stigma index studies do not allow us to identify what exact programs or developments have contributed to this trend or how, the fact that HIV-related stigma and discrimination has declined so steadily and consistently suggests that Ukraine is largely getting its response to this challenge right.

Megan: In Jamaica, the Philippines, and Indonesia, I was most impressed by the extent to which access-to-justice programs were integrated into HIV prevention, testing, and treatment services. Each country I worked in took a different approach, but the combination of legal literacy and legal assistance to clients of health facilities was truly transformative for health care outcomes. For example, in Jamaica, one of the largest community-led health care providers had a legal team operating at each of its clinics in three regions. Peer educators acted as legal "focal points," and all case managers, clinical staff, and outreach workers were trained to identify and make referrals to the legal team for clients experiencing gender-based violence, discrimination, or other legal problems. Often, these issues were causing people to struggle to stay in care or fall out of care altogether—but assistance from the para legals and lawyers allowed them to return.

Mina: I agree with Megan on the point about integration. In the Philippines, I was impressed by the Love Yourself Project, which emphasized the grassroots implementation of activities—mobilizing peer navigators, building local capacities, and serving as a testing center and treatment hub. With offices strategically located in communities, the project improved visibility and had a welcoming atmosphere to make HIV/AIDS programs an inclusive engagement at the community level. It is also thinking about sustainability, having expanded its funding base and now receiving compensation from PhilHealth (Philippine Health Insurance Company) for services rendered to people living with HIV.

Nina: *Now let's look at some specific interventions. What did the evaluation find in relation to efforts to eliminate HIV- and TB-related stigma and discrimination? Julie, what stood out for you in your assessment in the Democratic Republic of Congo?*

Julie: In the Democratic Republic of Congo (DRC)—and really everywhere—stigma and discrimination against transgender and gender-diverse people can be severe, and deadly. In the fight against HIV, they represent one of the most invisible populations. In DRC, we met a transgender woman who started working on HIV issues as an activist with Progrès Santé Sans Prix, an organization caring for orphans, vulnerable children, and people living with HIV. A few years ago, this activist decided to launch Entre Nous Plus, an organization focused on the situation of transgender people in DRC. She has personally faced numerous arrests and abuses of all kinds, but through her organization and her participation in workshops, training sessions, and advocacy activities, she has led a change of perception in DRC toward transgender individuals. For instance, her intervention during a training session for the police ended in the police commissioner making commitments to transgender issues and even sharing his phone number in case of someone's arrest. This is just another example where you need to break down stigma and discrimination by forging new relationships. It's not quick work, though.

Mina: In the Philippines, ACHIEVE Inc. sought to address stigma and discrimination through legal and psychosocial support services to TB and HIV patients. It also developed and tested a Human Rights Score Card at the community level to measure trends in stigma and discrimination within health care services and by providers. The organization also organized a national network of TB support groups and provided them with organizational development and capacity-building.

Joanne: In Botswana, the Rainbow Identity Association, which advocates for the rights of transgender and intersex persons, took advantage of the national dialogue opened by a broad constitutional review exercise to push for greater respect for human rights. The organization arranged "town hall" sessions in communities with local chiefs and other authorities to enable people to hear directly from trans and intersex persons. There was partial success: The constitutional reform commission convened by the president wound up recommending legal protections for intersex people, but these protections were ultimately not included. The community meetings also helped reduce fear of trans people as the "unknown." To overcome the weak enforcement of anti-discrimination laws in Botswana, BONELA, which has worked on HIV and human rights for many years, recognized that better public awareness of U=U (undetectable = untransmittable) could help reduce discrimination and the labeling of people living with HIV as "vectors." They were just gearing up to go in that direction as we finished the assessment.

Kitty: In South Africa, TB HIV Care's work with communities to reduce community-level stigma and discrimination toward people who use drugs and to find solutions to address human rights issues affecting this population was exceptionally important. The organization worked with people who use drugs and multiple partners (e.g., health, social development, local government, police, private security companies, and civil society organizations) to set up community-level task teams, engaging communities to find solutions in terms of housing, access to harm reduction, employment, and psychosocial support for people who use drugs. The partnership approach has reduced community level stigma and discrimination, sensitized service providers, and helped overcome some of the structural and societal barriers to access to health care for people who use drugs. While past surveys found extremely high rates of discrimination against people who use drugs in health settings and in the community, recent assessments have unveiled real progress.

Joseph: *What was found about the impact of HIV and TB legal literacy and legal services interventions? Mikhail, you have worked in this area for a long time—what did you find in Kyrgyzstan?*

Mikhail: One of the most impactful examples of HIV and TB legal literacy work that I found was the work of key population-led groups and peer "street lawyers" in Kyrgyzstan. What makes this work stand out is the fact that these street lawyers come from within the community—many of them are people who use drugs and have an intimate understanding of the specific challenges and needs of their peers. These individuals are quick learners, driven by a deep sense of pride in being able to help their community. Their work goes beyond the duration of any specific program or funding; they remain with the community, offering ongoing support and advocacy even after formal programs end. In Kyrgyzstan, there have been numerous instances where street lawyers from the community of people who use drugs successfully prevented unjust persecution by the police, who often attempted to extort bribes. In many cases, simply providing information about the legal threshold quantities of controlled substances was enough to fend off police harassment. This approach not only protected individuals from wrongful prosecution but also empowered the broader community, reducing their vulnerability to HIV and TB by fostering a sense of agency and resilience. The work of these peer street lawyers is a powerful example of how grassroots legal literacy initiatives can have a lasting and meaningful impact on marginalized communities.

I also just want to mention the work of Fond Soros Kyrgyzstan (FSK) too. FSK's advocacy work with civil society and professional lawyers resulted in amendments to the law concerning access to free legal aid that not only provided greater access to professional lawyers and civil society paralegals but also established the first training program to certify paralegals within the free legal aid system. This program enables civil society paralegals, including those who serve as peer street lawyers, to obtain certification and become an integral part of the state-guaranteed free legal aid framework.

Julie: The impact of paralegals has been remarkable in DRC. Our interviews suggested major improvements among key populations in knowledge of rights in parallel to a huge reduction of self-stigma and greater confidence, all as a result of "know your rights" activities. In addition, paralegals are closely connected to the legal clinics and the different types of services they provide (psychosocial support, legal support, and judicial support). Another element highlighted during our visit to DRC is the importance of mediation led by paralegals on the ground. This constitutes alternative and community forms of dispute resolution, which is often the method of dispute resolution preferred by key populations (as compared with litigation).

Kitty: In South Africa, the South African National AIDS Council set up a national process covering six of the nine provinces, working with communities at the district level to discuss HIV- and TB-related human rights issues affecting key and vulnerable populations and to develop district-level human rights charters. In some districts and areas which have been slow to implement stigma- and discrimination-reduction programs, the researchers noted a marked difference in levels of legal literacy about HIV, TB, law, and human rights: the process of developing the human rights charters led to strengthened legal literacy and to the development of and commitment to community-owned human rights charters (as well as provincial charters and a national charter). These charters have now laid the basis for further action-oriented community-centered human rights programming (stigma- and discrimination-reduction programs) that will be built into the new cycle of Global Fund grants.

Ria: In Indonesia, the ORBIT Foundation in Jawa Timur is exceptionally important in improving the legal literacy of key populations and people living with HIV. It provided paralegal training to representatives of all key populations and people living with HIV in Surabaya and Sidoarjo districts. In addition, the foundation was able to raise funds locally to provide legal aid for marginalized communities. With limited funding from the Global Fund, it was also able to train representatives of all key populations in Sidoarjo and Surabaya on human rights.

Florence: The Uganda Network on Law Ethics and HIV/AIDS (UGANET) and Human Rights Awareness and Promotion Forum (HRAPF) in Uganda have been using the community paralegals model to improve access to justice, with UGANET focusing on the provision of legal services to persons living with HIV and HRAPF focusing on the provision of legal services to key populations. The model is structured in such a way that these organizations identify individuals from within the community—and in the case of key populations, the key populations themselves—and provide them with training. Community paralegals act as frontliners in advancing access to justice, identifying community members in need of legal services, providing basic legal advice, and, for individuals with needs beyond their capacity, referring these individuals to UGANET, HRAPF, or other legal services providers for further assistance. The two organizations also implement community reporting tools by which they are able to monitor, document, and profile human rights violations against people living with HIV and key populations. Information generated through these tools is critical for informing advocacy and programming for key populations.

Nina: *We've heard of the impact of police discrimination in communities, as well as efforts by paralegals and lawyers to ensure that rights are respected and that people—especially key populations—have access to HIV and TB services. But what about higher-level factors—such as laws, regulations, and policies—that can reinforce stigma and discrimination or help prevent it? What efforts are being made at that level?*

Sheilla: That's definitely an important area of work that we saw in Kenya. For example, KELIN (the Kenya Legal and Ethical Issues Network) engaged in strategic litigation related to women living with HIV who were sterilized without their knowledge or consent, and in December 2022 the Kenyan High Court delivered a landmark judgment finding that the nonconsensual tubal ligation of a woman living with HIV violated her rights to dignity, to freedom from discrimination, to the highest attainable standard of health, and to found a family, and awarded damages to the claimants. KELIN has been doing this kind of work for a long time—in 2018, it published an assessment of the TB-related legal environment, providing a critical foundation to inform advocacy to address rights-related barriers to TB services.

Florence: In Uganda, HRAPF has also worked for a long time to improve laws, regulations, and policies, engaging with policy makers and pursuing strategic litigation. For example, in 2021–2022, when the Sexual Offences Bill was passed, HRAPF and others successfully lobbied the president of Uganda to return the bill to Parliament for reconsideration. No further action was taken on the bill, which remains seated in Parliament. But this work is difficult, and not every battle is won. This same approach was applied when the Anti-Homosexuality Act of 2023 was passed. Soon after enactment, HRAPF and others used strategic litigation to petition the Constitutional Court to challenge the constitutionality of the act. The Constitutional Court panel of five judges unanimously declined to annul the act, holding that it complies with the Constitution. However, the court also nullified sections 3(2)(c), 9, 11(2)(d), and 14 of the act for contravening the Constitution. For example, section 14 mandated health workers to report persons involved in same-sex relations to police, and section 9 made it an offense punishable by seven years to rent or lease property to a person engaged in same-sex relations. HRAPF and other petitioners filed an appeal against the Constitutional Court ruling, and this appeal is currently awaiting a decision by the Supreme Court, so it's possible we'll see more success.

Joanne: In Botswana, we also saw mixed results from efforts to improve the legal environment. After an amazingly thoughtful statement by the High Court decriminalizing same-sex relations, the Evangelical Fellowship of Botswana organized considerable pushback. With allies in Parliament, it promoted the idea that the High Court decision couldn't be final until Parliament passed a law explicitly protecting people in same-sex relationships. We consulted with constitutional lawyers, who said unanimously that this interpretation was incorrect—that the court's decision made anti-discrimination protections the law of the land. An unfortunate part of this story is that when we asked the police if rank-and-file officers were being trained about the court decision, they said that they wouldn't train their personnel until there was a parliamentary decision. But nongovernmental organizations, including LEGABIBO, the main LGBTQ rights organization in the country, are taking up this fight.

Joseph: *Strategic litigation and advocacy on legislation often needs to be complemented by community mobilization. How has funding from the Breaking Down Barriers project supported those efforts?*

Karyn: In Indonesia, we saw really strong community mobilization activities among TB survivor groups and civil society networks around removing rights- and gender-related barriers faced by TB survivors. A significant body of related research, supported in part by the Global Fund, had recently been completed, including a TB stigma assessment and the launch of an online platform where communities can access TB- and rights-related information and report incidents of stigma and discrimination. But there is also an enormous need for ramped-up training, advocacy, and mobilization activities to get more organizations involved. One of the targets of community mobilization and advocacy right now is related to local budgeting for TB and the need to increase domestic funding for programs that promote TB-related human rights.

Diederik: In Côte d'Ivoire, organizations of people who use drugs and Médecins du Monde engaged in a multi-year effort to build support for changes to the country's drug law to shift it from a law enforcement to a public health approach. Over the course of several years, Médecins du Monde supported nascent community organizations, helping them build organizational strength to both provide effective services and build advocacy capacity. Community organizations then engaged in outreach to convince law makers and other key stakeholders of the importance of the legal changes they advocated, resulting in the adoption of important legal changes in May 2022 in Côte d'Ivoire's Senate. While the implementation of these legal changes—and practical changes in policing—remains a significant challenge, this work has shown the potential for legal change regarding a challenging and politically sensitive topic through an integrated approach to service provision, community mobilization, and advocacy.

Nina: *We haven't yet spoken about human rights-related barriers around malaria, which was a part of the assessment in Kenya and Uganda. What are some examples of this work from those countries? What kinds of successes and challenges are being seen?*

Sheilla: Many organizations working on malaria are not familiar with rights-based approaches, so there is a fair amount of work just getting organizations up to speed and aware of how rights-related barriers can also impede access to malaria prevention and treatment. Toward this aim, the Kenya NGOs Alliance Against Malaria (KeNAAM) carried out a rapid mapping of malaria civil society organizations in 2021 to inform the Malaria Matchbox Assessment. KeNAAM also conducted training to build the capacity of those organizations to meaningfully engage in the assessment. An introductory training curriculum for civil society organizations was developed that included content on human rights, vulnerable populations, nondiscriminatory health care, gender as a determinant of health, and gender roles in the context of malaria. KeNAAM conducted four virtual training sessions for 36 civil society organization representatives. It also supported capacity-building interventions for civil society organizations working in the malaria sector to enhance their capacity to participate in policy design and monitoring. In addition, community health promoters were trained to provide access to medicine and diagnostics for vulnerable groups, such as the fishing community and seasonal migrant workers.

Florence: In Uganda, the Program for Accessible Health, Communication, and Education (PACE) implemented community dialogues to explore gender roles and gender-related barriers as a model for engaging men as decision-makers and gatekeepers for household and community action regarding malaria prevention and control. As part of this effort, PACE developed an organization-wide Gender Action Plan for all its interventions and updated its monitoring tools to collect more comprehensive gender- and age-disaggregated data on its activities in communities. These were informing programming in terms of identifying and resolving emerging gender-related barriers, as well as documenting best practices. The challenge and opportunity in terms of working on rights-related barriers to malaria prevention and control in Uganda is that, previously, malaria stakeholders did not see malaria as a human rights issue. However, that perception is changing. To boost work in this area, we need groundbreaking studies such as legal environment assessments for malaria, followed by clear advocacy priorities and action plans to take this work forward.

Joseph: *Looking forward, what is the biggest remaining challenge to ensuring universal access to prevention and treatment for HIV, TB, and malaria? How could rights-based interventions overcome that challenge? Alistair and Alexandrina, why don't we start with you?*

Alistair: Three major challenges to ensuring universal access to prevention and treatment come to my mind. First is discrimination in the community—including in education and justice settings. Second are harmful laws and policies, including criminalization. Third is an implementation environment with limited resources. To address these issues, we need to continue to fund community and civil society organizations to do advocacy and engage with the judiciary and law enforcement to assure legal protection, the right to fair procedure, and redress. Governments need to increase domestic funding for community groups and for addressing these societal enabler interventions. In general, TB and malaria responses are under-funded, are mainly biomedical, and do not address key gender- and human rights-related barriers that negatively impact programmatic outcomes. These trends are compounded by wider economic challenges constraining the domestic fiscal space available for health in the medium run. With less money for health, investment in interventions to address structural barriers to HIV, TB, and malaria services is expected to be further deprioritized, while other social sector investments will also be reduced, with further deterioration in the socio-economic conditions of vulnerable populations.

Alexandrina: In my opinion, the biggest challenge hampering universal access to health services is complacency in the face of the multiple and concurrent crises. The world has believed it is on the cusp of ending HIV and TB as public health threats, and eliminating malaria, and it set ambitious health, equity, and justice targets under the Sustainable Development Goals. It then proceeded to move its attention elsewhere. However, we have seen how malaria rebounds given climate change and related disasters, how TB preys on those displaced and residing in cramped shelters in contexts of wars, and how the trajectory of HIV cases is on the rise in some middle-income countries that failed to allocate domestic resources or to provide evidence-informed services to marginalized and criminalized populations. In the current global pushback on human rights and gender, human rights programs are more important than ever. The othering and scapegoating of communities amplifies stigma and discrimination, driving key and vulnerable populations further underground. The shrinking space and voice of civil society unravels effective community-led health responses. Only rights will fix these wrongs.

Joseph: *I think there's going to be a lot of agreement in this group that these challenges—discrimination, punitive laws, lack of funding amid multiple and concurrent crises—are seen across all 20 countries in the assessment—and really everywhere.*

Mikhail: I agree. The first challenge that came to my mind in terms of ensuring universal access to HIV and TB prevention and treatment is the existence of discriminatory laws and practices aimed at key populations. But we need to look at what is driving these laws. In Kyrgyzstan, conservative trends have dominated the political agenda over the last five years. This shift has led to the enactment or stricter enforcement of laws that are particularly harmful to key populations. These include anti-gay propaganda laws, increased policing that targets sex workers, and legislation that discriminates against civil society organizations receiving foreign funding. Despite ongoing advocacy efforts by civil society organizations to implement mitigation mechanisms, these conservative trends continue to pose significant barriers. Rights-based interventions have a critical role to play in overcoming this challenge by advocating for the repeal or reform of discriminatory laws, promoting inclusive policies, and ensuring that key populations have legal protections that support their access to prevention and treatment services. Such interventions would help create an environment where universal access to essential HIV and TB services is truly achievable.

Rachel: I agree too. The biggest remaining challenge to ensuring universal access to prevention and treatment, particularly in Ghana, is persistent stigma and discrimination. This challenge manifests in several ways, including the reluctance of key populations to seek testing and treatment, and the enactment of laws that criminalize certain behaviors or identities associated with higher HIV and TB risk. Rights-based interventions that could overcome this challenge include legal reform and advocacy; decriminalization; anti-discrimination laws; community empowerment and education; public awareness campaigns; and empowering key populations. But we also need to strengthen health care systems by integrating human rights into health care delivery and strengthen accountability mechanisms.

Cécile: From my perspective, recurrent homophobic attacks and the politization of HIV- and human rights-related issues are significant barriers to the HIV response. They subject marginalized and key populations to violence and discrimination and encourage silence and fear. Multidisciplinary approaches and efforts to ensure country ownership are essential to human rights programs' integration within the HIV response.

Sheilla: A key challenge in Kenya, and in many countries, is not only punitive laws but also weak and inconsistent implementation and enforcement of good laws, such as anti-discrimination laws, and limited access to legal services when those laws are violated. More broadly, we need everywhere to increase scrutiny of the law through legal environment assessments that examine laws, policies, and practices that impact access to HIV, TB, and malaria services at both the national and county level. We also need to strengthen the capacity of community-led organizations and networks to effectively undertake community monitoring of and engagement in legislative processes and developments that impact communities affected by HIV, TB, and malaria.

Ria: I'd just like to highlight one challenge to universal access to prevention and treatment which hasn't been discussed much yet but is a part of the BDB initiative—and that is ensuring access to HIV and TB services among prisoners. In Indonesia, and everywhere, access to treatment for prisoners is very limited. Most prisons in Indonesia have only a small clinic with one doctor to serve all prisoners. And hospital care for prisoners is available in only a few areas. Funding for prisoner health is also very limited.

Florence: In Uganda, the evolving legal environment remains a challenge for ensuring universal access to prevention and treatment—and what we have seen, over and over, with laws such as the Penal Code, the HIV Prevention and Control Act, the Narcotics and Psychotropic Substances Control Act, and the Anti-Homosexuality Act is that these laws, even after being rejected by the courts, are just reintroduced.

Karyn: No matter what country, it's hard to imagine meaningful or sustainable progress without the crucial element of strong political leadership to achieve global and national HIV, TB, and human rights and gender goals. Without visionary, top-level political support (with strong civil society input and oversight) to institutionalize effective programming, unleash adequate resources, and ensure a legislatively and socially enabling environment, people are at a severe disadvantage in terms of the full realization of their human rights.

Diederik: I would go back to Alistair's point: stigma, discrimination, and criminalization all remain formidable obstacles to universal access to testing, prevention, and treatment. While human rights programs have shown clear potential for reducing and eventually removing these obstacles, these will not be quick wins. To make a real dent in these barriers, human rights programming will need to be implemented consistently and at scale. At present, however, in many countries, programming is still too ad hoc and small scale, lacks integration with services, and is not implemented consistently. We will need continued and consistent funding from the Global Fund, PEPFAR, and other donors, and we need to really focus on integrating human rights programs into HIV and TB services.

Julie: Building off Diederik's point about the need for continued and consistent funding, I think sustainability is still a critical concern. There's a need for more capacity-building of community organizations and collaboration between civil society organizations.

Joanne: I agree with everyone—funding, stigma and discrimination, and the need for capacity-building and involvement of key population-led organizations at the center of the response is critical. One thing I'd add is that at present, the evaluation of rights-oriented programs is often inadequate, leaving advocates without empirical grounding for program expansion.

Megan: I want to add a positive note here. I agree wholeheartedly that the persistent, and worsening, criminalization of the people most impacted by the HIV epidemic is a huge barrier and challenge to achieving "an end of AIDS." The recent wave of anti-LGBTQI laws and policies in Indonesia, Iraq, Uganda, Ghana, Kenya, and many US states not only undermines the HIV response but is part of a broader and very dangerous erosion of human rights around the globe. But we saw in the progress assessments how communities are fighting back in innovative and strategic ways, and those efforts are inspiring. It's more urgent than ever that donors such as the Global Fund continue to support this work with flexibility and commitment to what is going to be a long, difficult struggle.

