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FOREWORD

Romani Global Diaspora: Implementation of the Right to Health

RITA IZSÁK-NDIAYE

It has long been obvious that the general health status of Roma is much worse than that of non-Roma. Surveys have found that European Roma are disproportionately unvaccinated, have poorer-than-average nutrition, and experience higher rates of infant mortality and tuberculosis. Estimates in 12 European Union (EU) member states suggest that Roma live 7–20 fewer years than non-Roma.[1]

However, the lack of standardized and systematic disaggregated data prevents us from knowing what factors are rendering Roma more vulnerable to various specific diseases and sicknesses and what exact barriers they face when trying to access health care services. This is not the case in countries such as the United States, the United Kingdom, India, and Brazil, where disaggregated national data-collection schemes broken down by age, ethnicity, race, income, gender, and other variables highlight existing disparities in health status and access to health care. Thanks to such health statistics in the United States, for example, we know the differences between various racial groups regarding live births, smoking habits, obesity, hypertension, health insurance coverage, mortality, leading causes of death, and many other areas, which enables the formulation of appropriate legal and policy responses for the various population groups.[2]

Health care has always been one of the four main pillars of Roma rights advocacy, together with education, employment, and housing. For instance, it was part of the Decade of Roma Inclusion 2005–2015. In addition, the EU Framework on National Roma Integration Strategies—adopted by the EU Employment, Social Policy, Health and Consumer Affairs Council in 2011—invited member states to focus on access to health care, with particular emphasis on quality health care, including preventive health care and health education. However, this area was and remains the least researched, understood, and strategized field of work given the sensitive and closed nature of health data and health care services. Roma in general often feel mistreated by public authorities, who approach them with suspicion, prejudice, and even hostility. But when it comes to administrative procedures at municipal offices, employment bureaus, and educational institutions, much can be seen and overheard by the public at large, which might positively influence attitudes and behaviors. However, this is not the case in the health arena, where treatments happen behind closed doors and where public knowledge on the subject matters and on patients' rights in general is limited. Health care facilities are usually difficult places for everyone. Anyone who has ever been hospitalized due to sickness

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or childbirth can probably recall feelings of fear, stress, uncertainty, and vulnerability during their treatment. Such feelings are further exacerbated for minorities, who often sense a larger cultural and social distance from health care institutions and their personnel, where the underrepresentation of Roma workers can be acute.

This special section of the journal is therefore an important step forward in documenting existing problems and challenges for Roma in health care and suggesting steps that can be taken to improve their health status, remedy past violations, and empower them to claim their rights.

One of the gravest human rights violations ever committed against Roma and Romani women is the practice of coercive, forced, and involuntary sterilization. Authors in this special section explore current conceptual, legal, political, and social obstacles and their antecedents in 20th century notions of population control. Some also argue that an administrative mechanism is needed to provide financial compensation to victims because the road to remedy via the courts is effectively blocked.

Indeed, courts and judges need to be sensitized to have a better understanding of and approach toward Roma rights cases. I was in a courtroom in Hungary in 2003, when Ms. Sz. A., a Hungarian Roma woman, testified about a coercive sterilization performed on her in 2001. She was asked to explain what it meant in her community for a woman not to be able to bear a child anymore. She felt humiliated and ashamed to talk about this sensitive issue in front of a group of complete strangers in a cold and unfriendly courtroom, and silently sobbed instead of responding. It was a heartrending moment. In the end, although the appellate court found that the doctors had acted negligently in failing to provide her with detailed information, it turned down the appeal on the ground that the plaintiff had failed to prove a lasting handicap as a result of the hospital's conduct. Fortunately, her case ended up at the United Nations Committee on the Elimination of Discrimination against Women in 2006, which issued a positive ruling recommending that Hungary compensate the victim and take measures to ensure that health officials provide adequate information to patients and obtain their informed consent. Consequently, in 2008, Hungary amended its Public Health Act to ensure that women receive proper information regarding sterilization procedures, and in 2009, the Ministry of Social Affairs and Labour announced that it would compensate Ms. Sz. A. in line with the committee's recommendations. This clearly demonstrates that lawyers and judges at the national level should familiarize themselves with Romani culture and understand the issues of Roma women better so that they can establish a more welcoming and encouraging atmosphere for the discussion of such delicate matters and so that judges are enabled to deliver better rulings.

There are several studies across Europe that show that Roma are more reluctant to access health care services due to factors such as language and literacy barriers, limited knowledge of the health system, discrimination, a lack of trust, a lack of identification cards or insurance, and physical barriers.[3] The most likely encounter with health care facilities happens during pregnancy and childbirth. Many years ago, I led a research project on forced sterilization and discrimination against Romani women in the health care system. We conducted 131 interviews with Hungarian Roma women, documenting the existence of segregated maternity wards, negligent treatment of Romani women by medical professionals, verbal abuse, the provision of substandard health care services, and the requirement of payment when treatment was supposed to be free.[4]

Stereotyping and discrimination against Roma often happen because of the stigma associated with them. They are often labeled as dirty, smelly, and unclean, while at the same time being denied access to water and sanitation, which highlights one of the insidious qualities of stigma: it has a self-fulfilling and circular nature.[5] Although the United Nations General Assembly has confirmed the right to safe and clean drinking water and sanitation as a human right that is essential for the full enjoyment of life and all human rights, Roma lack even rudimentary access to water and sanitation in countries where non-Roma communities have universal access to them.[6] Unfortunately, this leads

not only to heightened barriers in accessing health care services but also to eviction. According to international human rights standards, access to water services and protection from forced eviction should not be made conditional on a person's land tenure status, such as living in an informal settlement.[7]

The dire situation of Roma is not limited to the European continent. In 2014, at the invitation of the Human Rights Council, I carried out a comprehensive study of the human rights situation of Roma worldwide, with a particular focus on the phenomenon of anti-Gypsyism.[8] My research found that Roma face similar challenges outside of Europe as well. For example, living conditions in Roma villages in central and southern Iraq are reportedly among the most deplorable in the country. Many Roma live in windowless mud houses without electricity, clean water, health care, or adequate food, and are cut off from social security services. And in Brazil, many Roma settlements reportedly have no electricity, safe drinking water, or sanitation, despite the fact that some of these settlements have been in existence for over 20 years. In general, for Roma around the world, poverty, a lack of identification documents, and a lack of transportation options from remote areas to health-care facilities all contribute to negative health impacts, which are compounded by poor living conditions, such as living near garbage dumps or polluted rivers. Factors precluding Roma access to health care include being refused medical treatment, having no access to emergency services, being subjected to verbal abuse, and being segregated in hospital facilities. Furthermore, lack of access to health care may result from indirect discriminatory practices, such as when Roma are required to provide identity or residency documents in order to register and qualify for health care benefits.

As the articles in this special section show, the tasks ahead of us are many, and they require a coordinated multisectoral approach. Measures addressing the socioeconomic vulnerability, including the poorer health status, of Roma must involve efforts not only to tackle poverty and marginalization but also to end widespread prejudice and discrimination toward Roma. Therefore, awareness-raising among the Roma population and civil society on health rights is essential.

These papers will further educate and inspire us to continue our struggle to ensure that appropriate laws, policies, programs, and projects are established to finally achieve equality for Roma both in rights and in dignity so that they become more aware, more empowered, and just as likely to live as long and as healthily as their non-Roma neighbors.

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EDITORIAL

The Critical Role of Research in Advancing Romani's Right to Health

JACQUELINE BHABHA, MARGARETA MATACHE, AND TERESA SORDE MARTI

As we finalize this special section on *Romani People and the Right to Health*, a landmark ruling on Roma health rights has just been handed down by the European Committee of Social Rights. On October 16, 2017, the committee accepted as admissible the European Roma Rights Centre's complaint against Bulgaria alleging systemic discrimination against Romani women in maternity wards.[1] The complaint details segregation, substandard and abusive maternity care, and disproportionate barriers in access to health insurance for this part of the Roma population.[2] The committee's finding advances official recognition of the intersectional discrimination affecting Romani women and girls across Europe and perhaps beyond. We use the word "perhaps" advisedly, for conclusive evidence documenting discriminatory and racist practices against Roma living on other continents is lacking, a point underlined in 2016 by Rita Izsak-Ndiaye, the United Nations (UN) Special Rapporteur on minority issues.[3]

Despite its significance, the Bulgarian case is not unique in Europe. A 2014 shadow report submitted to the UN Committee on Economic, Social and Cultural Rights by Romani CRISS, a Romanian Roma Rights organization, also drew attention to "the segregation of Roma patients, especially Roma women, in separate rooms" at Marie Curie Hospital in Bucharest, as well as three other locations in Romania.[4] According to the report, Romani women complained about "unrenovated … and untidy rooms; [the fact that] the nurses change the sheets very rarely; [and the fact that] babies receive treatment, such as syrups, with [already used] … unsterilized utensils."[5] A further ex officio investigation by Romani CRISS in partnership with the Equality Body revealed the segregation of Romani children in special wards at the Marie Curie Hospital in Bucharest.

This special section in *Health and Human Rights Journal* brings together a number of respected scholars who document unequal power relations, prejudicial practices, intersectional discrimination, and inequalities, looking at causes and suggesting remedies. While there have already been multiple efforts to document and analyze health-related human rights violations affecting Romani constituencies all over the world, the present collection of articles sheds light on new realities and provides fresh insights into how these violations can be reversed or remedied. Authors analyze anthropological, law, and policy perspectives

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addressing the right of Roma to health in different geographical contexts, deconstructing some of the underlying assumptions and frameworks. Some contributors examine the racialization of Roma in policy and practice and the health disparities between Roma and majority populations, while others investigate bias in the formulation of policies and their implementation. Yet others explore the tactics and stakeholders involved in health-based initiatives and grassroots and Roma-led efforts geared toward realizing Roma's equal access to health. The methodologies used by contributors vary from large-scale surveys to ethnography and policy analysis.

The papers by Claude Cahn and by Gwendolyn Albert and Marek Szilvasi demonstrate that discrimination has been a triggering cause of ill health for Roma. Both papers look at the intersection of gender and ethnicity in discriminatory policies, examining more than 50 years of policies supporting the forced sterilization of Romani women in the former Czechoslovakia and its successor states. Communist Czechoslovakia carried out sterilization practices starting in 1973, and both the Czech Republic and Slovakia, after they split in 1993, continued this practice until shortly before their entry into the European Union in 2004.[6] These cases involved evident power disparities between non-Roma health personnel and Romani patients along multiple dimensions, including ethnicity, gender, social and professional status, and educational attainment. Profoundly abusive measures were thus executed by paid public personnel. The cases raise awareness of the lack of free and informed consent, as well as how minority and other marginalized groups are protected in the medical context.

These sterilization cases relate to a longer eugenic history aimed at shrinking the size of the Roma population. In Sweden between 1935 and 1976, 60,000 Romani women were forcibly sterilized, as they were perceived as a "socially inferior element of society."[7] During the Holocaust, the Nazis also targeted Romani women for sterilization experiments on the basis of similar eugenic rationales. The idea of Roma racial inferiority as the underlying justification for these policies continues to exist in Europe and translates into substantial health discrepancies between Roma and non-Roma populations.

Analyses of health-related discrimination against Romani women in the essay by Kristefer Stojanovski, Alaka Holla, Ilir Hoxha, Elizabeth A. Howell, and Teresa Janevic address additional contexts, including access to quality antenatal care in Kosovo. The authors present evidence relating to antenatal care in Kosovo and explore disparities between Roma and non-Roma women. They show that Roma, Ashkali, and Balkan Egyptian women (all placed under the umbrella of the Romani population in Kosovo) receive inferior prenatal care compared to Kosovar Albanian and Serbian women and that women who are recent migrants or displaced refugees receive the worst care.

Other papers explore discrimination against Romani communities living in situations of extreme poverty and marginalization, often in ghettoized settlements on the outskirts of Western metropolises. Four articles focus on individual constituencies, distinguished by subgroup (Romani migrants, *Gens du voyage*, and "badocari"), by country of residence (France, Sweden, and Denmark), and by the particular setting (*villages d'insertion*, settlements, homeless, and caravan sites). Daniel Manson's article touches on the vulnerabilities of Romani people living in *villages d'insertion*, or integration villages, in France. Manson describes the *village d'insertion* as an expression of state power and of the division between "deserving and undeserving" in terms of the rights to health and shelter. Martha F. Davis and Natasha Ryan examine the marginalization of Roma through the denial of water and sanitation facilities in Sweden. Camilla Ida Ravnbøl documents the struggles of the "badocari," a particular group of homeless Romanian Roma living in Copenhagen. She offers a syndemic approach that stresses the links between social injustice, ethnicity, and disease. Finally, Lise Foisneau shows how health-related policies perpetuate the exoticization and exclusion of Roma. Her paper deconstructs political discourse and policies on the *gens du voyage* in France. She shows how areas reserved for the *gens du voyage*, allegedly to facilitate better health outcomes in practice, violate basic human rights pertaining to decent

living conditions and provide a tool for surveillance and intrinsic marginalization.

Despite this predominantly bleak picture, it would not be accurate to characterize all health-related developments concerning Romani populations in Europe as solely negative.[8] Roma nongovernmental organizations have developed programs explicitly targeting health-related discrimination, such as through the introduction of community-based health mediators who are familiar not only with communities' apprehensions but also with the urgent imperative of making mainstream health care more accessible and functional for them. Indeed, for almost two decades now, the emphasis of institutional initiatives on Roma access to health has been, above all, on health mediation. In Romania, for example, the mediation program started by Romani CRISS in 1996 and taken over by the Ministry of Health in 2001 includes among its goals the improvement of communication between Roma and medical personnel and increased Roma access to medical services. Despite good health outcomes in many communities, the mediators have not succeeded in reversing several enduring elements of anti-Roma discrimination.[9] Moreover, the mediators' presence has not neutralized the lack of anti-bias and anti-racist training for health personnel or the broader failures of health institutions to prioritize the elimination of pervasive discrimination in health care provision.

Another positive development with some encouraging results is the use of litigation as a strategy for tackling anti-Roma discrimination in the health sector.[10] Alphia Abdikeeva and Alina Covaci discuss the impact of legal advocacy on Roma's awareness of their health rights, using Macedonia as a case study. They argue that the increasing use of lawsuits has led to some reduction in the prevalence of violations of Roma health rights.

Overall, the articles presented here provide a comprehensive, diverse, and critical reflection on the state of Romani groups' access to health on the European continent. They remind us that this issue is still a major unresolved challenge on the human rights agenda. Racial discrimination, poor living conditions, and forced evictions are among the many factors that compound the unequal health status of Europe's Roma families and communities.

Research has a significant role to play in documenting health deficits, policy inadequacy, and productive strategies for advancing the enjoyment of health rights by all. We are enthusiastic about contributing to this aim through this special section of *Health and Human Rights Journal*, whose essays add to the knowledge production on Roma rights to health.

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Justice Delayed: The Right to Effective Remedy for Victims of Coercive Sterilization in the Czech Republic

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Abstract

Tens of thousands of women were coercively sterilized in Czechoslovakia and its successor states. Romani women were particularly targeted for these measures. These practices stopped only in 2004, as a result of international pressure. Although some measures have been taken to ensure that these practices are not repeated, to date neither the Czech Republic nor Slovakia have completed the work of providing effective remedy to victims, as is their right. This article focusses on efforts in the Czech Republic. It concludes that, *inter alia*, an administrative mechanism is needed to provide financial compensation to victims, since the road to remedy via courts is effectively blocked.

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Introduction

In addition to having been a practice of Nazi Germany, the coercive sterilization of women from pariah, marginalized, or stigmatized groups was a feature of a number of systems of social control in Europe that began as a result of the eugenics movement in the 1920s.[1] We still do not have a full account of all practices, but target groups appear to have included, in particular, women with disabilities (especially mental or intellectual disabilities), older women, and transsexuals. For example, between 1935 and 1975, around 63,000 people were sterilized in Sweden, of whom 93% were women and around 40% of whom were sterilized without any form of consent.[2] Very particularly targeted, however, have been persons—especially women—deemed degenerate or inferior, including Roma and minorities regarded as "Gypsies." Countries with strong social systems—the Nordic countries and those of central continental Europe—were particularly prone to adopting coercive sterilization as a mode of social control of Roma and related groups.[3]

Following World War II, in Western Europe, coercive sterilization practices—seen as "hard" and associated with Nazi Germany—were generally replaced (at least with regard to Roma and others deemed vagrant or antisocial) with measures such as the forced removal of children from families. These practices, which had also been ongoing since the 1920s, now became the primary mode of invasive social control of these persons and groups. By the mid-1970s, they appear to have ended as policy in key countries such as Switzerland, Norway, and Sweden.

For reasons that are unclear, precisely at the time that these practices were ending in Western Europe, both coercive sterilization and the forced removal of children from their families were reinvigorated as policy in communist Czechoslovakia. From the late 1960s until the end of communism, authorities in Czechoslovakia strongly pressured Romani women to undergo sterilization in exchange for monetary compensation and also used explicit and actionable threats to place their children into state care. These efforts became particularly intensive and frenetic toward the end of communism. The first post-communist government in Czechoslovakia explicitly ended these policies in 1990. However, doctors and social workers in Czechoslovakia and its successor states (the Czech Republic and Slovakia) continued these practices covertly, extensively, and systematically until the early 2000s, until a series of international advocacy efforts brought them generally to a halt. The late Czech ombudsman Otakar Motejl stated publicly in 2009 that he believed there were as many as 90,000 victims in the countries of the former Czechoslovakia.

Remedies for coercive sterilization tend to include three categories. The first involves acknowledging the practices, describing their general scope and details, and expressing regret or apologizing officially. This first category also frequently involves a competent setting out of the historical record. The second category involves ensuring that the practices are not repeated, which usually means designing and implementing measures and procedures to secure the genuine free and informed consent of the person concerned. Education measures for health care professionals and social workers is also a part of this category. Finally, the third category involves specific reparations for the victims—usually in the form of restorative surgery or other health measures, measures to address the psychological consequences of the actions, and monetary compensation reflective of the nature and gravity of the harms concerned. This last category is also deemed to require the punishment of perpetrators.

In recent years, Norway, Sweden, and Switzerland have undertaken efforts to provide remedies to victims of these practices. All three countries have delivered—between 1986 and 2017—significant segments of the remedies summarized above.[4] This has not happened all at once but rather in successive waves of efforts to rectify these abuses.

Meanwhile, the Czech Republic and Slovakia have begun efforts to provide remedies but have not yet had the success of the three countries named above. Attempts to provide both full acknowledgement and compensation to victims have faced great difficulties, in particular because of the widespread public view that Roma do not constitute "deserving victims." Even basic recognition that Roma have

been particularly targeted has sometimes been challenged, despite overwhelming evidence.[5]

This essay focusses on the Czech Republic, where, despite an official government "expression of regret" in 2009, very few victims have received any form of individual compensation or other reparations. Repeated obstacles—notably a hardened definition of the statute of limitations for court-ordered remedies that sets out a three-year limit for claims—have stood in the way of the provision of such remedies. This paper argues that without an *ex gratia* mechanism similar to the one adopted by Norway, Sweden, and Switzerland—one with lightened evidentiary burdens, recognition of a historical context of harm, minimal or no usage costs, and other specifications—the vast majority of victims in the Czech Republic effectively have no hope of securing justice.

Coercive sterilization of Romani women in the Czech Republic

Starting in the late 1960s, under the influence of resurgent eugenics, doctors in Czechoslovakia systematically coercively sterilized Romani women with the support of policy makers, official state organs, and social workers. Immediately following the fall of communism, the new democratic government endeavored to end these practices, but they endured throughout post-communism in both the Czech Republic and Slovakia.

Non-Romani women, including women with disabilities and older women, have also evidently been victims of these practices. However, coercive sterilization in the Czech Republic and Slovakia has had very clear racist underpinnings, with Romani women being explicitly targeted for invasive, degrading measures to end their ability to bear children.