Joseph and Nina: *Thank you everyone for the lively discussion! Further information on individual country assessments and an overall summary across all 20 countries can be found on the Global Fund's "Community, Rights and Gender" web page: https://www.theglobalfund.org/en/throughout-the-cycle/community-rights-gender/.*

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LETTER TO THE EDITOR

Rights-Based PrEP Delivery and Structural Challenges

HAORAN DENG

I recently read the article “Are Rights-Based Services Important? An Adolescent PrEP Demonstration Project in Brazil,” by Laura Ferguson et al. published in *Health and Human Rights*.[1] I want to express my admiration for the authors’ contribution to this increasingly important area of study. This study in particular highlights crucial aspects such as availability, accessibility, and the importance of a supportive, rights-based approach to health care. However, I would like to offer two key areas that I think still deserve further research and discussion.

First, while the authors advocate for transforming pre-exposure prophylaxis (PrEP) services into centers of holistic youth engagement, this vision presents significant logistical challenges. Specifically, the feasibility of integrating such a wide range of services within existing medical facilities requires further review. The authors rightly note the importance of on-the-ground personnel in developing relationships and an atmosphere that builds trust with groups that are often reticent to approach medical facilities. However, it will be difficult to expand these programs in any way from a policy side when they mainly rely on key personnel. In addition, the authors tend to focus on areas with high population densities. It is unclear how these programs may be able to be created or expanded within rural areas. In these areas, rather than having personnel focused solely on issues of sexual health and HIV prevention, medical personnel will take on multiple roles and it may be more difficult to implement the proper plans or training with those who already have multiple health care roles within communities.

Second, through the United Nations and World Health Organization, all member countries have committed themselves to strive to provide universal access to health care.[2] However, while the constitutional guarantee of health as a right in Brazil provides a solid foundation for these services, there remains a gap between policy and practice. The implementation of these rights will often be hampered by economic barriers. This is especially true for marginalized youth. I believe that addressing these structural barriers through targeted policy interventions should be an integral part of the strategy to improve adolescent PrEP services.

In conclusion, I commend the authors for shedding light on the potential of rights-based PrEP services for adolescents in Brazil. However, I suggest more examination of the practical challenges related to resource allocation for these areas. In addition, the gap between policy and practice still needs to be addressed. However, by addressing these challenges, we can go further in providing effective HIV prevention services for all young people.

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Authors' Response

We are grateful for these comments and agree with the correspondent that providing high-quality, integrated, rights-based care, particularly for marginalized populations, is an immense challenge. Promoting equity may require greater investment, and the right to nondiscrimination requires that resources be channeled to those in greatest need.

We sought to demonstrate what was feasible within government-run clinics in two cities in Brazil. Our findings have informed training materials and protocols for all government health workers providing PrEP services in Brazil, which is one step to promote implementation.

Our results are, of course, context-dependent. Each location—rural/urban, more/less conservative—should promote discussions with the community to organize rights-based services appropriately for its context. While no single study can resolve these challenges, we show that this path is feasible and beneficial. We hope that our findings and their incorporation into national guidance will help health workers and managers around the country prioritize rights-based PrEP delivery, including by addressing the structural barriers highlighted in this letter.

Laura Ferguson, Alexandre Grangeiro, Ana Alexandra Natividad, Paula Massa, Ayra Rodrigues, Dulce Ferraz, and Eliana Miura Zucchi

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EDITORIAL

Promises (Un)fulfilled: Navigating the Gap Between Law, Policy, and Practice to Secure Migrants' Health Rights

STEFANO ANGELERI AND JACQUELINE BHABHA

Good health is fundamental for human thriving, a key linchpin of individual, family, and community well-being.[1] Recognizing this, the architects of our current edifice of international human rights law, an edifice erected to secure future human well-being following the devastating inhumanity of World War II, included from the outset a universal right to health, linked to health care and social well-being.[2] Article 12(1) of the 1966 International Covenant on Economic, Social and Cultural Rights notes, "The States Parties to the present Covenant recognize the right of *everyone* to the enjoyment of the highest attainable standard of physical and mental health."[3] Eligibility is, thus, unqualified: neither citizenship nor legal immigration status nor long-term residency are prerequisites for the right to health.

It follows that the roughly 281 million contemporary international migrants and refugees, 3.6% of the global population, people who no longer live in the country of their birth, have the same right to enjoyment of "the highest attainable standard" of health as their non-migrant counterparts. Among this population are long-term residents, short-term visitors, work-permit holders, international students and businesspeople, and others who chose to migrate for family, work, or leisure. But this population also includes "distress migrants"—people forced to leave home because life there was intolerable, whether because of political persecution, violence, unbearable heat, the prospect of interminable destitution, or other factors rendering their life not worth living.[4] This category includes over 43 million refugees worldwide, people who have been granted a legal status because they are held to qualify for international protection due to their "well-founded fear of persecution."[5] But it also includes uncounted millions of others whose suffering may not be officially recognized as a basis for legal protection—people fleeing intolerable poverty, people

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fleeing state breakdown and violence, people fleeing extreme climate events.

All these distress migrants are, thanks to the capacious terms of article 12(1), entitled to the right to health, even though their legal status may be irregular. But despite this simple rule, the evolution of international human rights law has resulted in a fragmented tapestry of normative standards. While some states guarantee universal and equal health rights for both nationals and migrants, others carve out subsets of health-related entitlements tied to legal status—granting equal rights to regular or legal migrants but excluding irregular migrants and asylum seekers, though the latter enjoy somewhat more favorable protections than the former.[6]

To what extent does the reality on the ground reflect these normative standards? According to a 2024 study conducted by the International Organization for Migration, of 100 countries surveyed, only half afford all migrants the same access to government-funded health services as they afford their own nationals. A fuller answer is more complex, as international and domestic laws, bureaucratic practice, and official prejudice intersect to create a multilayered and inconsistent reality. This special section of the journal is an effort to engage with part of this reality, where the harsh conditions that distress migrants face—before, during, and after migration—are key determinants of their health and generate profound threats to their dignity and human rights.[7] The special section offers an evidence-based scrutiny of a range of situations in which distress migrants are denied the access to health care that international human rights law promises them, situations in which the challenges of displacement and loss are compounded by the struggle to maintain a safe and healthy life.

The papers selected cover a range of geographic settings—South Africa, Colombia, Greece, Ecuador, and the United States. Despite the very disparate contexts, with enormous differences in the relevant socioeconomic environments, some common themes related to distress migrants' inadequate access to the right to health emerge. Central among them is the pervasive impact of discrimination, a factor in some cases embedded in national policy, in others manifested in the way that decision-making discretion is exercised. Another is the troubling gap between legal entitlement and actual implementation, between rhetoric and rights in practice—in many contexts, the absence of robust monitoring or supervisory capacity, despite laudable court judgments in some cases, enables rights-violating practices, including the denial or deferral of needed care and the failure to appropriately protect vulnerable populations from predictable medical problems. Finally, all the papers point to the need for greater attention to preventative care, structural and social determinants, and the adoption of nondiscriminatory and equitable standards to further the fundamental goal of securing a universal right to health for all.

The opening piece in this special section is a viewpoint by Rebecca Walker and Jo Vearey entitled "Punishment over Protection: A Reflection on Distress Migrants, Health, and a State of (Un)care in South Africa." South Africa is a useful place to start the inquiry into distress migrants' access to the right to health. It has a progressive and inclusive legal framework, which enshrines the principles of international human rights law. The authors start by making the important point that, despite this legal entitlement and despite their small numbers, "distress migrants are targeted by the government's deliberate and public strategy of scapegoating them for its failures to deliver on post-apartheid promises." This weaponization of the "other" as a tool for political expediency is a pervasive contemporary phenomenon.[8] Much more than resource scarcity or unreasonable migrant demand, it explains the willful exposure of distress migrants to what the authors evocatively call "(un)care in the very spaces where they seek support." The key takeaway is that despite legislative inclusion, the willful absence of "migration awareness" in South Africa's national health strategies undermine distress migrants' access to care. Addressing linguistic, emotional, and economic challenges is essential for an inclusive, rights-based health service. The authors reveal how excluding migrant perspectives and adopting punitive over protective approaches nullifies the powerful rights enshrined in South Africa's Constitution.

The second paper shifts the focus from the Global South to the Global North, from South Africa to Greece. Here too a significant gap emerges between distress migrants' right to health in theory and in practice, in part because of similar failures to include appropriate awareness of the distinctive health and other socioeconomic needs of this population in the services offered, but in part also because of failures in the national health system that affect nationals too. Faye Ververidou and Tamara Hervey examine, in "Securing the Right to Health of Asylum Seekers: A Small-Scale Qualitative Case Study in Thessaloniki, Greece," how shortcomings in the structure of the Greek health service combine with poor-quality public health measures to negatively impact some health outcomes for distress migrants. Even though, as in South Africa, robust formal commitments to ensure the right to health for all have been adopted in Greece, and even though—unlike in South Africa—state actors accept that inclusive human rights entitlements apply equally to distress migrants, this paper finds inconsistent and sometimes inadequate care. Service failures and a lack of attention to key health determinants (such as housing quality and sanitation) combined in some of the cases studied to produce negative health outcomes. In short, the authors find that even where legislative guarantees are in place and service provider attitudes are inclusive and well-intentioned, fulfilling the right to health requires targeted attention to broader, contextual social determinants that disproportionately impact distress migrants.

Two studies from Latin America follow, both careful analyses of the interplay between the legal framework governing the health rights of distress migrants and the reality of health care delivery on the ground. A comparison between the two studies is generative, because whereas one country, Colombia, has a fragmented legal framework with incomplete access to care, the other, Ecuador, formally guarantees equitable access to health care for all, including distress migrants. In "A Primary Health Care-Anchored Migrant Right to Health: Insights from a Qualitative Study in Colombia," Stefano Angeleri—through an analysis of Colombia's legal, humanitarian, and community-based responses to Venezuelan migration—argues that primary health care as a core state obligation, along with promoting legal literacy of rights frameworks, could lay the foundation for a more equitable and robust framework to advocate for and implement measures targeting distress migrants' health. In advancing this point, we see a strong resonance with the point made, in the Greek context, by Ververidou and Hervey that attention to a broader canvas of health determinants are essential prerequisites of migrant health. In both Colombia and Greece, a flawed intersectoral implementation rather than overt discrimination, as in other contexts, is the target of the scholars' critique.

The second Latin American paper, by Mariana Pinto-Alvarez, Irene Torres, and Daniel López-Cevallos, entitled "Protecting Distressed Migrants' Right to Health in Ecuador: Are Legal Commitments Being Fulfilled?," broadens the discussion from health providers and other national and humanitarian institutions to the Ecuadorian Constitutional Court as a contributor to the realization of distress migrants' right to health. The authors describe Ecuador's inclusive legal framework—one that recalls the generous provisions offered by the South African Constitution—and show how, despite this robust legal backdrop, practical obstacles stymie the implementation of health rights in practice. They analyze a landmark Constitutional Court decision that engages with the translation of distress migrants' legal entitlement to health care into practical reality. The decision details particular obligations of state and local authorities and instructs these actors to revise their practices in line with the court judgment. This judicial level of intervention could, together with other sectoral interventions—in many jurisdictions, including neighboring Colombia—incentivize the "migration awareness" that is crucial to eliminating discrimination in practice.[9]

It is poignant to conclude this special section with papers focusing on the United States, which is now facing a new administration intent on targeting migrants and denying their human rights entitlements. The final two papers focus on a particular subset of the distress migrant population—migrant children—an important and, until recently, neglected constituency with distinctive and sometimes acute health needs. The first, Lars Lindgren and Karla Fredricks's "A Multi-Level Approach to Promoting the Health Rights of Immigrant Children in the United States," analyzes the broad institutional framework that governs distress migrants' right to health. Given the severe fragmentation within the US system, and the often dysfunctional communication efforts between different agencies at both the federal and state level, this viewpoint reviews the scope for multi-level integration to advance distress migrant children's best interests overall. So does the special section's final paper by Marina Plesons, Haley Hullfish, Priyashma Joshi, Stephen Symes, and Anjali Saxena entitled "Characteristics and Guardianship Status of Children Undergoing Forensic Medical and Psychological Evaluation for Asylum in Miami." The paper describes the profiles of a cohort of migrant children served by the Miami Human Rights Clinic over a period of 11 years. It highlights the complex, often daunting challenges faced by distress child migrants. It considers the vital role of forensic examinations and guardianship in improving the quality of asylum determinations and enhancing health protection measures for this vulnerable group, whose best interests should be recognized as primary concerns by adjudicators. Nowhere, in our view, is this perspective more crucial than in the wealthiest country on earth, where despite immense resources, basic human rights—including the health rights of distress migrants—will soon be targeted for draconian cutbacks, whatever the human cost.

We face a world where many countries, on all continents, embrace xenophobic and anti-migrant leaders who shore up their popularity by weaponizing racialized hatred and the fear of outsiders. The political space to advance egalitarian health rights is shrinking, eroded not only by exclusionary ideologies but also by policies that prioritize market efficiencies over equity and dismantle public spending on social services.[10] These dynamics exacerbate inequalities and undermine the infrastructure needed to uphold indivisible human rights for all. At this historical moment, as we prepare for 2025, we would do well to remember what motivated the framers of our current international human rights laws 75 years ago: the recognition that unspeakable cruelty could be inflicted by states unless people everywhere insisted on the nondiscriminatory implementation of basic human rights for all, including socioeconomic rights.

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VIEWPOINT

Punishment over Protection: A Reflection on Distress Migrants, Health, and a State of (Un)care in South Africa

REBECCA WALKER AND JO VEAREY

Introduction

Since South Africa's democratic transition in 1994, the country has been associated with a progressive Constitution and a rights-based legislative framework enshrining rights for all those within its borders.[1] For 30 years, the post-apartheid government's commitment to building robust and accessible public services, such as health and education, has offered hope of an inclusive and equitable approach to socioeconomic development for all.

However, in recent years, South Africa's legislative, political, and social erosion of its commitments to human rights and development has deepened inequalities and worsened development indicators.[2] The interplay of poor governance (characterized by corruption and political interference), resource constraints, and historical inequalities has negatively impacted all in South Africa and trapped many in cycles of poverty and unemployment.[3]

For distress migrants (asylum seekers, refugees, and undocumented migrants), these challenges are exacerbated by discriminatory policies and practices and institutional neglect.[4] Having left their countries of origin in search of safety, employment opportunities, and improved livelihoods, many distress migrants remain undocumented or in limbo for years in South Africa due to institutional inefficiencies and corruption.[5] Unable to regularize their status, distress migrants face barriers to accessing basic socioeconomic rights, including health care, secure housing, income-generation activities, and general safety.

Despite claims to the contrary, non-nationals (distress migrants and other migrant groups) compose only 3.9% of the overall population.[6] Yet distress migrants are targeted by the government's deliberate and

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public strategy of scapegoating them for its failures to deliver on post-apartheid promises.[7] Experienced as negative determinants of health, these challenges not only increase inequity in South Africa but compromise the health and well-being of distress migrants by exposing them to neglect and (un)care in the very spaces where they seek support.[8]

A state of (un)care in health care

The state of (un)care is particularly evident in the poorly managed and inefficient public health system. While most South Africans relying on public health care (approximately 80%) face challenges accessing care, it is distress migrants who are disproportionately vulnerable to poor treatment, denial of medication, and limited access to health care facilities.[9]

South Africa's Refugees Act guarantees asylum seekers and refugees the rights to work, study, access medical services and life-saving treatment, and enjoy freedom of movement.[10] Similarly, the National Health Act upholds the constitutional right to health by providing free primary health care access for all (with no mention of nationality or legal status).[11] The Uniform Fee Schedule confirms that refugees, asylum seekers, and undocumented migrants from the Southern African Development Community states are entitled to be treated in the same way as South African citizens in hospitals and to be means tested to determine their ability to pay for services.[12] Yet despite these legal protections, migrants frequently encounter discrimination, exclusion, and xenophobic attitudes from health care workers, negatively impacting their mental well-being (see Table 1).[13]

This neglect is also increasingly formalized through the deliberate exclusion of specific migrant groups in national policies, limiting the country's likelihood of achieving global health targets and negatively affecting health outcomes for all in South Africa.[14] For example, in 2020 the Gauteng Province Department of Health (where Johannesburg is located) violated the National Health Act, the Constitution, and the Bill of Rights by restricting access to free health care for pregnant and lactating migrant women and children under six years of age on the basis of their nationality and documentation status. Despite a court order mandating the provincial department of health to amend the policy, discriminatory practices reportedly continue unchecked.[15]

Furthermore, national strategies for addressing both communicable and noncommunicable diseases lack migration awareness.[16] This is evident in the exclusion of migration and migrants from pandemic preparedness plans, including, most recently, the national COVID-19 vaccine program.[17] Additionally, the newly passed National Health Insurance Act, based on the principles of universal health coverage, is poised to restrict access to free basic health care for asylum seekers and undocumented migrants.[18] This not only undermines South Africa's global health targets but contradicts the fundamental right to health enshrined in various global, continental, and regional governance frameworks the country has ratified (see Table 1).

Systemic neglect in the Department of Home Affairs

The state of (un)care is reflected by the Department of Home Affairs through its bureaucratic inefficiencies and corruption, which have led to massive backlogs in processing and adjudicating applications for asylum and other various visas and permits.[19] Instead of addressing the manifold structural challenges, the government has focused on an increasingly restrictive and securitized approach to immigration.[20] The recently revised White Paper on International Migration, for example, proposes relocating asylum processing to border areas, creating a dangerous de facto encampment policy while reducing access to basic services.[21] Additionally, the introduction of the Border Management Act, coupled with arbitrary arrests, detention, and deportation, all contribute to a climate of fear and vulnerabilities for distress migrants.[22]

Conclusion: Prioritizing punishment over protection

South Africa's current migration and health agenda, characterized by xenophobia and a prioritization of punishment over protection, disproportionately undermines the health and well-being of distress migrants. To foster a more inclusive and equitable society, the government must adopt a fundamentally different approach. This involves implementing migrant-inclusive health policies, strengthening anti-discrimination laws, and addressing the complex interplay between governance and structural and systematic factors that contribute to health disparities among distress migrants. Providing migrants with opportunities to regularize their immigration status is also critical to addressing the structural determinants of poor health and well-being for all in South Africa. By effectively addressing the contradictory position taken by the government, South Africa can align its policies with the principles of universal health coverage and the numerous international human rights and health agreements it has ratified. Ultimately extending care and protection toward distress migrants will contribute to a more just and equitable society for all.

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TABLE 1. National laws and policies protecting the right to health for all in South Africa

Measure	Description
National Health Act (2003)	Section 4(3)(a) obliges public clinics and community health centers to provide free primary health care to all lactating and pregnant women and children under six and in emergencies.
Constitution (1996)	Section 27 provides that everyone has the right to have access to health care services, including reproductive health care services, and that no one may be refused emergency medical treatment.
Immigration Amendment Act (2004)	Section 42 states that "when possible, any organ of state shall endeavour to ascertain the status or citizenship of the persons receiving its services and shall report to the Director-General any illegal foreigner, or any person whose status or citizenship could not be ascertained, provided that such requirement shall not prevent the rendering of services to which illegal foreigners and foreigners are entitled under the Constitution or any law."
Refugee Amendment Act (2017) & 2019 regulations	Section 27(g) provides that refugees have the same right to access health care as South African citizens. This right is widely interpreted to include asylum seekers. This also applies to undocumented migrants who are citizens of any country in the Southern African Development Community. For higher levels of care, refugees and migrants must pass a means test.
Department of Health 2007 Circular	Confirms that refugees and asylum seekers, with or without permits, can access the same basic health care services as South African citizens, including antiretroviral treatment in cases of HIV (this means free at the point of use but can be charged thereafter).
Uniform Fee Schedule	Confirms that refugees, asylum seekers, and undocumented migrants from countries in the Southern African Development Community who go to a hospital in South Africa are entitled to be treated in the same way as South African citizens and to be means tested to determine their ability to pay for services.
National Health Insurance Act (2023)	Repeals the provision of the National Health Act that provides free health services. Chapter 2 (4.2) states that asylum seekers and "illegal foreigners" are entitled only to emergency medical services and services for communicable diseases.

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Securing the Right to Health of Asylum Seekers: A Small-Scale Qualitative Case Study in Thessaloniki, Greece

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Abstract

Deploying legal analysis and a small-scale qualitative dataset, this paper considers the right to health of asylum seekers, as a subgroup of distress migrants, in Greece in the years preceding the COVID-19 pandemic and thereafter. The public health care system in Greece is operating under significant constraints stemming from austerity policies. We analyze the legal entitlements of asylum seekers as found in Greek and international law and confirm a significant gap between the right to health in theory and the right to health in practice. While some administrative matters have improved, in general, widespread human rights failures to provide the right to health for vulnerable asylum seekers arriving in Greece continue. In particular, shortcomings in the health care system's capacity and structure, as well as poor arrangements to secure the underlying conditions for good health, affect the practical realization of the right to health of asylum seekers, many of whom have complex health needs.