Contraceptive sterilization was governed, as a result of Ministry of Health directives adopted in the early 1970s, as a matter requiring the consent of the person concerned (evidenced by their signature), as well as the approval of a three-doctor panel. The sterilization of Romani women was actively promoted in Czechoslovakia via a number of measures, including a series of social benefits.[6] Financial incentives were coupled with strong pressure whereby social workers threatened to take the woman's children into state care if she did not agree. Pressure was also exerted on women to undergo abortion. Particularly striking is the fact that these measures were implemented in the context of pro-natalist birth policies that sought to avoid a declining general birth rate, which was seen as a threat to development.[7] One group, however, was to be stopped from having so many children. In the confines of political correctness prevailing under late communism, Roma were not named explicitly as a target of these policies.[8] Generally, references were made to those with "high, unhealthy" birth rates.[9] However, official reporting makes clear that the Roma were the target. Thus, reports such as this one—a 1979 report from the District National Committee in Tábor to the South Bohemian Regional National Committee—were typical:

> *Fifteen Gypsy children were born in our territory in 1978, of which three were with a low birth weight; all the children are alive. In 12 cases abortion was performed and sterilizations were performed on four Gypsy women.*[10]

In 1978, the Czech dissident group Charter 77 issued "Document 23" concerning the "situation of the Gypsies in Czechoslovakia," which, *inter alia*, protested the use of coercive sterilization as a tool in the service of "the solution of the Gypsy 'problem' in the elimination of this minority and its integration with the majority." The group argued that the government's approach was based on the idea that "[b]y eliminating the minority, one eliminates the minority problem."[11]

Despite Charter 77's efforts to protest these practices, they remained policy until the end of communism—and even appear to have become more frantic and intensive in the run-up to the collapse of communism. In 1989, dissidents Ruben Pellar and Zbyněk Andrš launched a field study among Czech and Slovak Romani women to map sterilization practices between 1967 and 1989. As a result of their research, they published a document entitled *Report on the Examination in the Issue of Sexual Sterilization of Romanies in Czechoslovakia*.

The authors concluded, among other things, that there had been a steady increase in sterilizations during this period, with a peak in 1988 and 1989: 38% of the women surveyed had been sterilized in those two years.[12]

The first post-communist Czechoslovak government, composed of many individuals who had taken part in the Charter 77 effort, acted quickly in 1990 to strike down a number of the laws and policies targeting Romani women for sterilization.

Also, the Czechoslovak General Prosecutor's Office used its powers to open an *ex officio* investigation into the coercive sterilization of Romani women. The federal prosecutor then forwarded the complaints to republic-level prosecutors in the Czech Republic and Slovakia so they could conduct inquiries. The prosecutors' inquiries followed two general strands: on the one hand, investigation into the impact of social benefits offered as incentives for sterilization and, on the other, non-compliance with binding law. Concerning their inquiry into compliance with binding law, the republic-level prosecutors requested that the district-level prosecutors investigate. In the Czech Republic, district-level prosecutors revealed that either no consent whatsoever had been obtained or that the procedure for obtaining consent had been extremely deficient or even in some cases entirely lacking; this latter scenario was the case in localities such as České Budějovice, Cheb, Kladno, and Ostrava. For example, in Kladno, "In the case of *J.G.*, the intervention was performed for health reasons on her third delivery, which was like the previous two by caesarean section … This woman however had not consented to the sterilization and as her testimony shows, the consent had not even been requested."[13]

The Czech General Prosecutor's Office concluded its investigation by requesting that Czech district prosecutors advise all medical authorities in areas where breaches of law had taken place that such breaches had occurred, and to retain sterilization as an area requiring the monitoring of legal compliance. In its response to the complainants, the prosecutor stated, "The findings of the General Prosecutor's Office of the Czech Republic suggest that the Commission of the Chief Expert for Gynaecology and Obstetrics in Prague is preparing draft amendments to the legal regulations on sterilization."[14] However, no such changes to law were made pursuant to this request. Such reforms would ultimately not be made for close to two decades.

Despite the cancellation in the early 1990s of explicit policies supporting the coercive sterilization of Romani women, these practices continued. In the absence of explicit policy, doctors and social workers appear to have colluded extensively to stop Romani women from conceiving or giving birth. Although cases varied extensively, a frequent scenario involved the application of a particular type of Caesarean section for Romani women pregnant with their second child, in which uterine rupture poses a significant risk in the case of a third pregnancy. Thereafter, during the second such birth, doctors would, with limited or no consent, sterilize the woman via tubal ligation while she was still on the operating table for the Caesarean section.

In aggregate, there were various profiles of (il) legality in the cases arising after 1989: (1) cases in which consent was reportedly not provided at all, whether in oral or written form, prior to sterilization; (2) cases in which consent was secured during or shortly before delivery, stages when the mother is in great pain or under intense stress; (3) cases in which consent appears to have been provided (a) on a mistaken understanding of terminology used, (b) after the provision of apparently manipulative information, or (c) absent explanations of consequences or possible side effects of sterilization, or adequate information on alternative methods of contraception; and (4) cases in which officials pressured Romani women to undergo sterilization, including through the use of financial incentives or threats to withhold social benefits. In some cases, racial animus was written explicitly into the file.

In 2004, on the basis of new documentation, the European Roma Rights Centre sent a communication to the United Nations Committee against Torture summarizing 31 individual cases of alleged coercive sterilization of Romani women between

1987 and 2003, plus a further three cases in which Romani women had been improperly pressured to undergo sterilization but had successfully refused. The cases provided by the European Roma Rights Centre triggered a chain of events leading to international and national pressure in the Czech Republic to end the practices. As a result, in 2004 the Czech Public Defender of Rights (Ombuds person's Office) opened a new investigation into the issue. The following year, the office issued a report summarizing its research into coercive sterilization. The report notes that the Ombudsperson's Office received more than 80 complaints during 2005 but that the report is based on the office's review of the first 50 such cases. A central conclusion of the report was that "the problem of sexual sterilization carried out in the Czech Republic, either with improper motivation or illegally, exists, and Czech society has to come to terms with this."[15] In 2009, the ombudsman stated publicly that he believed there had been as many as 90,000 victims of these practices in the former Czechoslovakia.

International law

Coercive sterilization as human rights harm

In Council of Europe jurisdictions, the international law of informed consent in any intervention in the health field is extensively elaborated as a result of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, also known as the Oviedo Convention.[16] Article 5 of the Oviedo Convention establishes the "general rule", which is as follows:

> *An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.*
>
> *This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as its consequences and risks.*
>
> *The person concerned may freely withdraw consent at any time.*

The norm of free and informed consent in matters related to family planning—and by implication, sterilization—explicitly enters international human rights treaty law via the article 10(h) guarantee in the 1979 Convention on the Elimination of All Forms of Discrimination against Women, which sets out that states parties have an obligation to take "all appropriate measures" to ensure "the health and well-being of families, including information and advice on family planning."[17]

In recent years, a number of international bodies have rendered ever more explicit normative guidance on the right to free and informed consent as a core principle of the rights of the patient. In 1994, the World Health Organization's (WHO) European Consultation on the Rights of Patients endorsed a document entitled *Principles of the Rights of Patients in Europe*. With regard to information, the document notes:

> *Patients have the right to be fully informed about their health status, including the medical facts about their condition; about the proposed medical procedures, together with the potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis and progress of treatment … Information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimizing the use of unfamiliar technical terminology.*[18]

In addition, with regard to consent, the document states, "The informed consent of the patient is a prerequisite for any medical intervention."[19]

In 2011, the International Federation of Gynecology and Obstetrics issued new ethical guidelines on female contraceptive sterilization. In terms of context, these guidelines recognize "a long history of forced and otherwise non-consensual sterilizations of women, including Roma women in Europe and women with disabilities."[20] The guidelines also importantly recognize that sterilization for the prevention of future pregnancy cannot be ethically justified on grounds of medical emergency: "Even if a future pregnancy may endanger a woman's life or health, she will not become pregnant immediately,

and therefore must be given the time and support she needs to consider her choice. Her informed decision must be respected, even if it is considered liable to be harmful to her health."[21]

In 2015, seven United Nations agencies, led by the World Health Organization, issued a comprehensive interagency statement entitled "Eliminating Forced, Coercive and Otherwise Involuntary Sterilization." It notes, among other things, that Roma have been victims of coercive sterilization policies and practices since the eugenic era during World War II, and they remain so currently. The statement summarizes the many ways in which Roma have been tricked or coerced into undergoing sterilization and describes how such practices violate international human rights law. It notes, "Responding to coerced sterilization of indigenous and minority women, particularly Roma women, human rights bodies have emphasized the need to take legal and policy steps to prevent such violations from occurring and to ensure effective remedies, including apologies, compensation and restoration of fertility for victims."[22]

Acts in the health field that are not carried out with free and informed consent are often called "involuntary" in normative guidance. Sterilization carried out without free and informed consent is also sometimes referred to as "forced." As a term of legal art, however, "coercion"—a term frequently found in the criminal or contraventional law of national legal systems—appears to better describe an absence of free and informed consent, and thus the violation of rights concerned. The United Nations Committee on the Elimination of Discrimination against Women (CEDAW Committee) has, in its General Recommendation No. 24, drawn an explicit link between coercion and "non-consensual sterilization," noting that states "should not permit forms of coercion such as non-consensual sterilization, mandatory testing for sexually transmitted diseases or mandatory pregnancy testing as a condition of employment that violate women's rights to informed consent and dignity."[23] In 2017, the Committee adopted General Recommendation No. 35 on gender-based violence against women, which sets out, *inter alia*, that violations of women's sexual and reproductive health and rights, including acts such as forced sterilization and forced abortion, may amount to torture or cruel, inhuman, or degrading treatment.[24] The committee has also found states in violation of the Convention on the Elimination of All Forms of Discrimination against Women in cases concerning the coercive sterilization of Romani women.[25]

The right to an effective remedy

International law requires that all victims of coercive sterilization have an effective remedy, including, at a minimum, recognition of harm; therapeutic measures to address the medical and psychological consequences of these practices; effective punishment of the perpetrators; and monetary compensation reflective of the nature and gravity of the harms concerned. Where sterilization has been carried out for reasons of racial or other forms of discrimination, this discriminatory element must be explicitly recognized and rectified. These obligations flow from a range of international human rights treaties to which the Czech Republic is a party, including the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social and Cultural Rights; the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; the Convention on the Elimination of All Forms of Discrimination against Women; and the International Convention on the Elimination of All Forms of Racial Discrimination.[26]

In European human rights law, the right to an effective remedy is explicitly protected in article 13 of the European Convention on Human Rights as a "dependent right," meaning that violations of it occur in connection with violations of a substantive right of the European Convention. However, the case law of the European Court of Human Rights also approaches the right to effective remedy as effectively pervasive throughout the substantive rights of the convention, including article 2 (right to life), article 3 (ban on torture and related forms of degrading treatment), and article 8 (right to private and family life), meaning that while the court sometimes specifies explicit violations of article 13, in other contexts

it holds that the right to effective remedy is included within articles 3 and 8 or within another substantive right of the European Convention.

In keeping with its consistent case law that the European Convention "is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective," the court has specified above all that a remedy must be "'effective' in practice as well as in law."[27] More important rights require more stringent remedies.[28] The court has additionally held that article 13 "must be interpreted as guaranteeing an 'effective remedy before a national authority' to everyone who claims that [her] rights and freedoms under the Convention have been violated."[29] The court has found states in violation of the obligation to provide an effective remedy as a result of deficiencies in their compensatory regime.[30] No absolute standard has been provided as to whether there is an arguable claim under article 13; this is deemed to flow from the nature of the facts and legal issues at hand.[31] As noted above, however, coercive sterilization harms have been identified as a very serious invasion of bodily autonomy and are therefore a harm of a very grave order.

Efforts to provide remedies in the Czech Republic

In 2009, four years after the Ombudsperson's Office published its report on the issue, the Czech government finally issued an official order expressing regret for the country's sterilization practices. Furthermore, it has since modified official guidance for doctors aimed at strengthening guarantees that sterilization must be carried out solely with the full, free, and informed consent of the person concerned.

With regard to individual remedies for victims, however, the Czech legal system has, to date, systematically failed. As noted above, the combined efforts of the Czechoslovak federal prosecutor and the republican prosecutors of both the Czech Republic and Slovakia were insufficient to hold any persons to account during the period following 1989. In the most recent wave of efforts, the Ombudsperson's Office appears to have forwarded at least eight cases to the General Prosecutor's Office pursuant to the 2004 Ombudsperson's Office inquiry.[32] These criminal investigations were generally suspended without any charges being filed by the investigating authorities, initially because of an interpretation of law whereby, apparently, medical practitioners could not be held criminally liable for acts undertaken in the course of their medical professional activities, and later for more nuanced reasons. In any case, it fell to civil society to appeal the suspended criminal complaints. Most were not appealed after being refused for a second time. In only two cases did the district prosecutor in the town of Most decide, in May 2007, that crimes had been committed by the two doctors performing the operation. However, in those cases, which concerned sterilizations performed in 1993 and 1998, respectively, criminal prosecution was deemed precluded by statutes of limitation.[33]

However, in some cases where the factual profiles were particularly strong, the refused investigations were repeatedly appealed. As a result, at least one criminal procedure reached the Czech Constitutional Court, where it was dismissed in February 2009. This case concerned the sterilization of 21-year-old Ms. I.Č. in 1997 in Ostrava City Hospital following the birth of her second child. The sterilization took place immediately following the birth, which occurred via Caesarean section. Ms. I.Č. had not been properly informed about the sterilization and did not know what it entailed when she signed what she believed was her consent to a Caesarean section; she signed this consent form while in labor and just prior to being operated on. Believing that she had been fitted with an intrauterine device, she did not realize that she was incapable of conceiving again until seven years after the operation, when she visited a doctor to have the device removed in order to have another child. The doctor informed her that in fact she had been sterilized.

In the case of I.Č., criminal proceedings filed by the Ombudsperson's Office and opened into the crime of harm to health (in accordance with articles 222(1) and (2)(b) of the Czech Criminal Code) had been discontinued by the Ostrava City Police in April 2006. A month later, the Ostrava district

prosecutor, accepting the applicant's appeal, struck down this decision and sent the case back to the Ostrava City Police Directorate, which ultimately decided not to proceed with the case. A complaint against this finding was then dismissed by the prosecutor. The following year, the general prosecutor ordered a review of the case, finding that the district prosecutor had not proceeded in accordance with the law. In October 2008, the Ostrava City Police Directorate found that the doctors of the Ostrava City Hospital had not committed the crime of inflicting bodily harm on Ms. I.Č. when sterilizing her. The next month, the Ostrava district prosecutor dismissed her complaint against this decision as unsubstantiated.

Ms. I.Č. appealed the latter decision to the Czech Constitutional Court. She based her complaint on articles 7(2), 10(2), and 36(1) and (2) of the country's Charter of Fundamental Rights and Freedoms, as well as international human rights law. She noted that the fact that the sterilization had been carried out without her free and informed consent was inhuman and degrading, and that its illegality had already been recognized in civil law proceedings concerning the protection of personality.

In dismissing the case, the Constitutional Court held—and with reference to "repeated past decisions by the Court"—that a decision to suspend criminal proceedings is not a formal decision in the framework of a criminal prosecution and therefore does not include a right of appeal.[34] It further held that "criminal proceedings do not have, in the framework of the Czech legal order, the character of medium for the protection of subjective rights of physical or legal persons, but rather concern in essence the form of participation of citizens during the realization of the public interest in the suppression of crime."[35] After further establishing that the Czech criminal law order did not include a right of "satisfaction" and that the victim did not have a fundamental right to "the punishment of the person who caused her harm," the court held that "[c]riminal proceedings do not concern the rights and interests of the harmed party, or of any other physical and legal subject … but rather concern the rights and interests of the state."[36]

Civil claims for damages are risky in the Czech Republic because there are significant costs associated with an unsuccessful claim. Despite the Czech government's repeated insistence at international fora that the courts are the sole venue for claiming reparations, it has never provided any assistance to potential plaintiffs, the overwhelming majority of whom are women in precarious circumstances who lack the economic means to initiate such proceedings.

Nevertheless, a handful of coercive sterilization cases have been brought, and some of them have succeeded in meeting evidentiary standards for civil harm under Czech law. Cases in which remedies have been provided are those which are very recent and where the facts concerned are sufficiently unequivocal for practitioners to wish to risk the costs of losing a civil claim for damages (the losing party is required to pay the costs of both sides in a failed civil claim). In all but one of these cases, international donors have provided legal assistance because state-provided legal aid for these types of claims is not available. A summary of most of the known proceedings follows below.

In 2000, a court in the town of Plzeň (western Bohemia) awarded CZK100,000 (at that time approximately 2,500 euros) in damages to a woman who had been sterilized there in 1998. She had repeatedly explicitly refused to be sterilized, but doctors performed the operation anyway. In another case, the District Court of Ostrava recognized violations of law concerning the coercive sterilization of Ms. H.F. by Czech medical practitioners in 2001. In October 2001, Ms. H.F. gave birth in Ostrava's Vitkovická Hospital to her second child by Caesarean section. Her first child had also been born via Caesarean section. At the time of her second birth, Ms. H.F. was also sterilized by tubal ligation. Although her files indicate that "the patient requests to be sterilized," legal requirements that consent be full and informed were not met. Although it had been foreseen well in advance of labor that she would give birth by Caesarean section, Ms. H.F.'s "consent" to the sterilization was secured by doctors only several minutes before the Caesarean operation, when she was already in labor.

Ruling in 2005, the Ostrava court recognized that Ms. H.F.'s sterilization was coercive and therefore illegal, and ordered the hospital to apologize in writing. The ruling was upheld on appeal, and the hospital's management has since provided an apology to Ms. H.F. The court, however, rejected Ms. H.F.'s claim for financial compensation with the reasoning that the statute of limitations for such a claim had expired.

The third case is that of Ms. I.Č., the facts of which are summarized above. In 2007, the Ostrava Regional Court ruled that Ms. I.Č. had suffered civil harms when she was sterilized without providing full and informed consent. In its ruling, the court ordered the payment of CZK500,000 (at that time approximately 18,200 euros) in damages. In 2008, the Czech High Court in Olomouc partially overturned the ruling and held that the three-year statute of limitations for compensation for violations of personality rights had expired. In so doing, the court interpreted very narrowly the three-year requirement to report an act of violation of rights, given Ms. I.Č.'s claim that she discovered her sterilization only a full seven years after the act had been carried out. The court ordered the Ostrava City Hospital to apologize to Ms. I.Č., but it did not order the payment of damages. However, in 2011, the Czech Supreme Court overturned the high court's ruling, holding that the high court had not sufficiently taken into account the individual circumstances of the case.[37] The Supreme Court sent the case back to the high court for revision. In December 2011, Czech media reported that the hospital and Ms. I.Č. had reached an agreement on compensation.[38] It was subsequently reported that the amount agreed on in the confidential agreement was CZK500,000 (approximately 20,340 euros) for damages or compensation, and CZK61,440 (approximately 2,457 euros) for the costs of her legal representation.[39]

The Czech media have also reported on awards for damages ordered by Czech high courts in other cases of coercively sterilized Romani women. In one case, the court reportedly ordered damages of CZK200,000 (around 8,000 euros) to a woman from northern Bohemia. Another woman was awarded CZK150,000 (around 6,000 euros) in compensation for the removal of her ovaries without her consent. In 2012, the Czech Constitutional Court reportedly rejected an appeal in the first of the two cases seeking higher damages.[40]

Thus, not more than five persons have succeeded in securing anything approximating due legal remedy. In all cases, these persons have succeeded in achieving such remedies only after protracted legal efforts, which were generally challenged. The vast majority of women in cases of coercive sterilization have been statute-barred from seeking remedies, including damages for these harms. Indeed, many times it has appeared that Czech jurisprudence has hardened precisely to preclude the provision of effective remedies to these particular women. As summarized by the European Roma Rights Centre, the current state of play in Czech law is as follows:

> *There is no specific remedy in Czech law for victims of forced sterilisation. A person who has undergone an unlawful medical intervention can seek redress by claiming a violation of her personality rights under the 2012 Civil Code (previously, the 1964 Civil Code). The general statute of limitation for civil claims is three years. In cases concerning personality rights, this limitation only affects the right to seek monetary compensation for violations. The law does not specify whether those bringing claims for violations of personality rights can seek non-pecuniary (i.e. moral) damages if they bring their claims after the three-year time limit has expired. However, the Constitutional Court, deciding a case of unlawful sterilisation in 2013, stated that plaintiffs who make their claims after the three-year time limit has expired cannot claim non-pecuniary damages, unless the effect would be contrary to "good manners" (dobré mravy). The notion of "good manners" is not explicitly defined in Czech law. The case law describes it as "a significant value in law that serves to balance legal norms and their realisation against the moral intention of the regulation or some notion of equity, such as a morality or equality of arms." The courts assess compatibility with "good manners" on a case-by-case basis. However, as a matter of practice, this notion is not applied in cases where the complainant was responsible for letting the limitation period expire. As a result, victims of forced sterilisation have only been able to make claims and secure compensation for non-pecuniary damage if they have complied with the general*

> *three-year statute of limitations or, in some cases, if they have applied to this Court; if they are outside the statute of limitations, under domestic law victims can only secure a finding of a breach of their rights and an apology.*[41]

In addition, in many cases, hospitals have claimed that medical records have been destroyed by flooding, giving rise to the dilemma that courts may not even accept as established fact that the woman concerned has in fact been sterilized.[42]

Efforts to secure remedies via the courts have also, in a number of cases, exposed victims to slander or other abuses of personal reputation, such as tabloid media reports, asserting that particular named women were interested solely in financial gain. Since these reports have generally been in local and regional media outlets, women have had their most intimate health issues publicly exposed and have also had their reputations impugned broadly in what are frequently small and close-knit communities.