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Introduction

The right to health is among the most important international human rights, pertaining to human dignity and life itself. Within Europe, the right to health is largely secured through publicly financed health care systems, many of which were severely impacted by the global financial crisis of 2009.[1]

Worldwide, distress migration (stemming from "desperation, vulnerability, and needs, from living circumstances that are experienced as unbearable or deeply unsatisfactory and that precipitate serious obstacles to a reasonable or tolerable life") has been continuously on the rise.[2] One source of desperation, vulnerability, and unbearable living circumstances—the armed conflict in the Middle East, particularly Syria—has led to massive and continuing inflows into Europe of a specific sub-category of distress migrants: those seeking international protection. According to the European Union's (EU) Qualification Directive, asylum seekers are individuals who have made a formal claim for international protection but whose application has not yet been processed.[3]

Situated at the southeastern edge of the EU, Greece received an estimated over one million new migrants during 2015–2018, and almost 204,000 more between 2019 and August 2024, according to the United Nations High Commissioner for Refugees.[4] Figures from the Greek Ministry of Asylum Statistics suggest even higher numbers.[5]

While health and immigration law have each attracted significant academic interest, studying their intersection offers added value because both fields are traditionally regarded as domains of national sovereignty. States have long designed their health care systems principally around exclusion, prioritizing the needs of nationals over non-nationals.[6] Similarly, the enjoyment of human rights by migrants has often been perceived as conflicting with state sovereignty.[7] This paper challenges such assumptions by examining the legal entitlements of asylum seekers in Greece, particularly with respect to the right to health, flowing from both domestic and international human rights law.

Under the Greek Constitution, international conventions take precedence over conflicting domestic legislation.[8] This underscores Greece's formal commitment to its international legal obligations, whether from the United Nations (UN), the Council of Europe, or the EU.[9] While the issue of whether international law also supersedes *constitutional* provisions remains unresolved in Greece, legal scholarship has suggested that international *human rights* law may do so when it provides greater protection.[10] Thus, international law holds a prominent place within the Greek domestic legal framework, with supra-legislative authority and, for human rights protection, potentially a supra-constitutional status. Within the UN human rights framework, Greece has ratified all major international conventions that include the right to health and is therefore legally bound by their provisions according to its own constitutional provisions.

Deploying legal analysis and a small-scale qualitative dataset in Greece, supplemented by secondary data, this paper explores a twofold research question: (1) whether asylum seekers, as a specific subset of distress migrants, are entitled to a right to health under the international human rights conventions ratified by Greece, and (2) how these legal entitlements are realized in practice, particularly in the period leading up to and following the COVID-19 pandemic. We analyze the practical and administrative barriers faced by asylum seekers and the health professionals responsible for their care. We identify gaps between (legal) theory and practice and show that, despite these gaps, both asylum seekers and health professionals share a strong belief in human rights as an important vector for health protection and human flourishing. We conclude by arguing that the assumptions that sovereign states organize their health care systems to exclude non-residents seeking asylum are not wholly supported in the context of a state like Greece, which at least strives to respect its obligations under international human rights law when it comes to the right to health for asylum-seeking migrants.

Methodology

The paper's research questions require a combined methodology, utilizing both "doctrinal" and "empirical socio-legal" approaches.[11] We employ a doctrinal method to analyze legal norms embedded in international human rights law and Greek legislation, relevant case law, and "soft law" documents.[12] Committees established by UN conventions offer authoritative interpretations of provisions through general comments, monitoring reports, and decisions on individual complaints.[13] These publications bridge the gap between international law on paper and national practice.[14] Thus, our doctrinal analysis focuses on the right to health in five international human rights instruments ratified by Greece, the pertinent national legislation, and an examination of 50 UN committee publications from 2011 to 2024, which are used to interpret state obligations (here, Greece's) under these international instruments. (The committees examined are the Committee on Economic, Social and Cultural Rights; the Committee on the Elimination of Racial Discrimination; the Committee on the Rights of the Child; the Committee on the Elimination of Discrimination Against Women; and the Committee on the Rights of Persons with Disabilities.)

We also employ empirical methods to investigate the practical application of the right to health of asylum seekers in Greece. Primary data were collected through 25 semi-structured interviews with Arab-speaking asylum seekers (n=15), aged 18–55, and health professionals (n=10), conducted between June and September 2019. Participants were selected using purposive and snowball sampling, respectively.[15] Thessaloniki's role as the second largest city in the country, the health care hub for Northern Greece, and its proximity to several reception centers for asylum seekers made it an ideal location for this study. The interview guide, tailored for each group of interviewees, was informed by the doctrinal legal analysis of the right to health, ensuring that the empirical research was grounded in the theoretical framework. Interviews with asylum seekers were facilitated by a native Arab-speaking interpreter through simultaneous interpretation, and all interviews were transcribed by Ververidou. Data saturation was reached despite the small sample size, respecting principles of data minimization.[16]

Thematic analysis, derived from the legal doctrine, was employed to systematically examine key themes across the interview data, allowing us to compare and contrast the theoretical legal obligations with practical challenges faced by asylum seekers.

Our primary data are complemented by secondary data on asylum seekers' access to health in Greece since 2020. This includes scholarship, gray literature, two European Court of Human Rights judgments, a UN monitoring report, news coverage, and nine reports from civil society organizations. These secondary data were also analyzed thematically, using key themes identified during the analysis of the primary data.

Legal context

The Greek legislative context for asylum seekers

Greece's legislative framework for asylum seekers, including their right to health, has been repeatedly reformed over the last decade, primarily to comply with EU law.[17] The current position is Law 4939/2022 (Asylum Code), which, despite successive legislative changes, has remained consistent on health care access, reception conditions, and medical screening for asylum seekers.[18] Here, Greek law aligns with and sometimes exceeds EU standards, which require emergency care and essential treatment.[19] Recognized by Greek law as a "socially vulnerable group," asylum seekers are entitled to free access to publicly provided primary and secondary health care, including pharmaceutical and hospital care, preventive care, sexual and reproductive health care, psychiatric care and mental health support, and chronic disease treatment.[20] This differs significantly from migrants who have not applied for asylum, whose access is limited to emergency care and psychosocial services.

Obtaining a social security number (AMKA) was a de facto requirement for asylum seekers to gain access to the public health care system. A July 2019 circular revoked asylum seekers' access to AMKA, effectively removing their right to receive medical treatment in public facilities. In November 2019, a new system for free health care access was introduced solely for asylum seekers—the Foreigner's Temporary Insurance and Health Coverage Number (or PAAYPA).[21] Nevertheless, this new system was not put into operation until April 2020. Hence, from July 2019 until April 2020, a large number of asylum seekers in Greece had access only to emergency public health care and relied on private health care to cover non-emergency health needs.

Greek law also provides that asylum seekers should have an adequate standard of living, taking into account their resources, to safeguard their physical and mental health.[22] Irrespective of whether an asylum application has been lodged, newly arrived migrants are subject to medical screening on public health grounds, primarily to prevent the spread of communicable diseases.[23] Part of the legally defined process involves an assessment of the "vulnerability" of arrived persons. Greek law non-exhaustively enumerates categories of "vulnerable" individuals and affirms that they are considered to have particular reception needs and thus are entitled to specialized care and protection.[24]

The right to health in UN international human rights law

The human right to health is enshrined in numerous international conventions. This paper focuses on UN conventions, given their broad scope and universal applicability. The UN system lacks definitional uniformity across different conventions; has no hierarchical system among its committees, leading to overlapping or conflicting interpretations; and does not hold states to a singular standard of the right to health, instead taking into account each state's resources.[25]

Despite these complexities, there is some definitional agreement. According to Brigit Toebes's widely accepted definition, the right to health covers both access to health care (such as medical treatment) and underlying determinants of health (such as living conditions and environmental safety).[26] Our analysis builds on that definition and focuses on the right to health in five UN conventions ratified by Greece: the International Convention on the Elimination of All Forms of Racial Discrimination (art. 5); the International Covenant on Economic, Social and Cultural Rights (art. 12); the Convention on the Rights of the Child (arts. 24 and 25, and its optional protocols); the Convention on the Elimination of All Forms of Discrimination Against Women (art. 12); and the Convention on the Rights of Persons with Disabilities (art. 25).

The AAAQ framework. The right to health is an expansive concept.[27] It is interdependent with other human rights, such as the rights to food, housing, work, and access to information.[28] In its authoritative interpretation of article 12 of the International Covenant on Economic, Social and Cultural Rights, the Committee on Economic, Social and Cultural Rights (CESCR) endorsed the AAAQ framework: availability, accessibility, acceptability, and quality. This framework is a practical tool to assess states' compliance with their convention-based, health-related obligations, and it has significantly influenced the activities of other international bodies.[29]

Availability refers to the presence of public health care programs, goods, facilities, and services, as well as access to safe and potable water, hygiene conditions, and essential medicines.[30] *Accessibility* encompasses nondiscriminatory, physical, and economic access to health care (affordability), based on equity and proportionality, and access to information. The inability to cover health expenses should not pose a barrier to enjoying health services, especially for impoverished or socially underprivileged populations.[31] *Acceptability* requires that health services be ethically and culturally appropriate, be gender and age sensitive, and respect privacy.[32] National health laws and strategies must promote the cultural training of health professionals.[33] *Quality* is associated with the availability of skilled health professionals, adequate medical infrastructure, scientifically approved medication appropriate for specific patient groups (such as children), and the provision of high-quality water and sanitation conditions.[34]

Progressive realization and the minimum core of the right to health. The International Covenant on Economic, Social and Cultural Rights recognizes the progressive nature of the right to health.[35]

Progressive realization means that states must work toward the full realization of rights based on available resources and their level of development. Immediate fulfillment may not be possible.[36] Scholars have attempted to strengthen the legal underpinnings of progressive realization by calling for accountability through examining state effort.[37] For others, however, progressive realization is impossible to define or effectively implement, rendering the right to health a mere aspirational goal.[38]

To address these concerns, the CESCR has articulated key limitations to the principle of progressive realization. States must continuously strive to realize rights as expeditiously as possible, through deliberate and targeted steps.[39] Any retrogressive measures must be justified.[40] Retrogression is measured by the country's current level of development, the severity of the alleged retrogression, and action by the state to find low-cost alternatives.[41] The nondiscrimination principle applies immediately.[42] Progressive realization does not affect the enjoyment of a minimum content of the right to health.[43]

The CESCR has developed an evolving list of such a "minimum core," beginning with access to primary health care and essential food and housing, and adding equitable and nondiscriminatory access to health facilities, goods, and services, especially for vulnerable individuals; essential medicines; safe and potable water; adequate and nutritional food; basic shelter and sanitation facilities; and a transparent and participatory national public health strategy.[44]

The CESCR's "minimum core" list is long and is not fixed.[45] The Committee on the Rights of the Child has compiled its own list of core right to health obligations, including universal coverage of primary preventive and curative health care services, and the preconditions of children's health.[46] We acknowledge the critiques of a "minimum core" approach.[47] However, for our purposes, recognition of a non-derogable core is valuable because it allows for an assessment of the human rights protection of vulnerable individuals—here, asylum seekers as a distinct category of distress migrants.

Results

Following Toebes's definition of the right to health, using the AAAQ categories of international law, we consider first access to health care, and second, the underlying determinants of health. We take into account the non-retrogression obligation and the obligation to provide a "minimum core" of protection.

Access to health care

Availability of services. Primary care, emergency care, and medical screening on arrival had been made available to at least some of the asylum seekers we interviewed.[48] However, not all asylum seekers had this experience: for example, AS5 reported a lack of vaccination for their baby, a finding that is reported more generally in the literature.[49] As noted by one health professional interviewee, asylum seekers prefer to go to hospital emergency services rather than book appointments with primary health care doctors.[50] Because referral from another doctor is not necessary, migrants accessing hospital outpatient health care have not necessarily accessed primary or secondary health care first.[51]

Some asylum seeker interviewees were able to access more than the "minimum core." For example, after initial difficulties arising from a lack of translation and information in their native language, AS1 reported access to secondary cancer care. But most of the interviewed asylum seekers were unable to access the treatment they felt necessary, reportedly primary care, or what they felt were essential medicines.[52]

On nondiscrimination in *accessibility*, views differed. Unsurprisingly, the health professionals we interviewed either felt that all patients are treated the same in the Greek health care system or, in one case, that asylum seekers should be treated differently because of their particular needs.[53] Among asylum seekers, AS1 felt that they were treated the same as Greek nationals, whereas AS2, AS5, and AS9 felt racism and a lack of professionalism from health professionals.

On practical accessibility, asylum seekers AS7 and AS8 had experienced easier access to health care provided by nongovernmental organizations

(NGOs) in the camps than state-provided health care once arriving on the mainland. Physical access to health care within the Greek system is also dependent on securing the necessary documentation. Interviewees with the relevant AMKA document found access easier. Health professionals are not involved in the documentation process, which is handled by hospital administrations.[54] D4, a health professional, explained that AMKA was used for registration in the hospital system and that health professionals asked for the patient's AMKA during a consultation. At the same time, some health professionals felt that no questions are asked about distress migrants' legal status, but rather that patients are all treated equally.[55]

However, some health professionals mentioned that they lacked information on how to proceed with prescriptions for migrants with and without AMKA; whether migrants have access to medication; and whether medical tests could be covered for those without insurance.[56] One health professional was clear that a lack of documentation would exclude an asylum seeker from access.[57]

Information accessibility is a prominent theme in our data. Lack of information about the right to health and unfamiliarity with the national health care system make practical access very difficult for asylum seekers.[58] Officially, there are no interpreters in the public health care system, which interviewees highlighted as a problem, especially for women and children.[59] NGOs were reported to be playing a critical and praiseworthy role, especially in information provision, in some hospitals.[60] Some asylum seekers were reliant on their own interpreters.[61] Lacking an available interpreter, AS8 resorted to the German language to communicate with a Greek doctor who also spoke German. D4 expressed the view that asylum seekers need to visit hospitals in an "organized manner," accompanied by someone who is aware of their medical and travel history and can facilitate communication.

Lack of interpretation significantly compromises the right to health. It can lead to delays in treatment.[62] Further, some interpreters were embarrassed to ask specific questions about medical issues related to cancer or fertility.[63] Some of the health professionals we interviewed felt that it was very challenging to get patients' full medical history, even when an interpreter was available.[64]

Many of the asylum seekers we interviewed had accessed health care through NGOs, especially Médecins de Monde, rather than the state.[65] Several reported that the state, by requiring documentation, had excluded them from even what they felt was very basic health care.[66]

Results concerning affordability were mixed. AS1 reported that costs were being met by the state. AS2 felt they had to pay for necessary (dental) treatment; AS9 reported being been told that they needed to pay for surgery. AS10 had used the private sector; AS5 was only using the private sector. D2 also linked the proximity to health care facilities with affordability, in the sense of migrants' capacity to afford the costs of traveling to hospitals.

Acceptability. Our interviews suggest some deficiencies in age-appropriate treatment.[67] Cultural and/or religious barriers to health care were also reported—for example, some health professionals noted resistance among patients to certain procedures (in fertility care, the husband was very reluctant to accept alternatives such as sperm donation) or when asked more personal questions.[68] Requesting a doctor of the same sex may also be driven by cultural or religious dimensions.[69] One health professional, D4, reported that a patient demanded that she remove the Christian Orthodox icons from her wall. Whether this is required by international human rights law is unclear.

In terms of health care, there is little about *quality* in our interviews. One asylum seeker, AS12, reported good prenatal and postnatal care for his wife and child. By contrast, AS2 felt that the treatment for kidney stones offered to them in Greece was not state-of-the art, citing what would be available in Lebanon as more advanced. Additionally, AS6 mentioned that the ophthalmologist provided the wrong prescription, which, combined with the general delays in finding medical appointments, left them without proper eyeglasses for several months.

Retrogression. Several asylum seeker interviewees described how the change in the Greek law in July 2019, which left a nine-month administrative gap in the ability to obtain a social security number, posed significant barriers to access to health care.[70]

Interviewees also expressed the view that the Greek state had done its best to respect the right to health within the resources available. As noted by one asylum seeker, "These camps need a country like America to take care of them."[71]

Underlying determinants of health

On the underlying determinants of health, we heard that no safe water was available in the island camps and that sanitation conditions were extremely poor.[72] While AS2 reported that essential food was available in the reception camps, AS12 had been housed four kilometers from the nearest market without access to any public transportation.

The effects of housing conditions on asylum seekers' health were prominent in our interviews. One interviewee had not been provided any housing and was living on the street.[73] Two had been housed in what they felt were unhealthy conditions and were now renting privately.[74] AS13 was also privately housed. Another, AS12, reported that a doctor had explained that the state-provided housing was the cause of their child's ill-health.

AS1 felt that their housing was unacceptable because it was unsanitary but also that the shared housing provided was detrimental to their mental health. AS4 reported that many migrants known to them were unhoused, living on the streets or squatting in unoccupied properties without water or electricity. AS13 described the island camps in a similar way, and one health professional, D1, stated that the living conditions there caused health problems. However, some interviewees felt that the conditions in the reception centers on the islands were better for their health than after moving on to Thessaloniki.[75]

Discussion

Our interview data confirm the findings of other studies in several respects, especially with regard to Greece's non-compliance with the human right to health. But in other respects—particularly in the case of asylum seekers falling into the category of vulnerable groups, who are protected not only in international law but also explicitly in Greek domestic law—our interviews paint a more positive picture of the state's compliance with and protection of the right to health.

Health care

Confirming our earlier data, overall, access to both primary and secondary health care was worse in the east Aegean Islands compared to the mainland in 2019–2020.[76] In practice, legal entitlements to medical screening on arrival, and necessary health care flowing from that, did not take place in the Moria refugee camp on Lesvos in 2019, and it is unclear whether it took place in any Greek reception centers in 2023.[77] In 2023–2024, the European Court of Human Rights granted interim measures after finding instances of insufficient access to medical treatment on Samos and Kos.[78] In one case, the court ordered the transfer to the mainland of a single mother and her infant, who was suffering from a serious heart condition, so that the child could receive proper treatment and accommodation.[79] In another, it found that two Afghan single-parent families were living in degrading conditions and should be granted "full access to reception conditions which respect human dignity."[80] In the Greek public health care system, the distinction between emergency, primary, secondary, and tertiary health care is unclear; in theory, hospitals constitute the tertiary level of health care, but in reality, hospitals offer emergency care and outpatient services as if they were primary health care units.

Delays in accessing emergency care (such as wait times for an ambulance) and secondary care (such as cervical cancer screening, mental health referrals, HIV care, contraception, and access to abortion) persist.[81] In 2024, the Committee on the Elimination of Discrimination Against Women confirmed limited access to sexual and reproductive health information, services, and contraceptives for migrant women.[82] Understaffing, particularly of pediatricians and psychologists, is regularly reported as a key cause of lack of access, again chiming with our data.[83]

Practical accessibility is compromised by physical distance.[84] In some areas, access to specialist treatment involves travel to a hospital in Athens, which poses difficulties in terms of organization and transportation costs.[85] Organizational barriers—such as the lack of clear referral pathways and inefficient coordination between various state and nonstate services (e.g., mental health providers at accommodation sites and public health care facilities, schools, law enforcement, teams working at accommodation settings)—also compromise accessibility.[86] Further, a lack of access to essential medicines persists.[87] Language is another important barrier to access, still present as of 2024.[88]

The view that access to health care must be affordable irrespective of the patient's financial circumstances is reflected in our interviews. Health professionals believe that the right to health is universal and includes free access to public health care irrespective of one's financial, social, or cultural status.[89] But, as noted above, administrative delays in obtaining the PAAYPA hampered access, forcing asylum seekers to use costly private health care or placing the burden on NGOs.[90] Even for people with AMKA or PAAYPA, as for Greek citizens, copayments are required for some medicines, reducing affordability.[91] For a state such as Greece to deprive people of the most basic aspects of the right to health under the pretext of insufficient resources would constitute a breach of international human rights obligations.

The obligation to provide culturally sensitive treatment arises immediately upon migrants' arrival to the country, during their medical screening.[92] Health care professionals must have cultural expertise, which is reportedly lacking vis-à-vis some migrant populations.[93] During a formal visit to Greece in 2017, the UN Special Rapporteur on the human rights of migrants found that overlooking cultural sensitivities and the lack of interpretation services within the health care system are barriers to the right to health care.[94] Our data confirm this.

Insufficient medical equipment on the islands' reception centers was also reported in 2024.[95] Inexperience, together with insufficient training and capacity-building among health care professionals, has also been reported as contributing to a lack of quality health care.[96]

Underlying determinants of health

On the underlying determinants of health, poor sanitation conditions and the lack of safe water in the island camps persisted into 2023.[97] Here, the data are mixed. Some of our interviews confirm that the conditions in the island camps did not meet minimum core rights. Despite a temporary improvement deriving from the decrease in numbers of arrivals during 2019–2022, with numbers on the rise again, several camps are operating beyond their nominal capacity. Thus, more recent secondary data from 2024 show that the underlying determinants of health—such as food, water, housing, and hygiene—are insufficiently available to secure compliance with Greece's international obligations on the right to health.[98] But some of our interviewees praised the arrangements in the island camps, especially in comparison with what was provided in Thessaloniki.[99]

Vulnerable groups. Our interviews show that gender and age have routinely been treated as determinants of special treatment in the health sector, featuring in most international health-related agreements and embodied in Greek law.[100]

However, in practice, health care for minors, especially mental health care, is deficient: there is a lack of funding for enriching activities to build mental resilience, use of compulsory psychiatric admissions due to inexperienced staff, and unnecessarily prolonged hospitalization because of a lack of suitable accommodation.[101] Similarly, in practice, pregnant people experience difficulty accessing health services, including a lack of access to medicines and appropriate food, as well as inadequate information.[102]

Another important deficiency is the time it takes for migrants to obtain a formal designation as legally "vulnerable," with the protections that flow from that status: reportedly, in 2019–2020 and more recently where a public hospital examination is required (all "non-obvious" cases and those needing a psychiatric examination), it has taken over six months, or even a year.[103] The quality of vulnerability assessments on the islands remains in doubt.[104] However, outside of minimum core obligations, nondiscrimination on nationality grounds, as opposed to grounds of race or ethnic origin, may be justified by legitimate and proportionate actions.[105] Potentially, the tightening of the AMKA rules represents such an action.