Ex gratia compensation

The extensive and elaborate battery of obstacles described above points clearly to the need for an administrative procedure that would reverse the burden to establish harm and that would facilitate access to acknowledgement, compensation, and other relevant remedies, without requiring the person concerned to go to court.

In the past decade, every relevant human rights mechanism reviewing the Czech Republic has commented—with increasing detail—on this matter. The establishment of an *ex gratia* compensation procedure or mechanism for victims of unlawful forced, coercive, or otherwise involuntary sterilization has been recommended repeatedly by treaty monitoring bodies, including the CEDAW Committee in 2006, 2010, and 2016; the Committee on the Elimination of Racial Discrimination in 2007, 2011, and 2015; the Human Rights Committee in 2007; and the Committee against Torture in 2012.[43] In 2004, the Committee against Torture requested that information "on compensation provided for victims or their families in accordance with article 14 of the Convention [against Torture]" be included in the Czech government's next periodic report.[44] In 2012, the same committee expressed concern over the "absence of statistical data concerning compensation to victims of torture and ill-treatment, including victims of involuntary sterilization."[45] A number of member states provided similar recommendations during the country's Universal Periodic Review in 2012, as well as during its first Universal Periodic Review in 2008.[46] In particular, they recommended that the Czech Republic "establish a roadmap with clear timelines to finalise the cases of sterilization of Roma women without consent and ensure adequate compensation and reparation for such women" and that it "adopt measures to ensure the payment of compensations to victims of forced sterilization."[47]

In 2016, the Czech Republic was reviewed by the CEDAW Committee. The committee regretted that "the State party has not fully implemented its previous recommendations ... to adopt a legal framework for the financial compensation for victims of coercive or nonconsensual sterilizations."[48] It also noted with concern that a bill to establish extrajudicial mechanisms for addressing this issue had recently been rejected. In addition, the committee "reiterate[d] its concern that most of the compensation claims brought by victims of forced sterilizations were dismissed."[49] Finally, it recommended that

> *[i]n accordance with its previous concluding observations ..., its general recommendations Nos. 19 (1992) on Violence against women and 24 (1999) on Article 12—Women and health, and the recommendations in the final statement dated 23 December 2005 of the Ombudsman in the matter of sterilizations performed in contravention of the law and proposed remedial measures, the Committee reiterates its call for the State party to: (a) Review the three-year time limit in the statute of limitations for bringing compensation claims in cases of coercive or non-consensual sterilizations with a view to extending it and, as a minimum, ensure that such time limit starts from the time of discovery of the real significance and all consequences of the sterilization by the victim rather than the time of injury; (b) Establish an ex gratia compensation procedure for victims of coercive or non-consensual sterilizations; (c) Provide all victims with assistance*

> *to access their medical records; (d) Prosecute and adequately punish perpetrator[s] of the illegal past practices of coercive or non-consensual sterilizations; and, (e) Appoint an independent committee to conduct research into the full extent of harm caused by the practice of involuntary sterilisation, and support ongoing outreach to all potential applicants for compensation.*[50]

In June 2016, under the auspices of the Organization for Security and Co-operation in Europe, a meeting was convened with the Czech government, civil society, and international experts, with a view toward moving forward on the matter of remedies for the victims. The timing of the meeting was auspicious, as Switzerland was on the verge of adopting a comprehensive compensation mechanism for victims of similar practices. Experts from Norway and Sweden also presented their experiences of overcoming opposition to arrive at justice for people targeted for coercive sterilization and related practices.

In Norway, beginning in the 1990s, the Tater/Romani community began advocating for comprehensive documentation and redress for harmful practices, including coercive sterilization. From 1996 to 2000, the Norwegian Research Council earmarked funding for studying forced sterilization, and in 2000 historian Per Haave published a study entitled *Sterilization of Taters 1934–1977: A Historical Study of Law and Practice*. The study documented the sterilization of 125 Tater/Roma people, predominantly women, under the Sterilization Act, although this figure is not deemed—and was not claimed to be—comprehensive. According to the author, Tater/Roma women were especially overrepresented among those forcibly sterilized during the 1930s and 1940s. These findings prompted a demand from Tater/Roma representatives for an inquiry commission, and in October 2002 the Norwegian Parliament established an inter-ministerial working group to consider compensation for victims. Its 2003 report concluded that most cases, if brought to court, would be statute-barred and emphasized that these cases must be viewed within a context acknowledging the particular ethnic dimension of these harms. Since 2004, therefore, a previously existing *ex gratia* mechanism has been extended to cover survivors of coercive sterilization.[51]

Sweden has had several generations of efforts to address coercive sterilization and to explore the extent to which Roma were targeted. In Sweden, 63,000 people—again overwhelmingly women—were subjected to systematic sterilization between the mid-1930s and the mid-1970s. This history was recognized in the 1990s, and a compensation mechanism was established. However, for various reasons—including the politics of having adopted the mechanism—there was no particular recognition of Roma victims. To address this gap, Sweden established a historical commission on the treatment of Roma. The commission published a white paper in 2014 that found a dark history when it comes to the country's treatment of Roma and Travellers, including efforts to expel Roma from Sweden, systematic ethnic monitoring, and coercive sterilization.[52]

Switzerland began addressing these issues when it issued an official apology in 1986 to victims of the "Children of the Highway" scheme, in which the government had, for around 40 years, supported efforts to remove children from families deemed or viewed as problematic—very heavily involving the Jenish/Traveller community, a Gypsy-affiliated group. In 2014, a popular initiative was launched demanding a full independent inquiry into the issue, as well as 500 million Swiss francs to compensate survivors. More than 100,000 signatures were gathered, and legislation was duly initiated. The bill included acknowledgment of the victims' suffering; regulations concerning access to archives that might contain relevant records; measures to raise public awareness and construct symbols of remembrance; support for an academic inquiry; and financial measures for the victims as a gesture of solidarity. The Swiss Parliament adopted the law in 2016, and it entered into force in 2017.[53]

In the Czech Republic, suggestions that a mechanism similar to those described above were raised as early as 2005, when the Ombudsperson's Office issued its report. The report makes extensive reference to the Swedish experience, including government efforts as of 2005.[54] In 2014, a new Czech government appeared open to the possibility of

adopting such an *ex gratia* remedy mechanism for victims of these practices. Adoption of such a mechanism was included in the government program, and in 2015 a compensation bill was submitted to the government for consideration. However, in a striking turn of events, support for the bill was abandoned by nearly all relevant government officials, and the effort was abruptly dropped.[55]

Indeed, the Czech government has not requested any further investigation into the historical background that gave rise to the coercive sterilization of 90,000 persons in the former Czechoslovakia and present-day Czech Republic, despite the statement in the report of the Ombudsperson's Office that "[i]t is a major debt of Czech historiography that very little literature has been dedicated to the Czechoslovak eugenic movement so far and that treatment of this chapter of Czech history is not consciously worked with in society."[56] Indeed, even the expression of regret by the Czech government in 2009 was worded in such a way as to communicate that these wrongs were "individual" (in other words, isolated) cases, downplaying the systemic nature of the acts.

The government's current position—that all victims should pursue remedies via the courts—has threatened to compromise the solidarity of the women concerned, effectively removing those few whose cases can plausibly be brought to court from the wider community of victims. It is a powerful credit both to the Ostrava-based Group of Women Harmed by Sterilization and to its spokeswoman, Elena Gorolová, that despite over a decade of effectively fruitless efforts, victims continue to meet regularly and endeavor to move forward with their agenda.

Conclusion

As currently constituted, the Czech legal system is manifestly incapable of providing effective remedies to victims of coercive sterilization, whose numbers are known to far exceed the five individuals who have received compensation after spending years in domestic courts, an undertaking that was possible largely thanks to financial assistance from international and other donors. Czech law should establish an *ex gratia* remedy mechanism for victims of these practices, as a component of wider measures to provide effective remedies to victims of coercive sterilization, as required under international law.

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Intersectional Discrimination of Romani Women Forcibly Sterilized in the Former Czechoslovakia and Czech Republic

GWENDOLYN ALBERT AND MAREK SZILVASI

Abstract

This paper reviews domestic and international activism seeking justice for Romani and other women harmed by coercive, forced, and involuntary sterilization in the former Czechoslovakia and Czech Republic. Framed by Michel Foucault's theory of biopower, it summarizes the history of these abuses and describes human rights campaigns involving domestic and international litigation, advocacy, and grassroots activism, as well as the responses of the Czech governments. The paper describes how legal and policy work during the past decade has led to recognition of coercive, forced, and involuntary sterilization as a present-day human rights issue worldwide, to the adoption of new guidelines on female sterilization, and to a joint statement on the issue by seven UN agencies. Relying on academic literature, reports by domestic and international human rights groups, state investigations, judgments from Czech courts and the European Court of Human Rights (ECHR), media reports, and the experience of the authors, who have been allies of the Romani women harmed in the Czech Republic since 2005 and 2012, respectively, the paper describes the current state of play with respect to achieving redress for them, including current conceptual, legal, political, and social obstacles and their antecedents in 20th century notions of population control.