Human rights breaches—yet belief

Overall, in theory, international human rights law places significant obligations on states that are the destinations of asylum seekers. But, as we have shown, these legal rights are far from being realized in practice. Every interview in the dataset mentions at least one—and usually more—practical barriers to the right to health. A recurring theme in our interviews with health professionals is the lack of sufficient resources to provide health care or the underlying determinants of health. Our data thus confirm the findings of other studies, both in Greece and elsewhere, that show that fulfilling the right to health in international law may be a necessary, but not sufficient, step in protecting the right to health of asylum seekers.[106]

As noted above, Greek law introduced a new system—PAAYPA—in 2020. In practice, however, the process was slow, with fewer than 35% of asylum seekers provided with this number by the end of 2020, and similar deficiencies persisting into 2022, though significantly improved by 2023.[107] Between July 2019 and the activation of the PAAYPA, even the most vulnerable migrants pending an asylum decision were de facto excluded from access to the public health care system beyond emergency care.[108] Whether the AMKA and subsequent PAAYPA legal changes constitute "retrogression" has not been legally established: at least arguably, they are a breach of Greece's relevant international legal obligations, but at the same time they may be justified given the austerity measures imposed on Greece by the Eurozone fiscal rules, especially in the islands.[109]

The asylum seekers and health professionals we interviewed share a strong belief in human rights as an important vector for human health protection and flourishing.[110] Every health professional we interviewed was treating the patients who reached them, irrespective of the patients' formal legal status. This is also reflected in our interviews with distress migrants themselves. As one asylum seeker noted:

> *Here in Thessaloniki, she asked me for the AMKA. So I made myself very tired and I made myself very sad and she [attended to] me.*[111]

Conclusion

A relatively complex narrative emerges from our data: it is not as simple as Greece being in clear breach of its domestic and international law obligations to respect the right to health. Overall, our data do reinforce other reports of widespread failures to fulfill the right to health for vulnerable distress migrants (here, asylum seekers arriving in Greece). A comparison with more recent secondary data shows that these failures continue in the post-pandemic era. Our data confirm the practical difficulties flowing from the need for formal legal documentation, especially for health care that is not emergency or primary care and for care for pregnant people and children.

However, key aspects of Greece's fulfillment of the right to health have improved. Because the acquisition of PAAYPA has been integrated into the application and registration process since April 2020, the vast majority of asylum seekers no longer face restrictions flowing from a lack of access to documentation. Some interviewees reported that they were accessing the public health care system in Greece at no cost to themselves. Some were able to access secondary health care therein. Some were accessing health care to which they were legally not entitled. While many interviewees reported that their right to health had not been protected, some praised the reception from the Greek health care system, and indeed the Greek state.

That said, accessibility deficiencies flowing from the remote location of reception centers, on both the mainland and the islands, combined with a lack of transportation services, continue, as do those deriving from a lack of interpretation services. Health care is often unavailable because of the understaffing of medically and psychosocially qualified professionals. Some restrictions arise from a lack of affordability; these seem to be worsening. Our interviewees recognized the limited nature of the right to health and the significant resource its protection requires.

Finally, this paper reveals that the intersecting domains of health and migration, where the needs and rights of nationals are expected to be prioritized over those of outsiders, are not necessarily characterized by traditional national sovereignty. Instead, a paradox in the Greek context emerges: while asylum seekers are ostensibly granted nearly the same primary and secondary health care rights as nationals, this formal equality does not consistently translate into fair and equitable access in practice. Asylum seekers experience the same systemic obstacles as nationals (such as delays and physical accessibility issues), while also facing additional barriers linked to substandard living conditions, linguistic differences, and financial constraints.

The legal concept of "vulnerability," embedded in both Greek and international law, currently provides enhanced human rights protection for specific groups of asylum seekers such as children and pregnant women. Recognizing and applying the right to health through the vulnerability lens for all asylum seekers could thus guide policy reforms aimed at true access equity. Future research is needed to examine which policy reforms could enable such a shift from equality to equity, as well as the potential inclusionary and exclusionary effects of a vulnerability-based policy approach to distress migrants.

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A Primary Health Care-Anchored Migrant Right to Health: Insights from a Qualitative Study in Colombia

STEFANO ANGELERI

Abstract

In recent years there has been a sustained rise in the number of international migrants, and scholarship and practice have increasingly focused on the relationship between health and migration. However, the entitlement to state-subsidized services for migrants with precarious or irregular legal status, often fleeing distressing living conditions, is typically limited to emergency lifesaving health treatment, with nonstate programs attempting to complement this constrained approach. This paper asks whether a primary health care (PHC) approach could serve as a blueprint for institutional priority-setting and for the realization of human rights obligations to help states meet their core international commitments regarding migrant health rights. I look at the multi-actor response in Colombia—where almost three million Venezuelans have sought to settle and many more have transited during the last nine years—as a case study to explore the possibility of a meaningful PHC-oriented right to health in the migration context. Using human rights law standards and commentaries, I suggest that, with some qualifications, this approach holds promise.

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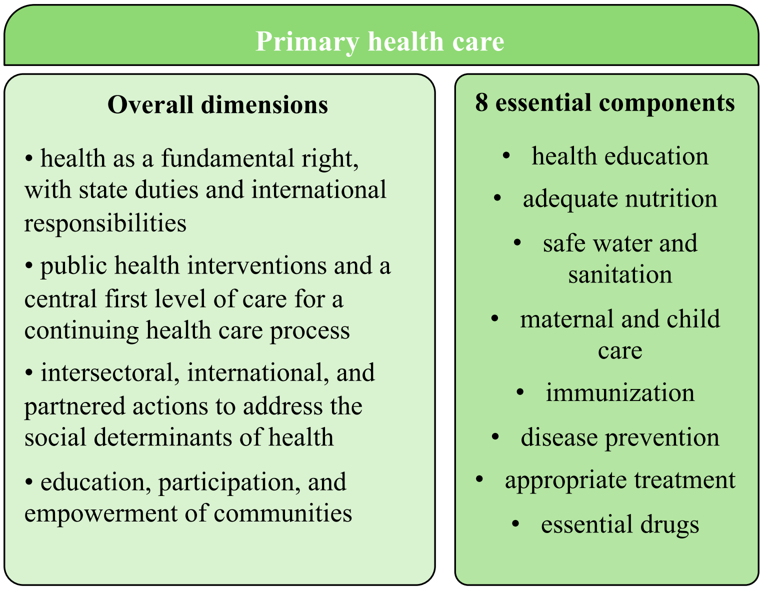
Introduction

With 281 million international migrants worldwide, the intricate link between migration and health has become a focus in both research and policy over the past two decades.[1] While migration can offer opportunities for improved well-being, migrants often confront serious health risks. They encounter violence, exploitation, and harsh living conditions, as well as family separation and systemic discrimination, challenges that are compounded by precarious legal status, threats of detention or deportation, and significant barriers to accessing health care. All these factors critically undermine migrants' health and well-being.[2] Society-wide responses to these unfavorable circumstances—including public health, humanitarian, and human rights interventions—offer potential solutions. Law is an essential tool for human rights advocates to hold states accountable for health-related rights violations.[3] However, international and regional human rights law are rather inconsistent and ambiguous on the nature of state obligations to migrants. They range from endorsements of a universal and nondiscriminatory right to health for all migrants to constrained approaches that limit the entitlement of people with irregular migration status to urgent (medical) care.[4] This fragmentation extends to domestic law, where migration status heavily influences access to health rights.[5] Public health evidence shows that medical care alone is insufficient to ensure health equity: the right to health for migrants must extend beyond emergency care to access to a broader range of health services and other key social determinants of health.[6]

This paper focuses on irregular migrants (non-nationals who do not meet legal entry or stay requirements) and migrants who, though lawfully present, have a precarious legal status (e.g., because they are awaiting decisions on their migration status, a "limbo" that can hinder access to welfare). Irregular migrants constitute a distinct subset of distress migrants, subject to state hostility and thus peculiarly exposed to vulnerabilities.[7]

The paper explores a proposal to address the gap between the universality of the right to health and its limited application to migrants with irregular or precarious status (from now on referred to as "irregular migrants"). The aim is to shift from a mere "bare survival" threshold to one that promotes "healthy subsistence."[8] The research question is, Would a stronger focus on a primary health care

Figure 1. The primary health care framework



Sources: International Conference on Primary Health Care, Declaration of Alma-Ata (1978); Global Conference on Primary Health Care, Declaration of Astana (2018).

(PHC) better fulfill the right to health for migrants? Related to that is the question of whether PHC should constitute a blueprint for priority-setting when seeking to realize migrants' right to health.

The authoritative 1978 Declaration of Alma-Ata defined PHC as an intersectoral approach to achieve health equity, with individual- and population-level interventions, grounded in the right to health and facilitated by national and international partnered actions.[9] Its essential components include health education, adequate nutrition, safe water and sanitation, maternal and child care, immunization, disease prevention, appropriate treatment, and the provision of essential drugs (see Figure 1). PHC has been recently recast by the 2018 Declaration of Astana, which, by contrast, emphasizes the need to implement integrated health systems with a central focus on the first point of contact with the health system (primary care) and public health interventions. It calls for multisectoral actions and the facilitation of community empowerment and participation.[10] Primary care in this framework is not the same as PHC; rather, the former "is the core of the *service*-fronting component of PHC."[11]

PHC is deemed a "cost-effective, equitable and accessible *route* to extending health services to *unreached* populations"—a key means to "materialize the right to health" without discrimination and a cornerstone of global efforts to achieve universal health coverage.[12]

It is thus unsurprising that PHC features as an essential element of health-related legal provisions in Convention on the Rights of the Child and the Additional Protocol to the American Convention on Human Rights, but it is also a benchmark in relation to state obligations on the right to health

FIGURE 2. The right to health: General and core obligations

Right to health

Overall framework

- progressive realization of the highest attainable standard of physical and mental health
- immediate duties to take concrete steps that ensure the realization of the right and to prevent discrimination
- availability, accessibility, acceptability, and quality of services and conditions (AAAQ)
- participation and accountability mechanisms

Priorities for action

Core obligations

- health services without discrimination (ensure access)
- safe and nutritious food and freedom from hunger (ensure access)
- basic shelter, housing and sanitation, and safe and potable water (ensure access)
- essential medicines, as defined by World Health Organization (provide)
- equitable distribution of health facilities, goods, and services (ensure)
- equitable national health plan of action (adopt/implement)

Obligations of comparable priority

- reproductive and prenatal and postnatal maternal and child health care (ensure)
- immunization for priority diseases (provide)
- epidemic and endemic diseases (prevent, treat, and control)
- health education (provide)
- appropriate training and education for health personnel (provide)

Sources: International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI) (1966), art. 12; Committee on Economic, Social and Cultural Rights, General Comment No. 14, UN Doc. E/C.12/2000/4 (2000).

in the framework of the International Covenant on Economic, Social and Cultural Rights.[13] Despite varying interpretations across legal frameworks, the right to health in international law obliges states to promptly and effectively work toward its *progressive realization* for all. This entails establishing and enhancing health systems that provide preventive, curative, and palliative services, as well as implementing measures addressing the social determinants of health. States must also take *immediate steps* to ensure nondiscrimination against vulnerable groups in existing services and interventions and undertake "deliberate, concrete, and targeted" actions toward fully realizing the right to health.[14] PHC appears to have influenced a list of core obligations and duties of comparable priority in developing rights-compliant health systems and multisectoral governance (see Figure 2).[15] This relates to the much-debated yet authoritative legal concept of core obligations concerning the right to health, which serves as a "minimum floor" for the conduct or outcomes expected of state authorities.[16]

The intersection between PHC and the right to health seems therefore crucial for identifying priority areas of intervention for vulnerable people, such as irregular migrants and asylum seekers, which states are obligated to address.[17] Indeed, within the United Nations and Inter-American frameworks, all migrants are recognized as rights holders, with nondiscrimination applying on the grounds of nationality and legal status.[18]

The Colombian response to Venezuelan migration serves as a case study in this paper to answer the research question in a specific context, avoiding the perception of law operating in a social vacuum and exploring "human rights in action ... [through] engagement with communities' actual needs."[19]

The context in Colombia

This case study is particularly significant for several compelling reasons. First, Colombia has a strong Constitutional Court, and international human rights law has contributed to the development of health standards and statutory legislation that protect the fundamental right to health.[20] The Colombian health system operates through public and private providers, with services accessible via insurance: the state subsidizes coverage for those classified as poor or vulnerable, while others must pay through work contributions or privately.[21] However, only nationals and those with regular migration status can access comprehensive health and social services, while irregular migrants or people in the process of regularizing their status, who are ineligible for social security and health insurance, are generally limited to receiving urgent medical care (see Table 1).[22] Strategic litigation has led to many judgments extending migrants' health entitlements, some of which are referenced in the discussion below.[23] However, a significant gap exists between the law and how it is implemented.[24]

Second, over the past decade, nearly three million Venezuelans have settled in Colombia, (whose population was 52 million as of 2024), with hundreds of thousands of others (Venezuelan and other nationalities) transiting through its territory annually.[25] Although many Venezuelans—fleeing massive human rights violations—might in principle qualify for international protection under

Table 1. Entitlements for citizens and migrants

Legal status	Legal entitlements
Citizens and regular migrants (holding various visas, residence permits, or regularized through the Venezuelan temporary protection statute) and asylum seekers with certified status (SC2) lasting up to 180 days, renewable once.	Access to comprehensive health care if they affiliate with the social security system, are classified as "poor," and register with a health insurer. They may also be eligible for additional social services, such as nutrition programs. Non-nationals must report their residence every four months. Those with the capacity to pay must directly register with a health insurer to access care.
Uninsured populations, including irregular migrants and individuals in the process of regularizing their status. Regular migrants during the first month of health insurance.	Access to urgent care, which by law (Res. 5269/2017) extends beyond emergency services.

the Cartagena Declaration, which is incorporated into Colombian legislation, they are rarely granted refugee status.[26] Despite the low success rate, data collection in this study showed that many individuals still strategically apply for asylum, as asylum seeker status grants non-nationals eligibility for at least temporary health care affiliation. However, the vast majority of Venezuelans hold "liminal" statuses, such as temporary protection obtained through long-lasting regularization processes (especially during 2021–2023), or remain as irregular migrants.[27]

Third, state authorities have created partnerships with many dynamic international agencies and nongovernmental organizations (NGOs) to respond to the health and social needs of migrants who do not hold regular status.[28] Organizations operating in the health sector, largely coordinated by the Pan-American Health Organization and the Ministry of Health, appear to be guided by a PHC approach in what they coordinate and offer, and some subscribe to a human rights-based approach.[29] This unfolds in a political context of deep polarization, violence, and weak state presence in certain regions, despite institutional efforts toward peace and justice.[30] Polarization extends to health, where a strong tradition of social medicine coexists with a highly privatized health system resisting attempts at reform.[31] For instance, a recent health reform bill—aimed at introducing a greater focus on preventive and primary care, but which was silent on the right to health of irregular (uninsured) migrants—stalled in Congress for over a year before ultimately being quashed in March 2024.[32]

Methods

This paper combines a literature search and empirical data collection and analysis. The literature search covered judicial decisions, laws and policies, and secondary sources (scholarly analyses and commentaries of institutional bodies and NGOs) identified through relevant databases and institutional websites using a combination of keywords such as "primary health care," "human rights (law)," "right to health," "Venezuelan migration," "migrant," and "Colombia" in Spanish and English.[33] Empirical work, conducted in Spanish, had three elements:

- Diaries from two periods of participant observation during February–May 2022 with two humanitarian actors (Jesuit Refugee Service and the International Organization for Migration) in Bogotá, Cundinamarca, and Norte de Santander.
- Semi-structured interviews with 30 administrative, managerial, legal, and clinical staff across 20 public institutions and humanitarian and community organizations, held in person and online, in the same territories, during the period of May–December 2022. The sample started with the identification of key organizations via participant observations, and complemented with snowball identification (names of the organizations available from the author on request). Interviewees were 65% women and 35% men.
- Four in-person focus groups with 38 migrant and Colombian social leaders acting as community health workers (CHWs) in the cities of Bogotá, Soacha (Cundinamarca), Villa del Rosario (Norte de Santander), and Cúcuta (Norte de Santander). The focus group participants were 70% women and 30% men, as well as 60% Venezuelan and 40% Colombian.

During the semi-structured interviews and the in-person focus groups (see Annex), conversation, exercises, and prompts explored essential components, crosscutting principles, and challenges related to PHC and the right to health as applied to migrant communities in the country (with a focus on not-yet-regularized migrants, who were the majority of people during data collection).

I selected the aforementioned territories because, when the study design started in 2021, these were among the areas of the country with the highest concentration of migrant communities, whether settled, in transit, or of pendular migration. However, my research is limited by its geographical scope, as it excludes rural areas where health rights may be more neglected due to armed groups, limited infrastructure, and local budget constraints. Additionally, the study's focus on Venezuelan migrants does not account for the growing number of migrants from other nationalities now transiting through Colombia.

Diaries and transcripts containing the opinions of participants were analyzed through qualitative thematic analysis using NVivo, which led to the identification of 300+ codes and the extraction of three macro themes (described below).[34] The findings are subsequently triangulated with the literature in the discussion section to assess whether a PHC approach could improve migrant health equity and rights.

Results: Three macro themes

My thematic analysis of empirical data found the following macro themes: (1) iterations of the human right to health and its facilitators; (2) the value of PHC in migrant-targeted actions; and (3) approach constraints. Given the breadth of the research question, this section aims to provide a short "thematic description of the entire data set"; however, a more detailed account is given for the dimensions of theme 2.[35]

Iterations of the human right to health and its facilitators

Study participants were particularly eager to share their views on the foundation and scope of the right to health (in general and in relation to migrants), as well as the mechanisms for ensuring its realization. Many emphasized "health and well-being" as the human *interests underlying* this right for everyone (e.g., FG1, I-9), further noting that "the right to health is functional to protect social determinants of health beyond urgent lifesaving medical care" because it is "framed as the highest attainable standard of health and well-being" (e.g., FG1, I-1). Others stated that this right is instrumental in protecting life, either a "dignified one" (FG-3) or in cases of "critical lifesaving situations" (e.g., FG4, I-9).

Regarding the *scope* and *nature* of rights and obligations, many participants, especially non-nationals, felt that state authorities were breaching their legal and moral obligations: "It cannot be that the right to health means 'I am dying, I have the right to health,' as in the case of uninsured migrants. This [right] should encompass timely care and services based on the patient's needs without engaging in discrimination" (I-7). Or, as one other participant stated, the right to health should encompass "at least some *essential* services for everyone regardless of nationality and status" (I-9, emphasis added). Others highlighted the "progressive nature of the right to health for migrants," emphasizing that there would be a "duty to provide emergency care to protect the right to life while gradually extending coverage" (I-4, similarly I-16).

All participants frequently reported that state and nonstate responses inadequately protected migrants' right to mental health, given the limited focus on one-time crisis management in emergency care and only limited mental health support through NGO-sponsored packages (I-2, I-9, I-18) (see Table 2).

Discussions further highlighted *how* irregular or not-yet-regularized migrants (the majority during data collection) enjoy the right to health. *Intermediaries* such as legal clinics, NGOs, and pro bono legal advisors are deemed "essential for their assistance in securing access to health services by engaging with ombudspersons, filing petitions, asylum applications, and protection writs" (e.g., FG1, FG-4). Additionally, the significant presence of development agencies with migrant health programs (mostly focused on primary care, children, and maternal care) also plays a key role, leading

TABLE 2. Mental health is a human right

A single mother of two participating in a focus group
"We arrived in Colombia with heavy hearts. Imagine watching your children and neighbors lose weight from hunger, walking for days through heat and cold, only to be treated as less than human because you're poor and foreign. Mental health must be recognized and actioned upon as human right" (FG-1).

many to feel that "[their] right to health is upheld by NGOs and agencies like the International Organization for Migration" (FG-1, similarly FG-3). However, some agencies caution that "it is not our function to realize human rights, but we do minimize risks of rights violations; we stay there, we support" (I-9), "within the limits of our projects that do not always ensure continuity of services, or as you want to put it, rights realization" (I-10).

The value of PHC in migrant-targeted actions

To evaluate whether a stronger focus on PHC could support the fulfillment of migrants' right to health, participants were briefly introduced to PHC dimensions and the eight essential components (see Figure 1) and asked to identify which should constitute a "minimum floor" in migrant-targeted actions and why. Below, responses are grouped into four sub-themes, consolidating the most referenced PHC elements.

Primary care, immunization programs, and essential drugs. While it should be reasserted that primary care, as the first level of care, is only one component of PHC, it was arguably identified by study participants as representing one of the biggest gaps in the institutional response to the right to health for irregular migrants in Colombia. A United Nations employee noted that "primary care provision would allow us not to move to a higher level of complexity and costs, … preventing complications and unnecessary suffering, so it can constitute *appropriate treatment* in the face of certain communicable and noncommunicable diseases" (I-17, emphasis added). For that reason, "many development actors resorted to purchasing primary care packages in private and public health centers for uninsured migrants" (I-10) and created "mobile units" (I-10, I-14). These complementary primary care services "typically also address psychological distress by offering psychological first aid, with or without the involvement of psychologists (I-9)" and "referrals to specialized or urgent services when available" (I-3).

Venezuelan nationals in focus groups, regardless of their legal status, overwhelmingly wished that state-subsidized care included access to *primary care clinics* for immunization programs and for screening, treatment, and check-ups for common communicable and noncommunicable diseases, in order to avoid suffering, worsened conditions, and service denials in urgent care. They viewed this as "a human right, which should, in turn, trigger accountability and redress mechanisms" (FG-1). Colombian nationals, who are entitled to comprehensive health services, were mostly concerned with the "real opportunity to have access to affordable *essential drugs*, which are often unavailable for free or at a subsidized price" (FG-3, emphasis added).

Institutional actors and community-based organizations working in the visited territories agreed that *immunization programs* have been "widely accessible in public hospitals and mobile units, at least since 2019" (I-5, I-18). Further, "six months after COVID-19 vaccines were available to insured populations, they were extended to irregular migrants … to mitigate public health risks" (I-14).

Community strategies and health education. Strongly related to primary and territorial care are community health interventions, which "target all communities without distinctions" (I-14) but which "are chronically affected by funding shortages" (I-17).[36] According to PHC, such interventions include the involvement of CHWs. Informants highlighted CHWs' contributions, including to "promote public vaccinations for children and against COVID-19" (FG-2); "close information gaps about healthy behaviors and procedures to access services" (I-10); and "facilitate psychosocial interventions" (I-9).

Feedback on the activities and potential of CHWs highlighted their crucial position as receivers and providers of both health and human rights education. As for *health education* (an essential component of PHC and a core obligation), institutional participants admitted that they "lack targeted efforts for migrants, relying instead on development actors as information and workshops providers" (I-14, I-5). To address these shortcomings, NGOs and development organizations provide migrant and host CHWs with "training on disease prevention and health promotion, as well as on framing these as human rights issues" (FG-2). The latter includes training on "legal and practical protection mechanisms, which are vital for empowering [marginalized] communities and social justice" (FG-1). Such trainings also promise to strengthen the quality of *social participation* of these communities; however, participants in the focus groups admitted that "we have been invited to speak to public authorities only when the national health plan was underway; otherwise, we do not participate directly in policymaking" (FG-1, similarly FG-2).[37]

Children and maternal care. Study participants valued the PHC focus on maternal and child health and noted that "international funding dynamics prioritize these groups" (I-11) and that "the number of pregnant women and mothers traveling alone with young children [had] increased in recent waves of migration" (I-8). Many interviewees, especially in focus groups, expressed outrage over the limited antenatal and child care available to irregular (and thus uninsured) migrants outside humanitarian programs. Beyond childbirth, emergency care, and abortion services, hospitals offer little to migrants without legal status. As one social leader exclaimed, "Migrant children without regular status can only access urgent care, just like adults. I think this is completely inhumane and discriminatory" (FG-3).

Social determinants of health. Many interviewees raised compelling points about the impact of dire living and working conditions, as well as their underlying factors (e.g., legal status, poverty, and gender), on the health of vulnerable migrant communities. These concerns included reports of normalized trafficking, sexual exploitation, sex for the survival of women and girls (especially in border towns) (I-10), and dangerous housing and labor conditions (I-1, FG1). Regarding the latter, for instance, on several occasions, interviewees discussed these circumstances in terms of human rights; as one stated, "There is no right to health without *basic needs* and *decent employment*. Migrants in the informal job market earn between 10,000 pesos [US$2.5] and 30,000 pesos [US$8] per day. If they attend a medical visit, they risk not being paid or losing their job, so many, especially men, avoid checking their health conditions until they're severe" (I-12).

Regarding the *essential* components of PHC (and core obligations), migrants may access food, water, nutrient supplements, and emergency accommodation at humanitarian centers along major migration routes.[38] However, this assistance is often provided on a "once-off basis" (I-10), with "projects … not ensuring continuity of provision" (I-16), making it more of a charity than a right. Particularly concerning for participants was the right to access to water in shanty towns (I-10, I-4) and the management of malnutrition in children in irregular situations, which is limited to treating their acute malnutrition, giving rise to a "periodic revolving-door phenomenon" (I-12). All migrant children, for focus groups participants, should have access to the "comprehensive program against malnutrition of the Family Welfare Institute," which is currently an entitlement only for nationals and regular migrants (FG-1).

Perceived constraints of a PHC-anchored migrant right to health

Finally, some participants raised doubts about whether a stronger focus on PHC is desirable for fulfilling migrants' right to health (Table 3). These perceived constraints can be categorized as either "invisibilization risks" (where *selective* PHC approaches may overlook vulnerable individuals and certain essential services) or "business as usual" (suggesting that even a PHC-anchored migrant right to health may not help overcome the broader political, social, and economic factors underlying the operationalization of human rights).

Discussion

This section discusses the case study in relation to domestic and international human rights norms and commentaries. Since the law in Colombia restricts entitlements to health care for migrants without regular status, it must also be part of the solution. The goal is to evaluate whether integrating PHC into a rights-and-obligations framework represents an equitable and practical step toward better realizing migrants' right to health and advancing universal health coverage.

From iterations of the right to health to compliance with international law

Most study participants viewed the right to physical and mental health as protecting "health and well-being" and requiring state obligations for prevention, treatment, and health promotion, aligning with international declarations on PHC and obligations reflected in constitutional and statutory law.[39] However, this sharply contrasts with the reality for migrants who are poor and have precarious legal status, as these factors prevent them from enrolling with a health insurer. In Colombia, *national law* restricts irregular migrants to accessing only *urgent* care, which participants identify as the primary barrier to their right to health: the legal framework ends up protecting their right to life in health care rather than the right to health.[40] Given the prominent role of international human rights treaties in Colombian law, and the resonance of international jurisprudence with judges, placing greater emphasis on PHC components as embedded in core obligations could help legal advocates foster the development of more protective normative standards for all.[41]

Diverse opinions emerged regarding the *nature of obligations* tied to migrant health rights. The progressive realization of socioeconomic rights was often misinterpreted to justify delays in fulfilling irregular migrants' health rights. Denying services based solely on irregular legal status, while other groups are entitled to them, is prima facie discriminatory under human rights law. Nondiscrimination is not subject to progressive realization and imposes an immediate duty to include migrants in health policies and ensure access to existing services, unless reasonable, objective, and proportionate justifications are provided to limit rights beyond their core content.[42] Distressed migrants in Latin America, including in Colombia, face multiple vulnerabilities to rights abuses.[43] Instead of imposing unjustified restrictions, human rights law compels states to devise special measures to promote this population's substantive equality.[44] Relatedly, this paper argues that essential PHC services and interventions, being highly valued and part of core obligations, should be considered special measures of priority realization, invalidating

TABLE 3. Perceived approach constraints

Risks of "invisibilization"	Business as usual
Vulnerable people who are not pregnant women or children "International agencies and NGOs focus mainly on migrant children and pregnant women, but this is insufficient" (I-20). "Selective PHC centered on children and maternal care risks overlooking the health needs and rights of other vulnerable groups" (I-2).	Political will "You can present technical, ethical, and human rights arguments, but if the government says no, change is hard. There was political will for the 2021 Venezuelan regularization scheme, and they still collaborate with humanitarian actors, but we don't see political space to extend state-subsidized care beyond emergencies or creating special routes" (I-17)
Inadequate access to urgent care "You speak of PHC, but we often need judicial orders to access our entitlement to urgent care, even for migrant children" (FG-1). "You need to insist, and we frequently ask the ombudsperson to intervene" (FG-2); "quality is also an issue; many are dismissed with just a blood test and acetaminophen" (FG-3).	Costs "Health care for migrants is costly, which is why the government doesn't cover it comprehensively or gradually extend services" (I-6). "We regularly transfer hundreds of millions of pesos to regional authorities for urgent care, which is already a big effort" (I-14).
Social determinants of health "PHC's essential components cover basics like water and nutrition, but we need more, migrants need more. The social determinants and the right to health go beyond that" (I-1). "It is hard to envision migrants' right to favorable health determinants in a middle-income country like Colombia, where 50% of the population is socioeconomically vulnerable or poor" (I-17).	Structural problems of the health system "Structural issues block measures for migrants: the system has improved but remains fragmented, privatized, underfunded, urban-centered and the national level lacks strong regulatory powers" (I-1). "Even if reforms extended migrants' entitlements, major barriers like high out-of-pocket costs, xenophobia, and discrimination from health care and security staff would still exist" (I-19).

any state justification excluding irregular migrants from their provision. Understanding these legal concepts is crucial for courts, nonstate actors, and humanitarian organizations to strengthen rights-based approaches and the capacity of duty bearers. Additionally, it is important for communities to understand international duties as tools for mobilization, empowerment, and contestation that allow them to advocate for social change in the treatment of marginalized individuals.[45]

Against severely constrained legal rights, numerous humanitarian actors, NGOs, and grassroots organizations in Colombia run programs targeting essential PHC components, focusing on the protection and promotion of the physical, mental, and social health and well-being of migrants (and other vulnerable communities).[46] This strategy is prima facie compatible with human rights law: article 2 of the International Covenant on Economic, Social and Cultural Rights demands that states adopt a broad array of measures "individually and through international assistance and co-operation," and partnerships for the right to health are deemed essential.[47] However, this case study reveals that program-based interventions for migrants often fall short of human rights standards. Common issues include the lack of geographic availability and continuity of services, neglect of accountability, and the unintended consequence of absolving the state of its obligations, effectively legitimizing the reduction of *public* safety nets for the most vulnerable.[48] It is particular concerning, as noted by an international organization employee, that "after years of complementary services, the Colombian government takes what we [humanitarian actors and NGOs] do for granted and is unwilling to extend health rights to irregular migrants beyond emergency care" (I-11). Even well-intentioned actors implementing rights-based approaches inevitably face trade-offs: "[They] operate like private entities; if funding dries up, the program ends, and the 'user' cannot expect their rights to be realized" (I-10).[49] This highlights the importance of *legally recognizing* essential PHC services and interventions for migrants as minimum standards to fulfill their right to health, which is vital for *institutionalization* and *accountability*.[50]

PHC components: From value to obligations

The results section flags how the components of PHC are widely valued across sectors for reducing health inequity, especially for irregular migrants. These components align with core obligations and state priorities for realizing the right to health.

The centrality of *primary care* for interviewees clashes against the fact that this level of care is accessible only via status regularization and enrollment with an insurer in Colombia. As the core service component of PHC, "it would be difficult not to consider it as key means for realizing a right to health for all" (I-16).[51] Studies estimate that primary care is adequate for 75% to 80% of cases when medical help is needed, and the United Nations Committee on Economic, Social and Cultural Rights specifies that such care, as well as immunization against priority diseases, must be accessible to all regardless of legal status.[52] Constitutional case law includes immunization programs for migrants within the right to *urgent* health care (to protect public health), with field feedback and gray literature describing these programs as a "success story in practice" (I-9) and an area where "institutions showed notable commitment and resource allocation" (I-8).[53] The same cannot be said regarding access to *essential* drugs (as defined by the World Health Organization), a core obligation of the right to health and an essential component of PHC, which are available to irregular migrants only if they are hospitalized for emergency services.[54]

Participants revealed the critical role of CHWs in "bridging the gaps" between health systems and marginalized communities.[55] As part of PHC and the right to health frameworks, *community strategies* help facilitate nondiscriminatory access to services and contribute to *disease prevention and control*—core state obligations.[56] Colombia has a long history with CHWs, dating back to rural pilot projects in the late 1950s.[57] Recently, development actors have been training CHWs to support migrant communities, fostering empowerment by equipping them to advocate with communities for health rights and to participate in policymaking.[58] However, *social participation* remains an unfulfilled promise for migrants, as CHW engagement with health authorities is often mediated by humanitarian actors. State obligations for migrant health should include proper CHW training, funding, and integration into the health system, as recommended by World Health Organization guidelines.[59] A recent draft decree by Colombia's Ministry of Health proposes integrating CHWs as auxiliary staff but omits specific reference to (programs for) migrants.[60]

Participants unsurprisingly emphasized the importance of PHC components related to *maternal and child care* for migrants, highlighting these as the declared priorities of many development and humanitarian actors with whom they collaborate. State duties in these areas are reinforced by international human rights law and constitutional rulings, which highlight gender equality and the best interests of the child as taking precedence over migration policies.[61] Although Colombia's Constitutional Court has ruled in favor of providing *necessary* health services to uninsured children and perinatal care, access often comes only through litigation (I-6).[62] A legal expert noted that "progressive constitutional case law on individual writs would not be enough to influence policy as they normally have limited general validity" (I-2). A physician further pointed out practical challenges, explaining that while the Constitutional Court may mandate antenatal and children's services as urgent care, such services are not typically provided in urgent care departments: "ambulatory services like prenatal check-ups and pediatric care require migrant status regularization and enrollment with insurers under current normative and operational frameworks" (I-20).

If the "minimum floor" of health rights and obligations for irregular migrants were not framed as urgent care but around PHC components and core obligations, comprehensive care for migrant children and pregnant persons would be part of the standard package. Without implying equivalence between entitlement and access, legal recognition would arguably be the starting point to create "special service routes for irregular migrants" (I-10), as recently seen with abortion services, which eliminated the requirement of regular migration status.[63]

Finally, on numerous instances, *working and living conditions* were highlighted as key factors to fulfill the right to health of migrants. Clear data patterns were elusive except for the fact that targeted services for irregular migrants rely largely on humanitarian and development actors. However, international human rights law (incorporated into the Constitution) through core obligations embedding PHC elements could become the means for extending rights to basic nutrition, food, shelter, water, and sanitation for all.[64] While this minimal approach does not fully account for broader social and structural determinants of health, it offers a legal foundation for human rights advocates to pursue iterative advocacy and strategic litigation for ensuring that basic needs are addressed for all vulnerable groups, including irregular migrants.[65]

From constraints to legal literacy

While I am not suggesting that law should dominate discussions on social justice for migrants, I believe that expanding *legal literacy*—that is, as conceptualized by Murphy and Angeleri, fostering curiosity about both the potential and the limitations of human rights law as enacted by various intermediaries—is essential.[66] This approach could help address constraints, such as those identified in the fieldwork, that currently limit the contribution of PHC to reduce migrant inequity. The "risks of invisibilizing" certain *population groups* (with selective PHC focused primarily on child and maternal health) can be mitigated by adopting a human rights perspective, which mandates special legal protections and practical measures for *all* vulnerable people and groups facing discrimination.[67] For instance, addressing the concerns of several study participants, human rights-compliant PHC-based reforms and programs should ensure comprehensive sexual and reproductive care for all, including LGBTIQ+ migrants, and provide tailored support for transnational Indigenous populations and people with disabilities, regardless of legal status.[68] Furthermore, a PHC-based right to health does not focus solely on primary and preventive care but also promotes "strong linkages with timely acute care and effective referral systems at all levels."[69] Nonetheless, this *service integration* dimension appears less apparent in how participants understood PHC as a framework for realizing migrant health rights. Access to urgent care should continue to be fought for in courts and through other accountability mechanisms when legal and practical barriers hinder it: PHC does not conflict with it, nor does domestic law or international human rights law.[70] *Continued* access to secondary care may present more challenges if equalized standards are not embraced, but in Colombia, some services—such as treatment for sexually transmitted infections and cancer—are already recognized as judge-made entitlements for uninsured migrants as "urgent" care.[71] This highlights both the strengths and limitations of the proposed approach: a PHC-anchored migrant right to health—with priority services and interventions constituting legal entitlements to meet core obligations—provides a meaningful "minimum floor" for health protection while working toward full coverage and universal human rights protections for migrants.

Given the challenges of costs, structural issues, and political will, this paper seeks to leverage human rights law (embedding PHC standards) to counter government resistance by proposing a *temporary* subset of cost-effective universal services and interventions for irregular migrants. Furthermore, legal literacy can attenuate "business as usual" concerns, urging diverse stakeholders working in migrant health response to understand how human rights law might help navigate the *resource scarcity argument* in realizing socioeconomic rights. While this argument may justify a slow progression in overall right to health implementation, it cannot excuse the failure to meet core obligations—embedding PHC components—or support maintaining discriminatory rules.[72] On this note, compelling feedback from the fieldwork included that "a rights-based approach to health and migration should require the government to estimate funds necessary to provide a basic to comprehensive PHC-based package to all migrants, including the undocumented, to protect their rights beyond survival" (I-16). If a differentiated approach based on migration status persists, there must be reasonable, objective, proportionate justifications, along with a plan to address discrimination through stable and partnered rights-based solutions.[73]

Conclusion

International norms have yet to clearly and consistently define the right to health as it applies to non-citizens or non-residents. Colombia's Constitution and Constitutional Court, though, have established robust standards for this right for irregular migrants (even if not fully equal to those for citizens); however, law is not consistently applied in practice. This qualitative study employed PHC to expose gaps in migrant health protections and envision a more robust minimum framework for outlining state duties to fulfill the right to health. Triangulating empirical data and the literature revealed that anchoring the migrant right to health to the essential components of PHC would clarify state obligations to provide preventive care, health and human rights education, essential medicines, sexual and reproductive services, and comprehensive child health care to all migrants. Focusing on these elements, particularly primary care, would aid in detecting, treating and controlling common communicable and noncommunicable diseases, including mental health conditions. This foundational level of care requires legal, budgetary, and operational measures to ensure its effectiveness, including the promotion and funding of CHWs, mobile health units, and psychosocial interventions.

Participants indicated that the fulfillment of migrants' rights to the social determinants of health was more complex, although the imperative to commit to collaborative and partnered solutions remained evident, especially with regard to adequate nutrition, safe water, and shelter, which constitute core obligations. As data revealed that humanitarian and development actors play a key role in health and social service provision for irregular migrants in Colombia, the analysis demonstrated that these actors should at least facilitate rather than obstruct the participation of rights holders in health-related decisions and the accountability of duty bearers regarding human rights obligations concerning migrant health. Finally, there was a strong consensus that this "minimum floor" (PHC *essential components*) should not serve as a "protection ceiling."[74] Addressing deficiencies of urgent care and progressing toward more comprehensive PHC *overall dimensions* (see Figure 1) aimed at universal health coverage and promoting nondiscriminatory social determinants of health for everyone is deemed essential for legal, moral, and public health reasons.

The findings of this study cannot be fully generalized due to its specific focus, yet the analysis, grounded in international standards, could inspire human rights-centered reflection and actions in other contexts. Overall, this is a call for migrant grassroots advocates to mobilize human rights arguments and reclaim their role in health policymaking; for development actors to genuinely adopt a human rights-based approach; for policymakers to ensure that PHC models include all marginalized communities; for legal advocates to explore meta-legal standards and go beyond individual litigation; and for international human rights bodies to clarify state obligations on migrant health, potentially using PHC dimensions and components (as agreed-on means to reduce health inequity) as benchmarks for progressing toward universal and equal rights.

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Annex: List of interviews and focus groups

Citation	Description	Date
I-1	Interview with two development professionals at a UN agency's national office in Bogotá	May 2022
I-2	Interview with a physician and a lawyer at a community-based organization in Bogotá	June 2022
I-3	Interview with a physician and a project manager of a national NGO	June 2022
I-4	Interview with two health professionals at a UN agency's national office in Bogotá	June 2022
I-5	Interview with a high-level agent of a regional health unit in Cúcuta, Norte de Santander	June 2022
I-6	Interview with a former high-level agent of a regional health unit in Cúcuta, Norte de Santander	June 2022
I-7	Interview with a high-level agent of the Ombudsman's Office of Colombia	June 2022
I-8	Interview with the head of a religious national NGO	June 2022
I-9	Interview with an agent of an international NGO	June 2022
I-10	Interview with an agent of an NGO in Norte de Santander	Aug. 2022
I-11	Interview with an agent of a health-focused NGO in Norte de Santander	Aug. 2022
I-12	Interview with the head of a community-based organization in Cundinamarca	Sept. 2022
I-13	Interview with the head physician of a diaspora organization in Cundinamarca	Sept. 2022
I-14	Interview with two agents of the national health authority	Oct. 2022
I-15	Interview with a project manager of a humanitarian agency	Sept. 2022
I-16	Interview with an agent of an international NGO	Oct. 2022
I-17	Interview with a health professional at a UN agency operating in Cundinamarca	Oct. 2022
I-18	Interview with two agents of the health agency of Bogotá	Nov. 2022
I-19	Interview with a health professional at an international NGO	Nov. 2022
I-20	Interview with two nurses of a health center in Bogotá	Dec. 2022
FG-1	Focus group with CHWs in Soacha (12 people)	June 2022
FG-2	Focus group with CHWs in Bogotá (10 people)	July 2022
FG-3	Focus group with CHWs in Cúcuta (6 people)	Aug. 2022
FG-4	Focus group with CHWs in Villa del Rosario (8 people)	Aug. 2022

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Ethical approval

The Research Ethics Committees at Queen's University Belfast and at Universidad del Rosario approved data collection and use strategies on February 11 and 17, 2022, respectively.