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Introduction

Surgical sterilization is one of the most effective contraceptives, an elective procedure of no therapeutic value.[1] The medical consensus is that female contraceptive sterilization should be considered permanent.[2] Its elective, permanent nature means the decision to undergo it should be made voluntarily, based on an informed choice, and without coercion.[3] An informed choice means the woman understands the benefits and risks of sterilization and other contraceptives, freely decides which method suits her, and is free to change methods. A permanent procedure precludes being able to change methods, and therefore an adequate period between a medical consultation about sterilization and a definite request for such a procedure should apply to eliminate potential short-term bias in making this decision. According to leading ethicists in the reproductive health care field, health care providers' ethical obligations include respecting women's autonomy, doing no harm, and providing services equitably.[4]

These ethical obligations and their legal corollaries have been violated by cases of unethical sterilizations performed on women worldwide.[5] One set of cases of coerced, forced and involuntary sterilizations was initiated by communist Czechoslovakia in the early 1970s and perpetuated by its democratic successor states in the 1990s.[6] (Coerced sterilization involves the intention of a third party to induce consent to sterilization, either through a benefit or threat. Involuntary (non-consensual) sterilization is a procedure that happens against the will of or without the knowledge of the affected person. Forced sterilization involves sterilization without seeking consent.) This state-sponsored, systemic sterilization policy exemplifies how the eugenic discourse of invasive state interventions into family life, health and privacy persists to the present day and how the state, as embodied by health care and social care providers, continues to wield immense power over individuals' reproductive strategies.

As human rights have been infringed upon in the name of public health, human rights advocacy to combat such infringement has proliferated. One result of that advocacy is the global expansion and strengthening of informed consent policy. The principle of informed consent in medicine was introduced by the 1947 Nuremberg Code and has been refined ever since, including by the 2005 UNESCO Universal Declaration on Bioethics and Human Rights and the 2011 International Federation of Gynaecology and Obstetrics (FIGO) Guidelines.[7] Informed choice and consent are supposed to have become crucial, irreplaceable components of contraceptive sterilization by now.[8]

Origin and context of sterilization policies: Population control and eugenics

Czechoslovak (and later, Czech and Slovak) state policies targeting women for forced sterilization should not be deemed exceptional in the context of modern European states. As Michel Foucault has theorized, modern European states and invasive population control policies have been strongly mutually intertwined.[9]

Foucault sees the powers of the emerging modern state target the human body as early as the 18th century, cultivating and disciplining human reproduction.[10] With the emergence of the modern state, the human body is turned into an object of "disciplinary power," which focuses on controlling and curtailing its (re-)productive possibilities.[11] For Foucault, the human body is a heterogeneous multiplicity, an unorganized reservoir of bodily affects, mechanical energy and psychological processes, and what he termed "disciplinary power" is the technique of organizing these human multiplicities in a productive manner that fits the state's objectives.[12] Modern rulers assume the power to "make" people live or "let" them die according to the utility the individual can provide the state: "a new right which does not erase the old right [the right to kill] but which does penetrate it, permeate it. This is the right, or rather precisely the opposite right. It is the power to 'make' live and 'let' die."[13] The objective is to maximize individual human potential in terms of individual economic effectiveness and minimize human potential in terms of individual political resistance.[14] Human bodies therefore increase in

value to the state only so long as they are deemed both individually docile and useful.

This discourse has prevailed not only in health care, but in the realm of privacy and sexual life, transforming sexuality and reproduction into yet another means of production to serve the state. People were mainly supposed to have sex to procreate, to produce new human resources for the state, and all other aspects of sexuality were deemed "unproductive" and were therefore to be eliminated and suppressed.[15]

Apart from the modern state's focus on organizing individual human bodies to maximize their utility, Foucault analyzed the state as organizing and regulating the collective biological life of society—the population—beginning in the second half of the 18th century.[16] His concept of biopolitics (biopower) notoriously coined a discourse that discusses human societies as if they were easily comprehended, organized units.[17] When biopower is wielded, it does not approach people in society as individual human bodies or units of production, but as a collective biological body, as the aggregate population. Through biopower, the state assumed it would execute full control over the biological aspect of society by regulating population.[18] In this framework, states that fail to exercise their biopower to regulate sexual and reproductive behavior risk slipping into the biological phase of "degeneration."

According to Foucault, when state power invests itself into disciplining individual human bodies in order to regularize the population out of fear of degeneration, then racism emerges as a state doctrine in order to separate putatively biologically "degenerate" groups (which are politically identified) from the rest of society in order to control or eliminate them.[19] Racism introduces a war-like relationship within society that has its own perverted logic, as follows: The more such "degenerate" groups are eliminated, the better the "non-degenerate" (normal) group can live. Racism is, in Foucault's view, a method of organizing societal hierarchies according to the threat of "degeneration" that this or might group putatively poses to the population. The modern state assumes a responsibility to identify and control "degenerate" groups and thus assure the population will regenerate correctly.[20]

Forced sterilizations are a striking example of an intervention by the modern state to control populations and to limit the reproductive strategies of any group ideologically deemed to pose a "degenerative" threat to society as a whole. Forced sterilization policies introduced in the first half of the 20th century were based on the effort to eliminate the reproduction of disability or the reproduction of ethnic groups and also targeted the poor, the unmarried, and women seeking abortion. Forced sterilization policies in Europe were implemented in Sweden, Norway, Austria, Denmark, Finland, France, Germany, and Switzerland. By engaging in the forced sterilization of Romani women since the 1970s, Czechoslovakia (and the Czech and Slovak states later on) did not do anything exceptional; rather, they joined the ranks of modern states that have executed and still are executing biopower policies upon groups ideologically deemed "degenerate," be they the chronically ill, people living with disabilities, ethnic minorities, the politically unreliable, or the poor.

Sterilizations in former Czechoslovakia and successor states

During communism, social workers offered women financial inducements to undergo sterilization. Some women chose to be sterilized of their own free will, while others were coerced or misled into doing so. Health care providers also forcibly sterilized Romani women during other ob/gyn services or surgeries without seeking their consent. Hundreds of women have been illegally sterilized without their informed choice or consent, and nobody has ever been held responsible.[21]

Financial inducements for sterilization formally ended in 1991 after the 1989 transition to democracy. Social workers have reportedly coerced Romani women into sterilization through threats after 1991, and health care providers have continued to sterilize women without consent during other surgeries into the 21st century. Public discussion of these abuses has revealed intersectional persistence of ableist, antigypsyist, eugenic and racist motiva-

tions in Czechoslovak and then, respectively, Czech and Slovak society.[22]

Legal framework of biopower

In 1972, the health ministries of the federal republics of Czechoslovakia jointly issued a sterilization law; the guidelines issued then by the Czech Socialist Republic applied there until a new law took effect in the Czech Republic in 2011.[23] "Directive No. 01/1972 of Ministry of Health and Social Affairs of the Czech Socialist Republic" passed on 17 December 1971 and took effect on 1 January 1972. The Decree expanded the provisions of the Law on Public Health from 1966. Its guidelines described the various indicators under which sterilizations could lawfully be performed.

In 1988, a new decree amended the Social Security Act in the Czech Socialist Republic and stipulated compensation schemes for sterilization until such schemes were abolished in 1991.[24] Statistics from some Czechoslovak regions show that from 1972 until the 1990s, Romani women constituted a disproportionately large group among those sterilized—up to 36.6 % of all female sterilizations in those years were performed on Roma (who are estimated to have constituted less than 2% of the population).[25] Since 1989, at least 300 Romani women have complained to various authorities, including the courts, that doctors have sterilized them without consent.[26] At least two cases are now pending against the Czech Republic with international courts and committees alleging forced sterilization.[27]

Věra Sokolová discusses how Czechoslovak discourse about the "gypsy question" played on societal anxieties about "degeneracy" (in the Foucaultian sense), casting Roma as deviant, as not Czechoslovaks, and as people without an ethnic or national identity.[28] In this discourse, the term "gypsy" embodied social deviance, not ethnic identity. Sokolova notes that

> *the ethnic target of the sterilization policy was never fully enunciated from above nor fully institutionalized, but was rather always implicitly understood to refer to Romani women by local practitioners who inhabited a dual world between "official" discourse and unofficial racial bias; the documentary record and recollections of those involved reveal that "much of the initiative to urge or even pursue Romani women to undergo sterilization came from […] local offices.*[29]

Such local initiative was part of the larger project to enforce what Sokolová calls "the mechanisms of social control that enabled the discrimination of Czechoslovak Roma to flourish under the guise of social welfare."[30] Those drafting law and policy did so such that any discriminatory intent would not be apparent from the letter of the law. In a context of apparently falling fertility rates among non-Roma and apparently rising fertility rates among Roma, the "normalizing" action to take was obvious. Active targeting of Romani women was an element of population policy, driven by the state's eugenic concern over public health. Because the list of medical indications for sterilization included a "social" indicator, medical records sometimes even listed "gypsy origin" as the indication for sterilization.[31]

Czechoslovak population policy

The 1960 Czechoslovak Civil Code defined motherhood as an obligation.[32] Although state population policies from the 1950s onwards were dominated by pro-natal measures, not all children were considered to benefit "the nation." Pro-natal measures were focused exclusively on families whose offspring the state anticipated would be healthy and whose development would not be endangered by material deprivation.[33]

Communist elites had begun to undertake various disciplinary measures with respect to the Roma as a population in the 1950s. Czechoslovak state media alleged a Roma population "explosion," using rhetoric that was being deployed elsewhere in the Global North about its own minorities and populations of the Global South.[34] In this rhetoric, social ills were allegedly the genetically inevitable outcomes of "uncontrolled" minority procreation. The Commission of the Government of the Czech Socialist Republic for Gypsy Population Issues therefore recommended that Romani women spe-

cifically be given contraception free of charge, but many had no access to a range of contraceptive methods or information about them on which to base an informed choice.[35]

In 1969 the Czech and Slovak Socialist Republics became legislatively independent of each other.[36] By 1970, during "normalization," public health officials in the Czech Socialist Republic interpreted the reportedly slow uptake of contraception by Roma as meaning Roma were incapable of gauging how many children they could "properly" care for.[37] In 1972, the Czechoslovak Federal Ministry of Labor and Social Affairs issued a publication for social workers entitled "Care for Socially Unadjusted Citizens," which asserted that "material inequalities" had been eliminated by socialism, that the Czechoslovak population was "homogeneous," and that "social pathology" was a "residue" of the capitalist regime that was still being transmitted intergenerationally by the "culturally substandard" (the "degenerate," in Foucaultian terms).[38] What was never made explicit, because it was implicitly understood, was that this analysis pathologized Roma. Czechoslovak demographers even described the reported sex ratio among Roma as "unnatural" (more males), as opposed to the "natural," "Czechoslovak" ratio of more females. "Gypsies" were characterized as "ignorant" about reproduction in contrast to "civilized" "Czechoslovak" reproduction.[39]

A Czechoslovak gynecologist who was the head of his hospital department published a paper in 1975 about sterilizing Romani women for "socioeconomic reasons," calculating that the amount the state paid women as a sterilization incentive was far less than the "cost" of "genetically damaged" children.[40] Disability among Roma was assumed to result from alleged inbreeding, and another 1975 study described the population "explosion" of "Gypsies" as resulting in the "decreasing quality of the Gypsy population itself."[41] Roma were "abnormal," their apparently higher fertility viewed as a symptom of allegedly "bad" parenting.[42] Roma parents were caricatured as not disciplining their children, not loving their children, promoting substance abuse to them, and sexually abusing them.[43] Since Roma families allegedly endangered the social order, the state decided to control their procreation.