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Protecting Distress Migrants' Right to Health in Ecuador: Are Legal Commitments Being Fulfilled?

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Abstract

Ecuador's legal framework promises equitable access to health care for all. However, gaps in coverage are being exacerbated by the nearly 500,000 Venezuelan distress migrants remaining in the country over the past decade. The purpose of our study was to examine how the Ecuadorian health system responds to the needs of migrant populations arriving in poor health conditions. We conducted 28 key informant interviews with government officials, health care providers, and representatives of international cooperation agencies and migrant organizations, and analyzed documents from a related Constitutional Court sentence. We find that despite Ecuador's commitments, significant gaps exist in the implementation of protection mechanisms for distress migrants. Systemic obstacles, such as documentation requirements and exclusion from benefits granted by law, remain. Discriminatory practices and concerns about the allocation of limited resources can further impede access. The Constitutional Court case underscores how the judicialization of health may prompt the government to address distress migrants' right to health and document its progress. Ultimately, more comprehensive approaches are needed to promote a more equitable health system that addresses the specific experiences and needs of distress migrants in Ecuador.

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Introduction

The protracted crisis of the past decade in Venezuela has led to the displacement of millions of people, forcing them to migrate to other countries in the region.[1] By the end of 2023, approximately 7.7 million distress migrants from Venezuela had sought refuge across the Americas.[2] Ecuador, in relative proximity to Venezuela, has felt the impact of this migration surge; an estimated 500,000 Venezuelan migrants—a majority of whom are in an irregular situation—have remained in the country. In addition to instances of discrimination and xenophobia, the lack of a legal status exposes them to various challenges (e.g., preventing them from reporting potential human rights violations).[3] The 2022 census did not register all foreign-born populations in Ecuador, capturing only 231,686 Venezuelans, 97,832 Colombians, 10,768 Cubans, 14,837 Peruvians, and 14,424 US citizens among the largest migrant groups residing in the country.[4] Similarly to Venezuelans, the number of Colombian nationals is estimated to be much higher than census figures; such under-registration of migrants hinders the planning and allocation of resources.

Following Jacqueline Bhabha, we use the term "distress migrants" to characterize migration that "stems from desperation, vulnerability, and need, from living circumstances that are experienced as unbearable or deeply unsatisfactory and that precipitate serious obstacles to a reasonable or tolerable life."[5] Like Bhabha, we understand distress migration to encompass refugee, survival, and forced migrants, together with "people who have no choice but to leave home, but who do not fall into those categories."[6]

In 2021, approximately 19 million Venezuelans worldwide lacked adequate access to health care, including 10 million who were living with chronic conditions.[7] After arriving in host countries, distress migrants face increased vulnerability to developing new illnesses or exacerbating preexisting health issues. In addition, their migration journey, marked by instability, discrimination, and xenophobia, and lack of knowledge about other countries' health and social service systems, can further compromise their health.[8] According to the Interagency Coordination Platform for Refugees and Migrants from Venezuela, there are significant challenges for Venezuelan migrants and refugees in accessing health care in the Latin American region.[9] In Ecuador, approximately 67% of all migrants lack regular migration status; 84% work in sectors that do not match their skills, experience, or qualifications; and 73% of Venezuelan migrant households report an average monthly per capita income of only US$86.[10] Also for this country, 27% of Venezuelan refugee and migrant respondents cite access to health services as their main need, while only 24% can afford health services.[11]

Ecuador has made efforts to uphold the rights of migrants in accordance with international and regional agreements, primarily through its legal framework, including the 2008 Constitution and the 2017 Organic Mobility Law.[12] For instance, Ecuador was the first Latin American country to incorporate the expanded refugee definition of the 1984 Cartagena Declaration into its national legislation.[13] Asylum seekers have 90 days to file a petition for refugee status once they arrive in the country. Moreover, Ecuador's Constitution guarantees access to care to all individuals regardless of immigration status.[14] Despite such protections, the reality on the ground is somewhat mixed. Recent research has found gaps in the implementation of the country's legal framework (from the national to the local levels) guaranteeing access to care for migrant populations.[15] Some patients have resorted to judicializing access to health care, including a Colombian refugee family in Ecuador (Constitutional Court case no. 983-18-JP/21, hereafter referred to as the *Ramirez* case).[16] According to the Ecuadorian Constitution, the right to health must be guaranteed by the state, and its realization is linked to the exercise of other rights, including the rights to water, food, education, physical culture, work, social security, a healthy environment, and others that support "good living" (*buen vivir* in Spanish) (art. 32).[17] Similarly, the Constitution mandates the health system with protecting and restoring people's capabilities for a healthy and integral life—both individually and collectively—and recognizing social and cultural diversity, in line with the principles of inclusion, social equity, sufficiency, and interculturality (art. 358). The Constitution also states that the health system must ensure promotion, prevention, recovery, and rehabilitation at all levels (art. 359). However, there is evidence that the Ecuadorian government has systematically excluded civil society from decision-making processes, including in the health sector.[18]

Ecuador's health care system operates on constitutional principles that emphasize health as a fundamental human right.[19] Because less than 40% of the population is privately or publicly insured, approximately 60% of the population (including most migrants) depends on the Ministry of Health (MoH) network for free health services. However, the country has been experiencing a financial crisis since at least 2015, which has left the public system without the resources to provide needed services. As a result, out-of-pocket spending accounts for more than 32% of total health spending in Ecuador.[20] In addition, the public system prioritizes tertiary care, weakening the primary care network (whose gaps are expected to be filled by health personnel during their mandatory service year, particularly in rural and marginalized urban areas).[21]

Using a right to health approach (i.e., one seeking the highest attainable standard of health for all peoples), the purpose of our study was to examine how the Ecuadorian health system responds to the needs of distress migrants. To this end, we conducted interviews with government officials, health providers, and representatives of migrant, intergovernmental, and nongovernmental organizations and international cooperation agencies. Concurrently, we analyzed the *Ramirez* case, which prompted the MoH to make changes toward guaranteeing access to health care for all migrants in practice.

Methods

Analytical framework

The overarching framework of this study's parent project in the Andean region used a migrants' right to health framework, which guided the development of key informant questionnaires and the review of existing literature.[22] The right to health is a fundamental human right to "the enjoyment of the highest attainable standard of physical and mental health."[23] This includes respecting the principles of equality and nondiscrimination, which are essential to migrants' right to health. When access to health care is determined by legal status or when migrants are discriminated against in policy and practice, the right to health of migrants may not be realized.[24] Distress migrants often lack regular legal status, which puts them at greater risk of losing access to essential social determinants of health, thereby jeopardizing their right to health protection.[25]

For the present study, we used the Boli Peng and Li Ling framework to examine health services used by migrants.[26] This framework classifies migrants' determinants of health service utilization into three levels: (1) macro-structural or contextual factors, (2) characteristics of the health delivery system, and (3) characteristics of the population at risk. In our results section, we start from the micro (characteristics of the population at risk) and move to the macro (structural and contextual factors) to describe our findings.[27] Using a right to health lens, we analyzed the data at the three levels of the Peng and Ling framework.

Analytical sample

This study is part of a larger research project that examines the health of migrants in four Andean countries (Chile, Peru, Ecuador, and Colombia). Using interviews with key informants and documents from Ecuador's Constitutional Court, this study focuses on the right to health of distress migrants. The data collection process included 28 interviews with high- and mid-level decision makers from the national government and city governments and public sector medical practitioners from Tulcán and Lago Agrio (near the border with Colombia) and Huaquillas (near the border with Peru), as well as leaders of migrant groups and representatives of intergovernmental organizations, international cooperation agencies, and NGOs. The research team conducted a systematic mapping of informants by country borders, decision level and role, knowledge of social service networks in border regions, and experience representing migrants through civil society associations. In addition, our study examined the *Ramirez* case and five associated documents describing the response of the MoH and other public institutions. The *Ramirez* case mandated the MoH to improve health services for all migrants.[28]

Content analysis. A thematic analysis, following Virginia Braun and Victoria Clarke's approach, was conducted using texts from transcribed interviews and documents related to the *Ramirez* case.[29] We systematically explored the content with specific key terms in Spanish, such as health, human rights, access to care, and health care provision. We also used terms consistent with the Constitution's emphasis on priority populations: child, boy, girl, adolescent, and family. Text segments containing the specified terms were extracted and assigned to thematic categories based on patterns identified using the analytical framework. The primary concepts were identified by recognizing recurring responses from the informants. Finally, informants' statements that encapsulated the dominant concept were highlighted.

Results

Characteristics of the population at risk

The informants agreed that the Venezuelan migrant population arrives in Ecuador in very poor health conditions due to the low level of health care in their country of origin and, subsequently, to the hardships of the extended migration journey under difficult conditions (including weather extremes and limited food and fresh water). They also highlighted that Venezuelan family members, from grandparents to young children, commonly migrate together. In their opinion, the hardships endured in their country of origin and during the journey, as well as mobilizing with women, children, adolescents, and senior citizens, increase the likelihood of being exposed to sexual and gender-based violence. In addition, respondents mentioned that most migrants are pregnant women, malnourished children, older adults with noncommunicable diseases without treatment, young people with psychoactive substance use disorders, and people with mental health issues.

> *The last waves of Venezuelans are people whose rights have been tremendously violated. They are very deprived in every way.* (civil society representative 1)

Another issue related to access to health care is the precarious economic situation of distress migrants. Although the right to health is guaranteed on paper in Ecuador, limitations in resources implicate high out-of-pocket spending (32.6% of all health expenditures), while most migrants cannot afford the cost of medicines, blood tests, specialized medicine, or even transportation to a health facility.[30] Finally, interviewees highlighted challenges in health care, such as migrants experiencing discrimination and a lack of sensitivity on the part of health care providers to recognize and respond to the specific needs and experiences of migrants.

> *You can train health workers, but if they do not have the sensitivity to put themselves in the other person's shoes and effectively recognize that this person … is a human being beyond* [their] *migratory status.* (international cooperation representative 2)

In the *Ramirez* case, a baby died 12 hours after birth due to a failure to transfer the patient to a higher level of care in the Ecuadorian health system. Following their request for a *tutela* (a constitutional injunction), the Constitutional Court ordered the MoH to issue a public apology, provide economic compensation to the family, and take steps to improve the delivery of care for migrant populations.

Characteristics of the health delivery system

Key informants, such as NGO workers and migrant leaders, agreed that primary care is a guaranteed right and should be free of charge. However, medical resources such as gloves, catheters, laboratory reagents, and drugs may become scarce in MoH facilities, meaning that many patients need to buy them themselves. Furthermore, there are limitations in access to specialized care, such as from a gynecologist or pediatrician; the public sector does not have enough specialists to meet the demands of services from either the local or migrant population. These constraints have an impact on the quality of health services and are an obstacle to the right to health. NGO representatives mentioned that while emergency care may be guaranteed for migrants, there are times when health care workers discriminate against migrants based on their physical appearance or because migrants do not follow the "regular way" of making appointments. In other cases, health care workers do not provide services for the treatment of noncommunicable diseases because they do not trust migrants' declarations about their medical diagnoses and previously prescribed treatments. Finally, other services such as sexually transmitted disease screening programs, treatment for tuberculosis, and mental health consultations may not be provided because facilities do not have such capacity.

> *To get care, you have to make an appointment, unless it is an emergency. So, for example, we see that in many of the populations, especially those that are border crossers, migrants cannot schedule care because they are passing through [in transit]. So they need that care as soon as possible, and that has created a bit of a problem.* (intergovernmental organization representative 2)

Several interviewees mentioned that in some cases migrants find it difficult to access outpatient care because they are requested to provide an identification document even though there is no legal obligation to do so. Still, migrant leaders mention that they appreciate the health care services they receive because other countries in the region have more restrictions (eroding their right to health).

> *There is a lack of strength and resources. It is not that they do not want to take care of us, it is just that, for example, the hospitals do not have all the supplies and medicines that the specialists need to take care of our needs.* (civil society representative 5)

In response to the *Ramirez* case, the MoH was required to provide evidence of its ongoing progress toward disseminating the ruling among the health center staff in the areas responsible for providing urgent and emergency care to minors and pregnant women, and to issue a protocol for the health care of pregnant women and newborns within 120 days. In January 2022, the MoH reported that it had provided training in maternal and newborn care to 26,657 health professionals (nurses, general practitioners, and specialists). However, according to MoH data, the issue may lie not in the lack of training but in the short-staffed health facilities. In Ecuador, there are 1.35 obstetricians per 10,000 inhabitants and an estimated 23.44 physicians per 10,000 inhabitants.[31] This is a lower rate than in countries such as the United States (36.08), although similar to others in the region such as Brazil (21.42) and Colombia (24.51).[32]

MoH officials interviewed said that since 2018, the number of migrants has been growing at a faster rate, straining existing capacity, but that the government is working on improvements through increased cooperation between health institutions and NGOs, strengthening telemedicine, and opening specific health facilities at the border.

> *We want to strengthen telemedicine in Ecuador to avoid the barriers that sometimes exist in health facilities and to provide this option and avoid xenophobia.* (national government representative 1)

Migrant group leaders and NGO representatives mentioned that discrimination is a barrier to access, as locals' perception is that migrants take up their limited resources. Migrant leaders also report migrants experiencing rude behavior from doctors and nurses.

> *There is a perception among the local population that migrants take away their care and resources. But this is a general problem in Ecuador, which does not guarantee access to health care.* (civil society representative 3)

Discriminatory behavior was similarly addressed in the *Ramirez* case. As a result, the MoH developed a "Training Plan for Health Personnel of the MoH in Border Provinces" to build knowledge, skills, and behaviors contributing to a comprehensive health care based on theoretical and practical tools linked to the study of human rights and the human mobility approach, with a target population of 9,780 health workers.[33]

Another barrier mentioned by informants is the difficulty in scheduling medical appointments, since this requires having a phone with prepaid airtime, internet capabilities and connection, or traveling to a different city to make an appointment in person—all options that most migrants cannot afford. In addition, communication about health services—especially information about the free availability of critical services such as vaccinations, prenatal checkups, and emergency care—is poor.

> *Currently, to get care, you must make an appointment, unless it is an emergency. So, for example, we see that in many of the populations, especially those who are crossing the border, people cannot schedule health care attention because they are crossing.* (intergovernmental organization representative 2)

Macro-structural and contextual factors

The Ecuadorian Constitution protects migrants, guaranteeing the right to equality and nondiscrimination (art. 11), the right to health (art. 32), the right to seek refuge (art. 41), the right to migrate (art. 40), and the right to humanitarian assistance (art. 42).[34] The relevance of constitutional protections was echoed in the interviews. Informants agreed that Ecuador has many laws that enshrine access to health care as a right for everyone in the country, regardless of nationality and migration status. Interviewees pointed to the Constitution, the Human Mobility Law, and programs and policies that acknowledge the importance of cultural-, mobility-, and gender-centered approaches when working with migrants.

National and local health authorities across the country agreed that the migrants should have the same rights as the local population, as guaranteed by the Constitution. Informants pointed out that, according to regulations, health services should be comprehensive (addressing issues such as health promotion, disease prevention, and sexual and reproductive health). However, some informants voiced the need for specific approaches to serve LGBTQIA+ people and pregnant women, and for specific recognition of the rights of children, adolescents, and older people among migrant populations.

> *We are trying to ensure that health, education, and other services are universal, regardless of whether you are Venezuelan, Colombian, or whatever, whether they have a valid identity document or not.* (local government representative 8)

Interviewees mentioned that in most cases, migrant populations are not aware that they can access health services for free, and thus there is a need for greater dissemination of information on the legal guarantees around accessing health care without restrictions within Ecuadorian borders. Distress migrants who may be familiar with the rules are often still afraid of being deported or imprisoned because of their irregular status, which prevents them from seeking care at public facilities. In addition, the primary care level may provide care without consideration for migration status or even the possession of an identity document; however, at the secondary and tertiary levels, the lack of any identity document or of a local identity document (which requires regular migration status) may become a barrier. For these reasons, informants noted that the active participation of the migrant community in health committees is essential to identify shortcomings and improve the public system. The regularization of migrants is seen as a method of expanding access to health care by facilitating the accurate identification of the health needs of this population, which can support better decision-making in the health care system.

> *Human mobility as a right should be worked on and policies should be changed because, although there is a Constitution that protects people in human mobility, the local policies are designed only for the local population.* (international NGO representative 2)

According to key informants, the right to health is similarly restricted due to the exclusion of migrants from policies such as disability certification, which is granted only to the local population, which has exclusive access to subsidies with it. At the same time, several interviewees pointed out that some Ecuadorians believe that international organizations' focus on migrant populations is discriminatory against the host population and that the government's shifting of resources to give health coverage to migrants affects the right to health of the host population.

> *We would like for there to be a regulation to make the cooperation agencies take care of our nationals, because there is also extreme poverty, malnutrition, and people have learned that somehow there is more attention to the foreign population, and this triggers the social problem of discrimination.* (local government representative 8)

The *Ramirez* decision recognized the violation of several fundamental rights of the family, such as the right to health, the right to life, the right to migrate, the right to humanitarian assistance, the right to refuge, the right to a family, and the principle of equality and nondiscrimination based on ethnicity, place of birth, age, sex, and gender identity. In addition, the court stated that the MoH must establish a protocol to ensure that a similar situation does not take place again and must issue a public apology for failing to respond to the needs of the baby.[35]

Discussion

Using a right to health approach, our study drew on interviews with key informants and an analysis of the *Ramirez* case to examine how the Ecuadorian health system responds to the needs of distress migrants. Our findings show that access to health care for distress migrants in Ecuador depends on a complex interplay of legal protections, delivery system challenges, and specific vulnerabilities. While the country's legal framework promises extensive protections of the right to health of migrants, including access to health care, the translation of these rights into effective practice remains uneven, signaling gaps in the availability, accessibility, and quality of health services for distress migrants. Interviewees highlighted several challenges, such as migrants experiencing discrimination and a lack of sensitivity of the health care system to recognize and respond to their specific needs and experiences. Challenges in health care delivery, such as limited resources and specialized care, exacerbate the difficulties faced by migrants, who often arrive in poor health. Moreover, interviewees mentioned that in some cases migrants are requested to provide an identification document even though there is no legal obligation to do so.

Similar to several other Latin American countries, universal access to public health care services is legally guaranteed in Ecuador, regardless of nationality. However, in many countries in the region, migrants face challenges in accessing care, as well as limits in the kinds of services they can access. For instance, migrants may not have the necessary information on how to access health services or the necessary resources to buy medicines or to travel to a health facility. In countries such as Colombia and Peru, these types of complaints from migrants have also been documented.[36]

In our findings, there was consistent testimony from interviewees that the health of Venezuelan distress migrants arriving to Ecuador is significantly compromised. This may be due to a combination of factors, including poor health care services in their country of origin and the harsh conditions of the migrant journey, resulting in neglected chronic diseases and an increase in infectious diseases.[37] Similar findings have been described in Mexico, where one of the difficulties in addressing the health of migrants is the poor health conditions in which they arrive.[38] Among the Venezuelan population in particular, an increase in infectious diseases such as measles, malaria, and HIV has been documented on the Colombian-Venezuelan and Brazilian-Venezuelan borders.[39]

It is important to note that care for irregular migrants in Ecuador is limited to the public health system, since the social security system does not cover migrants without documentation and stable employment. Health care for the uninsured, under the MoH's responsibility, has limited resources and must strike a balance between not neglecting the local population and providing care to Venezuelan migrants. The limited resources available in the public sector often result in patients paying out of pocket for services and medicines; further, a tertiary care focus erodes the capacity of primary care services to prevent disease and promote health. These conditions affect the most vulnerable Ecuadorian and migrant populations who cannot afford private services or secure medical appointments in the public system and who lack access to regular and quality preventive care services at free-of-cost facilities.[40]

Our study shows that discrimination and xenophobia are important barriers to accessing health services; this paper documents the discrimination against migrants in Ecuador, with health workers expressing negative views about migrants, while the local population is critical of the assistance provided by NGOs to migrant populations, which is not extended in the same way to them. Similarly, in countries such as Colombia, xenophobic attitudes toward low-income Venezuelans entering the country have been reported, and in Peru, higher levels of xenophobia toward Venezuelan migrant women have been documented.[41] It is worth mentioning that this phenomenon is not unique to health care. There are cases in which even government officials engage in discriminatory statements or practices. For example, in 2018, the Ecuadorian president made stigmatizing statements toward Venezuelans, blaming them for the increase in violence in the country and creating barriers for Venezuelans entering Ecuador, such as criminal record checks.[42] In April 2024, political disagreements between Ecuador and Venezuela escalated, leading to the closing of the Venezuelan embassy in Quito, further limiting consular support for Venezuelan migrants in the country.[43] All of these reinforce stigma against such migrants and in some ways may encourage discriminatory practices.

Furthermore, there is a need for comprehensive sexual and reproductive health care with a gender-sensitive approach that also recognizes the LGBTQIA+ population, as stressed by the interviewees. The continued lack of investment in and implementation of a gender-centered response can lead to the invisibility of distress migrant women's needs; sexual violence during migration and due to migrant status; and the exacerbation of the gender gap in the host population, as outlined in a recent International Organization for Migration and MoH report on sexual health and violence.[44]

Our research also evaluated the *Ramirez* case, in which Ecuador's Constitutional Court recognized the violation of several of the family's fundamental rights, such as the rights to life, health, equality, migration, and a family.[45] The Ramirez family had prior knowledge of the *tutela* mechanism in Colombia, where they had filed a *tutela* with the Unit for the Comprehensive Care and Reparation for Victims, a national entity under the Colombian executive branch. Leveraging this experience, the family found a way to defend their rights in Ecuador, which led to the first Constitutional Court sentence recognizing the right to health care for a migrant family in the country. This case marks a significant development in Ecuador, where the judiciary intervened in executive functions to ensure access to health care (similar to what is happening in Colombia, where fundamental rights such as health enshrined in the Constitution are enforced through the remedy of protection). The *Ramirez* case successfully applied existing legal frameworks and set a precedent that (as ordered by the court) applies to all migrant families.