Who was being sterilized in Czechoslovakia (and why) did not go unnoticed by those who had eyes to see and ears to hear. The International Covenant on Civil and Political Rights had been ratified by Czechoslovakia in 1975 and was seized upon by the dissident movement as a tool to monitor adherence to human rights. The Charter 77 organization was created and in 1978 published "Document 23" on the situation of "Gypsies," reporting that Romani women's consent to sterilization was being obtained by "suspicious" means and that social workers' performances were being judged according to how many Romani women they coerced into undergoing sterilization. Document 23 warned that "Czechoslovak institutions will soon have to answer charges that they are committing genocide."[44]

While the rights of persons seeking sterilization were prescribed and explicit consent was required in writing, social workers coerced signatures through incentives or threats (reportedly as recently as 2007). Sometimes consent was never sought and sterilization was done during other surgery, or sought under circumstances that rendered the signature invalid as an expression of intent. Women were asked to sign when they were in labor, or were asked to "consent" to sterilization after the fact.[45]

Activism, advocacy, and litigation

Researchers Andrš and Pellar interviewed Romani women throughout Czechoslovakia in an effort to map sterilization in the Roma community between 1967 and 1989.[46] Doctors discussed Roma reproduction with these male researchers in dehumanizing terms and freely admitted to automatically sterilizing Romani women during Caesarean section deliveries, justifying this as necessitated by the "inferior quality" of Romani children and the alleged cost to society of caring for them.[47]

In 1990, the Czechoslovak government's human rights committee asked the Czech and Slovak general prosecutor to investigate allegations of the coercive sterilization of Romani women.[48] The investigation was concluded in 1991 by recommending

legislative changes and asking district prosecutors to advise all local medical authorities where sterilizations had been performed unlawfully that this was the case (a request that was apparently ignored or had no effect if undertaken).[49] Helsinki Human Rights Watch also reported on the issue.[50]

The Czech and Slovak Federative Republic ratified the European Convention for the Protection of Fundamental Rights and Human Freedoms in 1992. That made it possible for victims to complain to the European Court of Human Rights (ECtHR).

Seeking justice in the Czech Republic 1993–present

Sokolova reports that from 1995 on, the issue of the forced sterilization of Romani women was increasingly discussed by civil society.[51] The first lawsuits over forced sterilizations were filed at this time, with varying success.

In 2003, the European Roma Rights Centre (ERRC), an international human rights organization, approached the Czech government's human rights commissioner regarding forced sterilization of Roma in the Czech Republic. He recommended the issue be raised with the Czech public defender of rights (the ombudsman).[52] In 2004, the ERRC presented some allegations of coerced or forced sterilization to the ombudsman and other allegations to the United Nations Committee against Torture.[53]

The ombudsman asked the Czech health ministry to review the medical records of 50 (out of 87) women who sent complaints to the ombudsman.[54] The ministry responded by setting up a panel including other cabinet representatives and a Council of Europe legal expert. The ombudsman forwarded the cases to the Czech prosecutor-general; all were dismissed for procedural reasons or because the statute of limitations meant victims could only claim compensation within three years of suffering the harm. The ombudsman published a final statement on his investigation in 2005, contrasting the ministry's findings with his own and declaring the vast majority of cases to have been illegal.[55] He also concluded that state policy and practice, up to 1991, had been motivated by eugenics.[56]

Coercive sterilization in the Czech Republic at the European Court of Human Rights

In 2005, a Czech court ruled that Helena *Ferenčíková*, a Roma plaintiff, had been sterilized in 2001 without her informed consent, ordering the hospital to apologize in writing but not awarding damages. Both sides appealed, the verdict was upheld, and the hospital apologized in 2007. *Ferenčíková* appealed for compensation and the ECtHR declared her case admissible in 2010. She settled in 2011; the Czech government informed the ECtHR it would pay her EUR10, 000 to cover court costs and damages.[57]

Civil and criminal verdicts in other cases began to emerge. In 2007, police investigated two complaints forwarded from the ombudsman's office and found that while crimes had happened, they could not be prosecuted because of the statute of limitations.[58] In 2007, a Czech court awarded EUR18, 200 in damages to Roma plaintiff Iveta Červeňáková, who was forcibly sterilized but not informed of that fact at the time; she did not come to understand the kind of procedure that had been performed on her and its implications for her reproductive future until seven years after the operation. That ruling was overturned; she was told the statute of limitations applied from the time she had been sterilized, not the time she had become aware of her sterilization, and that she had sued too late. The hospital was instructed to apologize. In 2011, the Supreme Court upheld the original ruling and returned the case to the High Court. It was declared admissible before the ECtHR in 2012 but was not pursued; she settled with the hospital for EUR20, 340 in damages and EUR2,457 for court costs.

The case of R.K. v. the Czech Republic also ended with a friendly settlement in November 2012 after four years pending before the ECtHR. First and second-instance rulings had established the rights violation and ordered financial compensation.[59] The parties agreed to a financial award of EUR10,000. The government admitted the case had been an "exceptional" failure by the state, but denied any systemic practice.

In 2010, Czech courts awarded damages

in two other such cases; media reporting on the awards did not mention the dates or locations of the sterilizations or the ethnicity of the plaintiffs.[60] In December 2015, the ERRC and the League of Human Rights, an NGO, submitted a third-party intervention to another such case against the Czech Republic before the ECtHR.[61]

While the ECtHR has been open to ruling on cases of coercive or forced sterilization of Romani women in the Czech Republic and Slovakia as gross human rights violations,[62] In Slovakia, the *Body and Soul* report produced by the Center for Civil and Human Rights Poradna and the Center for Reproductive Rights (CRR) about the involuntary sterilization of Romani women was published in 2003, followed by several cases submitted to the domestic courts which eventually made their way to Strasbourg. Despite three ECtHR cases having since decided against Slovakia (*V.C. v Slovakia* (2011), *N.B. v Slovakia* (2012), and *I.G. and others v. Slovakia* (2012)), and despite a recent case confirming compensation for involuntary sterilization by a Slovak District Court (2017), the Slovak government's response has only acknowledged "individual failures" and has refused to introduce any direct compensation measures. The ECtHR judgments have so far not found ethnic discrimination or intersectional injustice against these women.[63]

Advocacy beyond the courts

In 2006, Romani women who had been forcibly sterilized began their activism. The spokesperson for the informal Group of Women Harmed by Forced Sterilization, Elena Gorolová, spoke to the UN Committee on the Elimination of Discrimination against Women (CEDAW) while her fellow survivors simultaneously demonstrated in Ostrava, receiving national media attention. CEDAW noted the final statement from the ombudsman's office and recommended the state take "urgent action" to compensate the victims.[64] Ever since, survivors unable to sue have worked domestically and internationally to seek redress from the government.

Other international human rights bodies followed suit. In 2007, the UN Committee on the Elimination of Racial Discrimination (CERD) echoed CEDAW's findings.[65] In 2008, the UN Human Rights Council's Universal Periodic Review (UPR) called on the Czech government to provide reparations.[66] Those calls have been reiterated by progressively more countries involved in the UPR processes of 2012 and 2017.[67]

In 2009, the Czech government's Human Rights Council recommended that the government introduce compensation. In July 2009, the government rejected that motion, but in November 2009 it adopted a resolution expressing regret "over the instances of errors found to have occurred in the performance of sterilizations." The Human Rights Council reiterated its compensation recommendation in 2012.[68]

In 2013, the Czech Helsinki Committee, an NGO, drafted an ex gratia compensation bill.[69] Their draft was submitted to the Czech human rights minister, whose team drafted its own version of such a bill and submitted it to the government in February 2015. The government rejected it in September 2015 without explanation.[70]

In 2016, the human rights commissioner of the Council of Europe raised the Czech government's rejection of the compensation bill with the prime minister and received a response, which the commissioner then released.[71] The prime minister maintains that the state has never supported systemic sterilization among Roma women and recommends that all previously harmed women sue.[72] He states the belief that victims have always had the option of suing health care facilities and says the government decided not to establish a compensation mechanism because allegedly "the assessment of individual cases from distant past [sic] would be difficult and questionable also due to the possible failure to retain medical documentation or other evidence." Finally, he claims court fees can be waived, legal representation can be provided at the state's expense, and NGOs might bear the financial burden of representing plaintiffs (a remarkable assertion for a government to make), finally alleging that the state is on the brink of providing a free legal aid system that will address all

potential obstacles.

This approach means local facilities would be the entities to sue and begs the question of whom to sue should the facilities no longer exist. The claim that "legal representation can be appointed at the state's expense" is belied by the current bill on free legal aid being discussed by the Czech legislature, which proposes no such thing.[73]

The ERRC and League of Human Rights also submitted a joint individual complaint on behalf of six affected Roma women to CEDAW in February 2016.[74] All of those cases are statute-barred under Czech law.

Given that litigation has proven less than satisfactory when it comes to the scale of the numbers of victims requiring restitution, avenues beyond the courts have been approached for advocacy.