This practice of filing a *tutela* to claim the right to health has been referred to in the literature as the "judicialization of health"—that is, the use of rights-based litigation to demand access to health care services.[46] While relatively rare in Ecuador, it is a more common phenomenon in other countries in the region, such as Colombia, Uruguay, Brazil, Argentina, and Costa Rica.[47] For instance, in Colombia, between January and September 2022, 109,825 *tutelas* related to the right to health were registered.[48] While *tutelas* can be an important instrument to protect the right to health, some argue their use can be counterproductive, running the risk of interfering with medical decisions, threatening the economic sustainability of the health system, and exacerbating inequities.[49] It has also been argued that the judicialization of health care can undermine efforts to expand coverage.[50] Others argue that litigation has helped fill "regulatory compliance gaps" and bring down the prices of services and medications.[51] To our knowledge, the *Ramirez* case is the first "migrant/refugee health" case to date that the Ecuadorian Constitutional Court has selected for review to establish binding case law. This precedent-setting decision is significant for legal advocates seeking to defend migrant health rights in *tutela* proceedings before lower courts. However, the aforementioned criticisms to judicialization remain relevant. Four other Constitutional Court cases have addressed the right to access essential medicines for the treatment of HIV/AIDS and Laron syndrome.[52] Given the universal scope of the right to health in Ecuador, these cases are relevant for identifying roadmaps for services that should be extended to both migrant and local populations.

Similarly, the Constitutional Court underscored the need for the MoH to report on health and human resources providing maternal and perinatal care. In 2022, the MoH reported that there were 26,657 health care workers in the public sector (including the social security system) providing maternal and perinatal health services.[53] However, this figure is equivalent to 52% of the medical and nursing staff in the public network, which in 2020 included 29,586 doctors and 21,905 nurses.[54] Therefore, there is a discrepancy between the report and the reality of MoH, pointing to the limitations in capacity to effectively provide access to free, essential health services. These gaps could lead to fatal outcomes, as evidenced in the case of the refugee family.

Several limitations of our study must be acknowledged. First, the key informants were selected from people who agreed to participate in the study and may have specific interests that we did not identify. Second, although the judicialization of health emerged as an issue in the interviews, our interview guide did not include questions on the topic that would allow us to draw conclusions about the informants' related perceptions and opinions. Third, our qualitative analysis is susceptible to researcher bias, as the interpretation and coding of data are influenced by our preconceptions and perspectives. Fourth, while we interviewed informants working in the health system, government, international cooperation agencies, and representatives of migrant associations, we did not interview distress migrants directly. Fifth, future research could benefit from utilizing other right to health frameworks, such as the "availability, accessibility, acceptability, and quality" framework (the AAAQ framework), to evaluate the fulfillment of distress migrants' right to health in Ecuador and elsewhere in the region.[55]

Conclusion

Distress migrants escape from structural inequality and vulnerability that impede people's ability to fully enjoy their right to health. Once they arrive in their host country, they are often excluded from obtaining refugee or other forms of legal status that could allow them access to health care (but even then, it is not guaranteed, as depicted by the *Ramirez* case). Access to quality health services by migrant populations in Ecuador is significantly limited because the health system is not prepared to meet the needs of migrants. These challenges are exacerbated by low incomes among distress migrants, as well as family migration. Even though the Constitution protects the right to health of both migrants and Ecuadorians, the former face additional obstacles in the ability to make appointments, use regular health services, and purchase medicines and medical supplies. Also, distress migrants commonly lack documentation that may be demanded by health providers to provide care, even when such documentation is not required by law, thus constituting discrimination. There is evidence of difficulties in service provision due to limited coverage by the public health care system and a lack of medicines and other supplies, which implies the need for patients to make out-of-pocket payments. Finally, local populations may see migrants as competition for aid from the government and other organizations, which prevents them from supporting actions to protect migrants' right to health.

The *Ramirez* case and the ensuing responses by public health officials highlight the potential (yet not fully realized) role of the judiciary in ensuring compliance toward protecting distress migrants' right to health. Concurrently, the judicialization of health access may not be able to address most challenges or to correct instances of discrimination. Overall, key informants agreed in their assessment of the health system and the needs of migrant populations. Among the challenges they identified are the resource limitations of the government to provide health care for the uninsured and discrimination against migrants. Nevertheless, there are potential pathways to health care access via social and nongovernmental organizations. Whether the public or the private health sector can provide adequate access, however, will depend on the promotion of a more inclusive and culturally sensitive approach to health care provision—one that acknowledges and responds to the specific experiences and needs of migrant populations.

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Ethics approval

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Translation

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

Consent for publication

All participants were adults (18 years of age or older); they participated anonymously and provided verbal consent after being informed in writing of the study's objectives, methods, and potential use. Documents related to Sentence 983-18-JP/21 of the Constitutional Court of Ecuador are publicly available at https://portal.corteconstitucional.gob.ec/FichaRelatoria.aspx?numdocumento=983-18-JP/21.

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VIEWPOINT

A Multi-Level Approach to Promoting the Health Rights of Immigrant Children in the United States

LARS LINDGREN AND KARLA FREDRICKS

Introduction

The Convention on the Rights of the Child (CRC) stresses the importance of children's right to the highest attainable standard of health. The CRC outlines the health rights to which all children are entitled, and it has been ratified by 196 countries—the United States being the only holdout—highlighting the global consensus on the importance of protecting child health rights. Likewise, other human rights sources, such as article 25 of the Universal Declaration of Human Rights and article 12 of the International Covenant on Economic, Social and Cultural Rights, emphasize the special importance of child health and development. Due to children's unique vulnerability and the disproportionate harm that they stand to face from the denial of a healthy upbringing, these documents make it clear that the obligation to protect these rights is indiscriminate and without regard for citizenship or immigration status.

While sweeping reforms that pursue health rights for marginalized groups, such as immigrant children, are well suited for national-level (federal) governments to implement, state- and local-level solutions are also practical and feasible ways to support a robust system of health services for all children when national policies or programs are insufficient. This viewpoint reviews initiatives in the United States across each level of governance to show how multi-level approaches can help fulfill the health rights of immigrant children, despite shortcomings at a national level.

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National-level approaches to addressing child health inequities

National governance plays a significant role in shaping health care accessibility for immigrant children within a country's borders. Some countries have national policies that ensure that all children, regardless of their immigration status, have access to health care. For example, Sweden introduced legislation in 2013 entitling undocumented migrants under the age of 18 to access the national health system, reflecting its commitment to upholding the health rights of immigrant children as equal to those of its own citizens. In contrast, countries such as the United Kingdom (despite having a national health care system) do not provide all immigrant children the same access to health care as their own citizens. The United States does not have a national health care system, nor does it ensure equal access to health care for all children.

It is possible that these inequities could be remedied through national lawmaking. For instance, in the United States, Congress could move federal policy in line with the 2023 statement from the American Academy of Pediatrics entitled "Medicaid and the Children's Health Insurance Program: Optimization to Promote Equity in Child and Young Adult Health," which calls for the universal eligibility of children for federally funded public health insurance coverage and improved and consistent access to high-quality pediatric care across state lines. Although some proposals (e.g., HEAL for Immigrant Families Act of 2023) have attempted to move toward this end, political divide in Congress makes advancing policies like these challenging. It is therefore important to alternatively consider how similar goals can be pursued at state and local levels, circumventing federal barriers.

Plugging gaps at the state level

In countries that do not adequately protect children's health rights at a national or federal level, action at the state or regional level can offer piecemeal remedies. For example, the United States' shared power between federal and state governments creates significant opportunities for states to plug gaps and implement recommendations from organizations like the American Academy of Pediatrics to enhance the health and well-being of all children within their borders.

States that have taken advantage of this flexibility can serve as models on how to expand health care access and improve child health. Although funded separately from states' federally endorsed Medicaid and Children's Health Insurance Program (CHIP) plans (which provide free or low-cost health coverage for children whose families cannot afford other health programs), many of these state-level health programs share equivalent eligibility requirements, benefits, and coverage for immigrant children who cannot access federally funded Medicaid (see Table 1).

States also have leeway to shape the benefits Medicaid provides. For example, section 1115 of the Social Security Act allows states to apply for waivers to federal Medicaid mandates and implement budget-neutral experimental demonstration projects. These waivers cannot be used to bypass citizenship requirements. However, they can augment the definition of what constitutes a medical emergency and therefore increase eligibility for emergency Medicaid coverage, fund uncompensated care pools to support safety-net hospitals that provide charity care for uninsured children, and establish support for health-related social needs, including housing, food, and transportation for low-resource communities.

A limited, but possibly more feasible, interim step for state expansion of immigrant health care access is available under section 214 of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), which allows states to waive the five-year waiting period for health care coverage for lawfully residing children. This option has resulted in 28 states or territories expanding immigrant children's access to CHIP and 39 states or territories expanding immigrant children's access to Medicaid. This can be especially important for child applicants for asylum or Special Immigrant Juvenile status, as both are considered to be lawfully residing. However, adopting section 214 of CHIPRA does not offer Medicaid or CHIP eligibility to all immigrant children—thus, while it can be a beneficial step, further reforms are still needed.

The role of local-level solutions

Local governmental and nongovernmental collaborations can create additional opportunities for children to receive health care services in the absence of, or supplementary to, state or federal programs. In the United States, organizations such as community health centers provide access to health services through sliding-scale discount programs for children and adults who are not able to obtain health insurance. Although service and coverage options at this level can be limited due to practical economic constraints and are vulnerable to political instability, they can still be effective. The Care for Kids program in Montgomery County, Maryland, and the Harris Health System financial assistance program in Harris County, Texas, are local initiatives that increase access to care in states that do not offer Medicaid or CHIP eligibility for all low-income children. Care for Kids uses county funds to provide low-cost or free health services at community and school-based providers to children who are not eligible for state or federal health insurance coverage options. Likewise, the Harris Health System uses a sliding-scale approach to mitigate the cost of care for low-income families.

Local solutions can also be tailored to the immediate health needs of the surrounding community. As one example, Colorado's Title V-funded program for children with special health care needs, known as HCP, is county based and administered through local public health departments to better connect families to community health organizations and other social services.

Conclusion

In the absence of equal access to national-level child health programs and services, state- and local-level programs can provide services to help achieve health equity. However, this should not distract from international human rights obligations on all governments to respect, protect, and fulfill children's right to health. Ultimately, a strong commitment at the federal level to uphold international

TABLE 1. US state-funded programs that expand public health insurance access to children regardless of immigration status

State	Name of expansion program (name of original program if it now includes expansion)	Age of eligibility	Family income threshold (% of federal poverty level)
California	Health4All Kids (Medi-Cal)	<19	266
Colorado	Cover All Coloradans/Health Benefits for Children and Pregnant Persons (Health First Colorado/CHP+) (comes into effect 1/1/2025)	<19	250
Connecticut	State HUSKY A/State HUSKY B for Children (HUSKY Health)	<16 (but available to age 18 if enrolled before age 16)	323
District of Columbia	Immigrant Children's Program	<21	200
Illinois	All Kids	<19	130*
Maine	MaineCare	<21	213
Massachusetts	Children's Medical Security Plan (MassHealth)	<19	Any income
New Jersey	NJ FamilyCare	<19	355
New York	Child Health Plus	<19	220*
Oregon	Cover All Kids (Oregon Health Plan)	<19	305
Rhode Island	Cover All Kids (RIte Care)	<19	261
Utah	State Children's Health Insurance Program	<19	200
Vermont	Immigrant Health Insurance Plan	<19	300
Washington	Apple Health for Kids	<19	215*

*Income threshold for free insurance; costs increase with higher income human rights agreements and implement inclusive health care policies remains crucial for further eliminating child health inequities and advancing public health goals within and across borders.

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Characteristics and Guardianship Status of Children Undergoing Forensic Medical and Psychological Evaluation for Asylum in Miami

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Abstract

To add to the limited evidence on forensic medical and psychological evaluations of children experiencing distress migration and seeking asylum in the United States, this paper describes the sociodemographic characteristics, nature of human rights violations, and guardianship status of the children served by the Human Rights Clinic of Miami from 2010 to 2021. Through a retrospective study of affidavits, we identified trends among sociodemographic characteristics and types of human rights violations and used bivariate analysis to determine factors associated with guardianship. Children constituted 17% of all evaluations conducted during this period. Approximately half were male, and two-thirds were aged 15–17 years. Honduras was the most common country of origin, and physical violence was the most reported human rights abuse, followed by gang violence. Most children reported being detained at the United States–Mexico border. Only a third had a guardian present during the evaluation, with guardianship significantly more likely for younger children. This study provides insight into the health needs of children affected by distress migration. It underscores how children's experiences of forced migration and the barriers they face in accessing essential safeguards illustrate critical gaps in protecting their right to health.

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Introduction

In 2023, there were 6.9 million asylum seekers—individuals seeking international protection from conflict or persecution—globally, including approximately 2 million children.[1] Particularly concerning from a human rights perspective is the sharp increase in the number of migrant children arriving in the United States. In 2022, over 300,000 children were apprehended at the United States–Mexico border, a five-fold increase since 2008.[2] The number of unaccompanied children—those most at risk of exploitation, violence, and neglect—also rose seventeen-fold between 2008 and 2019.[3] These children are often fleeing systemic violence, extreme poverty, and other conditions that constitute severe breaches of their human rights. These circumstances are characteristic of distress migration, or migration that "stems from desperation, vulnerability, and need, from living circumstances that are experienced as unbearable or deeply unsatisfactory and that precipitate serious obstacles to a reasonable or tolerable life."[4] Thus, their access to protection and care and their right to health are urgent global concerns.

The rights of asylum seekers are firmly established in international law as a cornerstone of human dignity and justice. While article 14 of the Universal Declaration of Human Rights proclaims that everyone has the right to seek and enjoy asylum from persecution in other countries, this article is aspirational and nonbinding, meant to set a global standard of rights that inspired later legally binding agreements. In contrast, the 1951 Refugee Convention, a binding international treaty, mandates that individuals seeking asylum must not be expelled or returned to situations where their lives or freedoms would be in danger.[5] Children, as particularly vulnerable individuals, are afforded further protections under the Convention on the Rights of the Child, including appropriate protection, humanitarian assistance, and family reunification.[6] In the United States, the Department of Justice's 1998 Guidelines for Children's Asylum Claims state that "the harm a child fears or has suffered may be relatively less than that of an adult and still qualify as persecution" and that "it is generally unrealistic to expect a child to testify with the precision expected of an adult."[7] These protections reflect a global commitment to safeguarding the rights of those displaced by violence, persecution, and severe adversity, especially those most vulnerable.

Despite the well-established human rights basis for asylum, political and legal systems have often undermined the timely and fair realization of these rights. In the United States, where the right to seek asylum is also articulated in the law, the backlog of immigration cases has surged over the past decade.[8] As of 2024, there are more than 3.3 million pending cases, with an average wait time of 762 days in 2023.[9] Further, asylum outcomes in the United States are heavily influenced by access to quality legal representation and the discretion of immigration judges.[10] Data from 2017–2022 for Miami, Florida, for example, show a stark contrast in outcomes, with asylum grant rates varying from 0.9% to 27.9%, depending on the judge presiding over the case.[11] This variability raises concerns about the consistency and fairness of asylum adjudications and highlights the importance of supporting fair asylum judgments through legal and medical interventions.

Forensic medical and psychological evaluations play a critical role in asylum claims, particularly those involving human rights abuses. During these evaluations, impartial and unbiased health professionals identify physical or psychological signs of trauma and determine the degree of consistency between these signs and the individual's history. They document their evaluation in an affidavit that is submitted as a component of the individual's asylum application and, in some cases, provide expert testimony in immigration courts. Finally, they identify medical or psychological needs for follow-up care. If the medical evidence matches the asylee's history, medical evaluations increase an individual's likelihood of being granted asylum.[12] For example, one analysis determined that 89% of individuals seeking asylum in the United States whose application included a forensic evaluation were granted asylum, compared to the national average of 37.5% among those whose applications did not include such an evaluation.[13]

While a limited body of evidence exists on the characteristics of adult asylum seekers receiving such forensic medical and psychological evaluations, even less is known about the characteristics of children receiving such evaluations. Likewise, while a handful of guidance documents and training materials are available that provide specific guidance on conducting forensic evaluations for children, there remains a lack of consensus on several issues, such as how to address guardianship (or lack thereof) and best practices for minimizing re-traumatization during the evaluation process.[14] Thus, to improve our understanding of the characteristics and health needs of children seeking such evaluations, this paper describes the sociodemographic characteristics, nature of human rights violations, and guardianship status of the children served by the Human Rights Clinic of Miami from 2010 to 2021. In examining these factors, we seek to shed light on the complex vulnerabilities of children navigating distress migration and underscore the urgent need to address gaps in safeguarding their right to health within the asylum process and beyond.

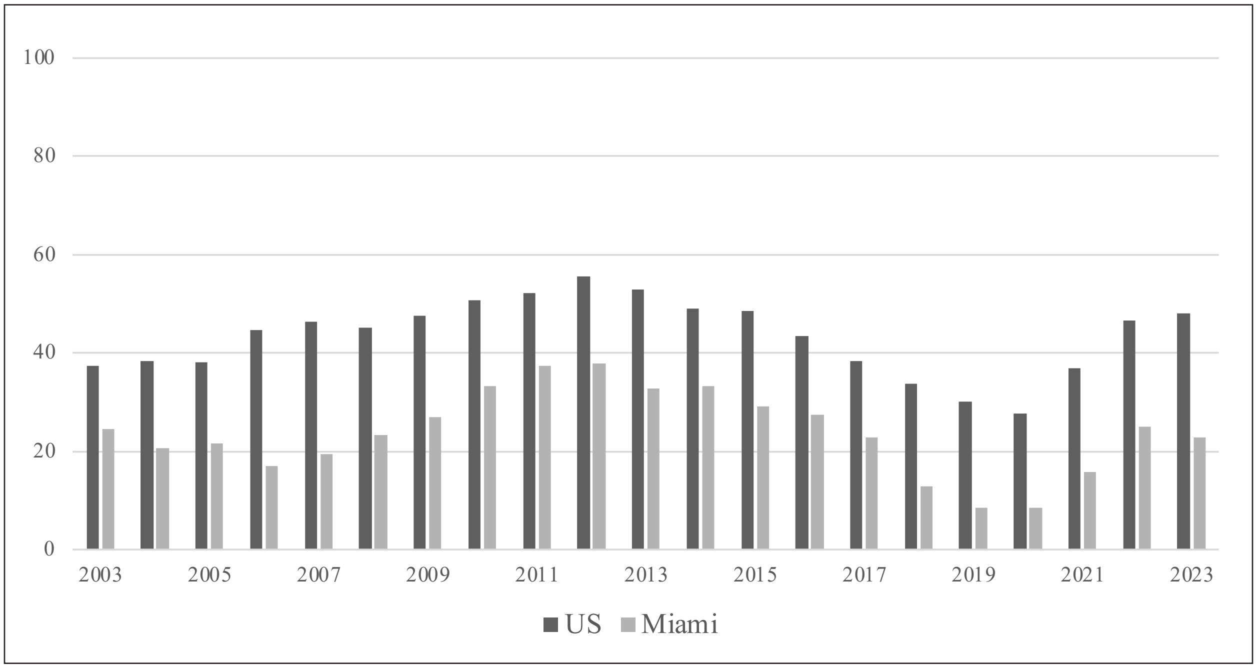
Methods

Study setting

As of August 2024, Miami-Dade County had the most pending immigration court cases in the United States, totaling over 325,000, with an average of 567 days pending.[15] The percentage of applications granted asylum in Miami is consistently below the national average; it decreased from a high of 37.9% in 2012 to a low of 8.4% in 2019, and has since increased again to 22.8% in 2022 (Figure 1).[16]

The Human Rights Clinic of Miami is affiliated with the University of Miami Miller School of Medicine and provides forensic medical and psychological evaluations for asylum seekers in Miami, Florida. It was established in 2010 and is the only medical student-run asylum clinic in Miami-Dade County. The clinic flow is as follows: the student scheduling director receives requests for medical or psychological evaluations from an individual seeking asylum in the United States or their lawyer; they then identify an available physician, student scribe, and translator (if needed) from the clinic's staff. The physician seeks consent from the individual seeking asylum (or their guardian in the case

FIGURE 1. Percentage of applications granted asylum in the United States as a whole vs. Miami, 2003–2023



of individuals less than 18 years of age) for (1) the collection of basic sociodemographic information for research purposes (importantly, the collection of this information is not required for the evaluation to take place) and (2) for the evaluation itself. If consent for the former is provided, a short survey is administered to collect basic sociodemographic information from the individual. If consent for the latter is provided, the physician then conducts the evaluation, while the student scribe documents the encounter. The student scribe prepares a draft affidavit, which is revised and finalized by the physician and shared with the individual or their lawyer for use in their asylum case. To maintain impartiality, the clinic does not directly provide medical or psychological services for needs identified during the evaluation; instead, a team of client navigators supports the individual in accessing relevant services after the evaluation.

Data collection

A retrospective chart review was conducted of all affidavits prepared by the Human Rights Clinic of Miami for individuals less than 18 years of age between 2010 and 2021. As described above, consent for the collection of basic sociodemographic information for research purposes was sought from the children's guardians, and assent was sought from the children themselves. Given the limitation that asylum seekers often lack formal guardianship documentation, we defined guardian as the adult appointed by the lawyer to accompany and consent for the child's evaluation. Before 2020, this consisted of written consent. In 2020 and 2021, this consisted of oral consent because evaluations were conducted via Zoom due to restrictions related to the COVID-19 pandemic; oral consent was witnessed and documented by at least two other staff members of the Human Rights Clinic of Miami. The consent process (as well as the evaluation itself) was conducted in the child and their guardian's language of choice either by the physician directly or via a staff translator.

Data were accessed from the clinic's database in January and February 2022 and were extracted using REDCap electronic data capture tools hosted at the University of Miami. During data extraction, the study team had access to information that could identify individual clients; however, efforts were made to ensure client confidentiality, and identifiable information was not extracted from the database.

Data analysis

Descriptive statistics were used to describe the sociodemographic characteristics and nature of human rights abuses of the children who received services from the Human Rights Clinic of Miami. Because a qualitative analysis of the nature of human rights abuses was beyond the scope of this analysis, this study used the categories recorded in the clinic's administrative data, namely physical violence, gang violence, sexual violence, political violence, and other. Bivariate analysis was used to compare children with and without a guardian present during the evaluation using Fisher's exact test for categorical variables. All statistical analyses were performed using SAS (OnDemand for Academics).

Results

From 2010 to 2021, the Human Rights Clinic of Miami conducted forensic medical or psychological evaluations for 64 children less than 18 years of age, constituting 17% of all evaluations conducted by the clinic during that time (Table 1). Just over half of the children were male (56%). The median age was 16 years (IQR 13–17); no children were less than 5 years old. Honduras was the most common country of origin (53%), followed by Guatemala (28%) and El Salvador (11%). The majority of children reported achieving some primary (i.e., elementary) school in their country of origin (64%), while 29% reported achieving some secondary (i.e., high) school, and 8% reported receiving no education.

Regarding the human rights abuses that the children experienced in their country of origin, physical violence was most reported (72%), followed by gang violence (53%), sexual violence (22%), and political violence (3%). Political violence is defined as the deliberate use of power and force to achieve political goals; it can include physical or psychological acts aimed at injuring or intimidating individuals or populations.[17] More boys reported experiencing gang violence than girls, while nearly all those who reported experiencing sexual and political violence were girls (Figure 2). Physical violence was reported by roughly the same number of boys and girls. Children aged 5–10 years reported experiencing physical violence most commonly, followed by gang violence; no children in this age group reported experiencing sexual or political violence (Figure 3). Most of those reporting sexual violence were 15–17 years of age.

The majority of children (87%) reported being

TABLE 1. Characteristics of children who received medical or psychological evaluations from the Human Rights Clinic of Miami, 2010–2021

Characteristic	Total sample	n
Age (median, IQR)	16 (13–17)	64
Age (n, %)		63
<5	0 (0)	
5–10	4 (6.2)	
11–14	17 (26.6)	
15–17	43 (67.2)	
Gender (n, %)		63
Female	28 (43.8)	
Male	36 (56.2)	
Ethnicity (n, %)		64
Hispanic	62 (95.4)	
Non-Hispanic	3 (4.6)	
Country of origin (n, %)		62
Honduras	34 (53.1)	
Guatemala	18 (28.1)	
El Salvador	7 (10.9)	
Haiti	1 (1.6)	
Highest level of education in country of origin (n, %)		51
None	4 (7.7)	
Some primary (elementary) school	33 (63.5)	
Some secondary (high) school	15 (28.8)	
Type of human rights abuse (n, %)		63
Physical violence	46 (71.9)	
Gang violence	34 (53.1)	
Sexual violence	14 (21.9)	
Political violence	2 (3.1)	
Other	1 (1.6)	
Detained at the border (n, %)	32 (86.5)	36
Number of people in house (n, %)		49
<5	32 (64.0)	
5–10	17 (34.0)	
>10	1 (2.0)	
Currently in school (n, %)	48 (96.0)	49
Guardian present during evaluation (n, %)	18 (31.0)	57
Guardian relationship (n, %)		18
Mother	15 (83.3)	
Father	1 (5.6)	
Sibling	2 (11.1)	

detained at the border upon entry into the United States. Regarding their current conditions in Miami, 64% reported living in a home with fewer than five people, while 34% reported living in a home with five to ten people. Nearly all the children (96%) were currently attending school.

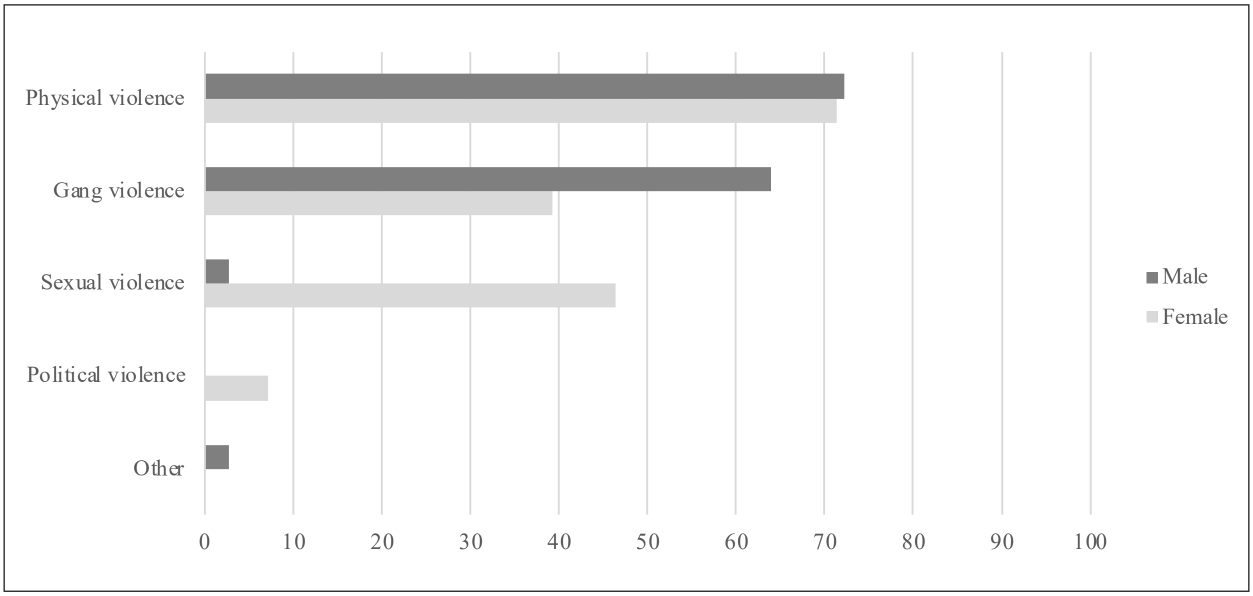
Only one in three children (31%) had a guardian present during the forensic medical and psychological evaluation. Of the guardians present, the majority were mothers (83%), followed by siblings (11%) and fathers (6%). When disaggregated by age (Figure 4), the percentage of children with a guardian present decreased from 100% of 5- to 10-year-olds, to approximately half of 11- to 14-year-olds, to only 20% of 15- to 17-year-olds. On bivariate analysis (Table 2), younger children and children with lower levels of education in their country of origin were significantly more likely to have a guardian present during the evaluation. There were no significant differences across gender, country of origin, or types of human rights abuse categories.

Discussion

This study describes the sociodemographic characteristics, nature of human rights violations, and guardianship status of children served by the Human Rights Clinic of Miami from 2010 to 2021, contributing several significant findings to the limited available data on who these children are and why they are seeking asylum. First, children constituted nearly 20% of the patients served during the study period by the Human Rights Clinic of Miami, the only student-run asylum clinic in Miami-Dade county, which is home to the highest number of pending immigration court claims in the United States. This figure was surprisingly high, considering that children receive derivative asylum when their parents receive asylum and thus often do not require independent asylee claims. A possible explanation is that many of our pediatric clients enter the United States as unaccompanied minors. Regardless, this finding underscores the critical need for specialized resources and tailored care for pediatric asylum seekers.

Second, the reasons for seeking asylum for children are notable: physical violence was the most common form, followed by gang-related, sexual, and political violence. The data indicate important gender differences: boys were more likely to experience gang violence, while girls reported higher levels of sexual and political violence. These findings highlight the need to approach forensic evaluations with a lens of gender equality, ensuring that gender-specific experiences, particularly sexual violence against girls, are adequately accounted

FIGURE 2. Percent of children reporting different human rights abuses, by gender



for. In addition, they highlight the crucial role of such clinics in connecting these children with health and social services that safeguard their right to health as migrants in the United States, including trauma-informed mental health support and medical services. It is important to note that many

Figure 3. Percent of children reporting different human rights abuses, by age

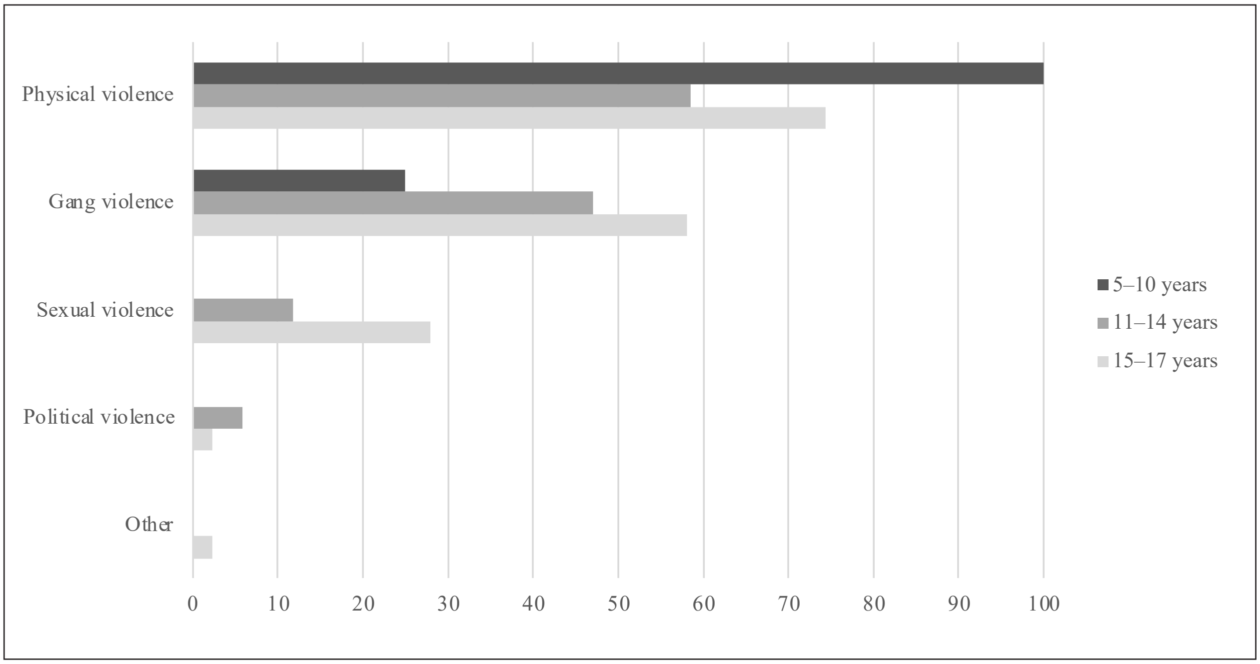


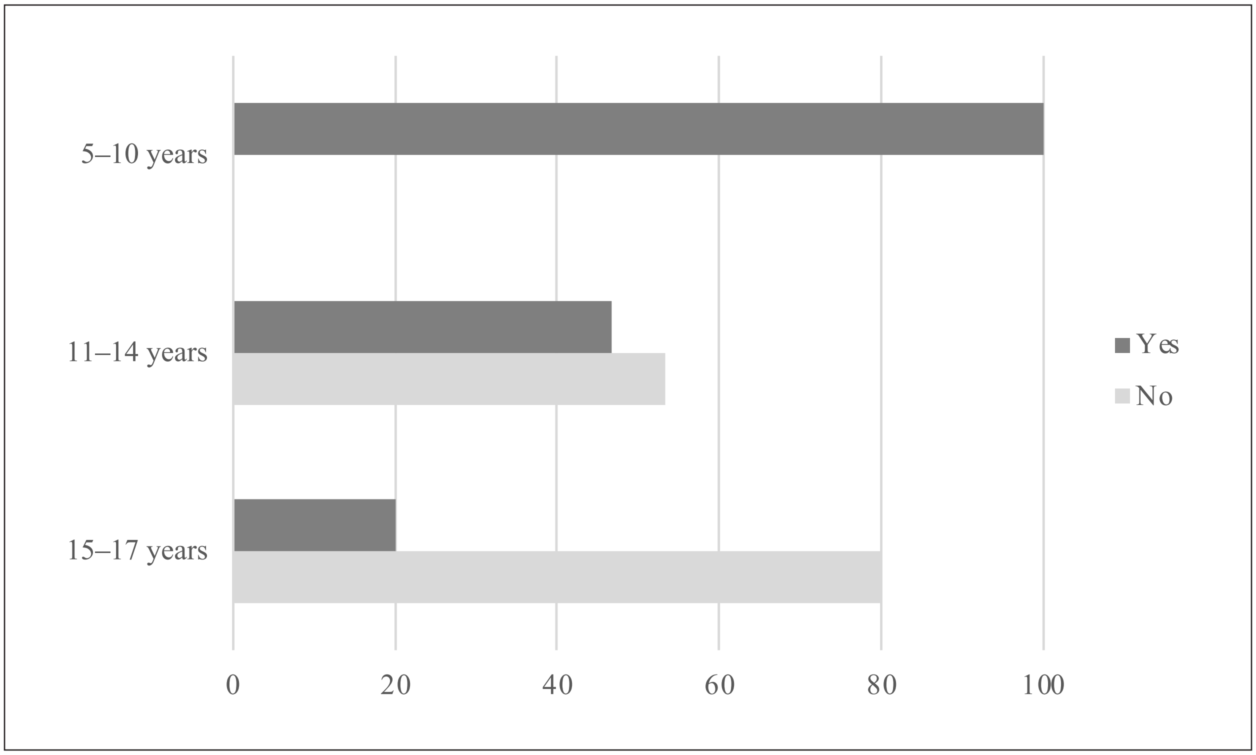
Table 2. Comparison of characteristics of children between those with and without a guardian present during their evaluation

Characteristic		Guardian present	Guardian not present	p value
Age (n, %)				0.005
	5–10	3 (100)	0 (0)	
	11–14	7 (46.7)	8 (53.3)	
	15–17	8 (20.0)	32 (80.0)	
Gender (n, %)				0.256
	Female	8 (24.2)	25 (75.8)	
	Male	10 (40.0)	15 (60.0)	
Country of origin (n, %)				0.557
	Honduras	10 (33.3)	20 (66.7)	
	Guatemala	5 (27.8)	13 (72.2)	
	El Salvador	2 (25.0)	6 (75.0)	
	Haiti	1 (100)	0 (0)	
Highest level of education in country of origin (n, %)				0.006
	None	4 (100)	0 (0)	
	Some primary (elementary) school	10 (32.3)	21 (67.7)	
	Some secondary (high) school	2 (14.3)	12 (85.71)	
Type of human rights abuse (n, %)				
	Physical violence	10 (24.4)	31 (75.6)	0.122
	Gang violence	10 (33.3)	20 (66.7)	0.780
	Sexual violence	6 (54.5)	5 (45.5)	0.079

children also flee their home country due to inadequate medical and legal infrastructure. In cases such as the violence documented in these affidavits, limited access to health care compounds trauma and underscores that returning to their country of origin may endanger their health and well-being. Children's right to health, integral to the asylum process, includes access to safe environments where they can live, learn, and play—essential factors in mitigating adverse childhood experiences, which are linked to chronic disease and early mortality.[18] Thus, the forensic evaluation process itself serves as a pathway to protecting the health rights of these vulnerable children.

Third, this study found that only a third of the Human Rights Clinic of Miami's pediatric patients had a guardian present during their evaluation, with older children significantly less likely than younger children to have a guardian present. This finding highlights the importance of addressing the issue of guardianship during forensic evaluations and the associated legal and ethical considerations of performing evaluations without a guardian present. In formal medical practice, the general standard is to not provide medical care without a guardian or proxy adult present. However, state laws and even individual clinics can vary in their exact rules and regulations regarding unaccompanied minors seeking medical care, and this is likely true for medical professionals who perform forensic asylum evaluations. Further, forensic evaluations for children seeking asylum have their own unique considerations. Evaluations commonly involve distressing discussions of violence, abuse, and trauma; thus, the presence of a guardian is crucial for supporting the child's emotional well-being. It is also considered normal for pediatric patients to not remember or be able to accurately describe relevant details about their experiences, especially those that occurred when they were very young; in such cases, a guardian can help by providing supplementary information. While the absence of a guardian provides the opportunity to screen for the child's safety, this can be accomplished with a guardian present by asking them to leave the room for part of the interview, and the benefits of their presence far

FIGURE 4. Percent of children with a guardian present during the evaluation, by age



outweigh the disadvantages. Although guardianship presents logistical challenges, especially in the case of unaccompanied minors at various stages in the process of receiving a court-appointed guardian, addressing this issue is essential to ensuring access to justice for these children and upholding their rights, including their right to health and well-being. Our clinic stresses the importance of a guardian being available during and after the interview for emotional support and clarifying questions; however, given the social complexity of this population, we practice on a case-by-case basis. Because our clinic does not provide medical or psychiatric treatment, we have a robust referral system in place to link patients to appropriate care. Likewise, because all the children we evaluate have legal representation that requested the interview, we continue with evaluations without a guardian present, if necessary, particularly with older children 16 years and up. Nonetheless, future protocols should prioritize securing guardianship, whether through remote consent, legal coordination, or alternative forms of support so that evaluations can take place in the legal time frame of their asylum cases. In the case that securing a guardian is not possible, unaccompanied minors would particularly benefit from the establishment of consensus guidelines to ensure that evaluations are appropriate and evidence based, given that they are an especially vulnerable population at risk for harm and misrepresentation.

The increase in children seeking asylum in the United States, and particularly unaccompanied minors, over the past decade has raised concerns regarding how best to address their distinct physical and psychological needs during forensic medical and psychological evaluations.[19] Unfortunately, there are still very few tailored resources to guide health professionals in evaluating the claims of pediatric asylum seekers, despite evidence demonstrating the importance of such evaluations in determining asylum outcomes.[20] As the number of children continues to rise, we are concerned by this lack of research and evidence-based guidelines for several reasons: (1) evaluations may miss important findings or may report findings inconsistently; (2) the objectivity of these evaluations is at a greater risk of being questioned if there is limited supportive research or consensus on practice guidelines; and (3) it will continue to be difficult to recruit pediatric trained health professionals to perform forensic evaluations in the absence of formal and standardized training. The resulting "de-professionalization" of our expertise will limit access to this important service and will widen the large inequity gap already faced by children seeking asylum. We hope that this study can serve as a launching point for further research to strengthen the field's understanding of the needs and circumstances of children seeking asylum and to maintain our high professional standard of upholding justice, equity, and the duty to do no harm.

This study's primary strength lies in its focus on children seeking asylum, a vulnerable population that is often underrepresented in legal literature, clinical practice, and research. The data gathered from the Human Rights Clinic of Miami provide valuable insights into the experiences and needs of these children. However, there are notable limitations. First, the study was conducted at a single asylum clinic with a relatively small sample size and in a particular geographic location with most individuals originating from Central and South America; therefore, the findings may not be generalizable to the broader US asylum-seeking population. Additionally, the categories of human rights abuses—physical violence, gang violence, sexual violence, political violence, and other—were limited to those recorded in the clinic's administrative data, which may not capture broader systemic issues such as socioeconomic deprivation and violations of basic rights, including the right to health, that can drive migration. Finally, while a standardized REDCap form was used to reduce variability, inconsistencies in data input, due in part to annual staff turnover, may have affected data completeness and consistency. Future research should expand this work by gathering more comprehensive data across multiple regions and asylum clinics and by further investigating the impact of guardianship and other protective factors on asylum outcomes.

Conclusion

This study sheds light on the sociodemographic characteristics, nature of human rights violations, and guardianship status of children served by the Human Rights Clinic of Miami between 2010 and 2021. The findings emphasize the need for pediatric-specific forensic evaluation protocols that address the unique vulnerabilities of child asylum seekers. The findings of this study contribute to the broader literature on distress migration and the right to health: children seeking asylum, especially those who are unaccompanied, often experience severe trauma, and their right to health—both physical and psychological—is central to their asylum claims. By applying human rights principles, such as substantive equality, gender equality, and access to justice, the field can better protect children's rights and well-being throughout the asylum process. Future research may investigate whether factors such as guardianship affect the outcome of asylum cases, and future programmatic efforts may include the development of pediatric-specific guidelines for conducting forensic medical and psychological evaluations of children seeking asylum.

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Ethics Approval

This study received ethics approval from the University of Miami Ethics Review Committee (IRB study number 20140865).

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