International responses to advocacy beyond the courts

The International Federation of Gynecology and Obstetrics (FIGO) is the only global organization representing national ob/gyn societies.[75] It has been refining its ethical guidance about contraceptive sterilization since 2003, when it adopted its "Resolution on Professional and Ethical Responsibilities Concerning Sexual and Reproductive Rights" urging professionals to protect women's rights in practice.[76] In 2004, FIGO published a code of ethics on sexual and reproductive rights that urges the profession to support decision-making that is "free from bias or coercion."[77]

In 2009, the Council of Europe and the Open Society Foundation's Women's Program supported a panel at FIGO's triennial congress with lectures about coerced, forced, or involuntary sterilization in Europe, India, and North and South America. This was followed by communication between activists and the FIGO Ethics Committee on refining FIGO's guidelines for female contraceptive sterilization, which were reissued in 2011 and mention the forced sterilization of Romani women and women living with disabilities.[78]

Open Society Foundations also launched the Campaign to End Torture in Health Care in 2010, including forced sterilization as an issue.[79] The 2012 FIGO congress featured a panel to discuss the new ethics guidelines. As a result, in part, of the campaign and many other advocates, the UN Special Rapporteur on torture published a 2013 report recognizing that treatment amounting to torture occurs in health care settings, including forced sterilization.[80]

Seven UN agencies—the Office of the High Commissioner for Human Rights, UNAIDS, the UNDP, UNICEF, the UN Population Fund, UN Women, and WHO—issued a 2014 joint statement on eliminating coercive, forced, and otherwise involuntary sterilization.[81] The recommendations were reviewed in 2015 by another FIGO panel. By including this content on the scientific program of its triennial congresses, FIGO has provided advocates the ability to reach health practitioners more directly than through the protracted tactic of litigation and to enlist them as allies.

The following UN and Council of Europe bodies have sent the Czech government recommendations of urgent action to investigate the extent of involuntary sterilizations and establish a compensation mechanism for the victims:

- CEDAW in 2006, 2010, and 2016;
- CERD in 2007 and 2011;
- the UN Human Rights Committee in 2007 and 2013;
- the UN Human Rights Council under the Universal Periodic Review in 2008, 2012 and 2017;
- the European Commission against Racism and Intolerance (ECRI) in 2009;
- the Commissioner for Human Rights of the Council of Europe in 2010;
- the UN Committee against Torture (CAT) in 2012;
- the UN Committee on the Rights of Persons with Disabilities (CRPD) in 2015;[82]
- Navanethem Pillay, UN High Commissioner for Human Rights (2008 to 2014);
- Gianni Magazzeni, Office of the High Commis-

sioner for Human Rights' Chief of the Americas, Europe and Central Asia Branch, Field Operations and Technical Cooperation Division;

- Nils Muižnieks, Council of Europe Commissioner for Human Rights;
- Mirjam Karoly, Senior Adviser on Roma and Sinti Issues at the Office for Democratic Institutions and Human Rights, Organization for Security and Cooperation in Europe (OSCE/ODIHR); and
- Soraya Post, Member of European Parliament.[83]

Forced sterilization in the 20th and 21st centuries has been prompted by fears of perpetuating the reproduction of people living with disabilities or people of stigmatized ethnicities, and has also targeted the poor, the unmarried, and women seeking abortion. Forced sterilization policies in Europe have been implemented in Austria, Canada, the Czech Republic, Denmark, Finland, France, Germany, Norway, Slovakia, Sweden, and Switzerland. Of those countries, Austria, Germany, Sweden, Norway, and Switzerland have assumed responsibility for those policies and enacted special remedies for victims, as have the American states of North Carolina and Virginia, with legislation planned for introduction in California. This progress is due to domestic and international advocacy that has created a platform for self-advocating women harmed by sterilization and civil society to join forces and pressure states.[84]

Conclusion

The dehumanizing cases of coerced, forced, and involuntary sterilizations from the former Czechoslovakia and its successor states are by no means singular or unique events. State sterilization policy targeting Romani women is one of the starkest manifestations of Foucault's theory of biopower. Introduced as an approach to curtail and control the size of the Roma population, which allegedly threatened to overtake the "majority" as defined in ethno-nationalist terms, and even more importantly, an approach to allegedly protect the Czechoslovak population against slipping collectively into alleged biological degeneration if the Roma were left to reproduce freely, these policies represent a case of modern (state) racism, defined by Foucault as biological warfare within a modern society. What makes Foucault's theory of biopower a particularly fitting explanatory framework for analyzing coercive sterilization policies is that those policies were the outcomes of the then-mainstream quasi-biological science of social engineering that spoke the language of "population control" unabashedly.

Throughout the 20th century, beginning in Sweden, many European states adopted coercive sterilization policies aimed at their minority groups which allegedly posed threats of biological degeneration and social disorder to the population, and Roma were the group constantly targeted. Czechoslovakia was among one of the last states to introduce these policies during its normalization era, but the ensuing years of systematic coercive sterilization and the persistence of this practice post-1989 represent one of the most drastic examples of biopower put into practice.

Human rights activism has managed to secure recognition of these violations internationally, including by the gynecological profession itself. The recalcitrance of the Czech authorities to take action to redress the individuals harmed indicates that, despite democratic governance, EU membership, and ratification of various human rights instruments, the Czech state is still insensitive to the fact that legal protection remains inaccessible to members of vulnerable groups, including victims of human rights abuse.

In November 2009, Czech Prime Minister Fischer expressed regret but did not acknowledge the state-supported, systematic nature of the practices he otherwise condemned.[85] That official action and the work of the Public Defender of Rights were responses to the efforts of civil society, especially self-advocating Romani women who decided to become activists committed to breaking the silence over these intimate atrocities. In September 2015, however, the Czech government added insult to injury by rejecting the compensation bill without public explanation.

Four self-advocating Romani women have since created a social theater performance, together with their allies, about their circumstances.[86] This was an exercise in raising awareness and a form of therapy for them to cope with their trauma. They and their civil society supporters, domestic and international, continue to fight for them to be compensated and for states to proactively ensure that no other women will ever endure such abuse at the hands of medical professionals or state authorities again.

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85. The Government of the Czech Republic, *Resolution of the Government of the Czech Republic 1424,* November 23, 2009. Available at http://racek.vlada.cz/usneseni/usneseni_webtest.nsf/0/6430E40ED2EFF39AC1257674004347C2/$FILE/1424%20uv091123.1424.pdf. See Czech Radio: http://www.rozhlas.cz/zpravy/politika/_zprava/661506.

86. M. Szilvasi, "When words fall on stony soil and hearts harden in the face of injustice: On coercive sterilisation and social theatre," in *Romea*, June 16, 2016. Available at http://www.romea.cz/en/news/czech/when-words-fall-on-stony-soil-and-hearts-harden-in-the-face-of-injustice-on-coercive-sterilisation-and-social-theatre. The social theater is available here: https://www.youtube.com/watch?v=ingQpd-dl05g&feature=youtu.be.

The Influence of Ethnicity and Displacement on Quality of Antenatal Care: The Case of Roma, Ashkali, and Balkan Egyptian Communities in Kosovo

KRISTEFER STOJANOVSKI, ALAKA HOLLA, ILIR HOXHA, ELIZABETH HOWELL, AND TERESA JANEVIC

Abstract

The conflict in Kosovo created mass displacement and a fractured health system. Roma, Ashkali, and Balkan Egyptian communities are particularly vulnerable to discrimination and exclusion from institutions. We aimed to examine Roma, Ashkali, and Balkan Egyptian disparities in quantity and quality of antenatal care received. We conducted a cross-sectional study in August 2012 with 603 women aged 15 or older who had given birth in the previous two years. We measured quantity of antenatal care using number of visits and quality of care using antenatal checklists. We used linear regression with interaction terms of displacement and type of health institution (for example, Serbian or Kosovar) to assess ethnic disparities in antenatal care. Women from Roma, Ashkali, and Balkan Egyptian communities received poorer quantity and quality of antenatal care compared to Kosovar Albanian and Serbian women. In adjusted models, Roma, Ashkali, and Balkan Egyptian women scored 3.5 points lower [95% CI (-5.2, -1.8)] on the checklists. Roma, Ashkali, and Balkan Egyptian women who were displaced received even poorer quality of care. Ethnic disparities exist in quality of antenatal care. Women from Roma, Ashkali, and Balkan Egyptian communities receive the poorest quality of services. As Kosovo strives to build a multiethnic health care system, a focus on equity is important to ensure the right to health for Roma, Ashkali, and Balkan Egyptian women.

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Background

Historical context

The countries of the former Yugoslavia faced extreme economic hardship, political instability, and social disconnectedness after the conflicts in the 1990s.[1] In Kosovo, the war created displacement and a refugee crisis of Kosovar Serbians, Kosovar Albanians, and Roma, Ashkali, and Balkan Egyptians.[2] Roma, Ashkali, and Balkan Egyptian communities in particular faced high levels of discrimination and prejudice during and after the conflict.[3] A crisis of lead poisoning among Roma, Ashkali, and Balkan Egyptians during the United Nations Interim Administration Mission in Kosovo in UN refugee camps, and the failure of UN and Kosovar political leaders to respond, serves as a stark example of discrimination experienced by the community.[4] More recently, segregation among ethnic groups in Kosovo, which was strongly present in the immediate years after the war, has decreased due to efforts by the international community, NGOs, and Kosovar government institutions. However, residential segregation remains in the municipality of Mitrovica where Kosovar Albanians and Kosovar Serbians live on opposite sides of the Ibar River.[5]

Who are Roma, Ashkali, and Balkan Egyptian communities?

Roma constitute Europe's largest ethnic minority with approximately 10–12 million Roma residing within European borders, of which the majority, 50–60%, reside in Central and Eastern Europe.[6] In the context of Kosovar ethnic tensions, populations that had historically been labelled as Roma began to identify themselves as Ashkali and Balkan Egyptian, with their own respective cultural and social norms, and predominant use of the Albanian language.[7] In the Kosovar context, the narratives and discourse of Roma, Ashkali, and Balkan Egyptian identities were complicated by the ethno-social and political environments during the time. Political forces at the time viewed Roma as more aligned to the Serbian cause, and deemed Ashkali and Balkan Egyptians as aligned with the Albanians during and after the war. The political and institutional systems further exploited these identities and narratives for political leverage.[8] In research of Roma, Ashkali, and Balkan Egyptian communities, the three ethnic groups are often considered together, although distinct, because of their socioeconomic position and health profiles relative to majority populations in the countries in which they live.[9]

Roma, Ashkali, and Balkan Egyptians have experienced oppressive disenfranchisement throughout Europe's history.[10] They have experienced discrimination and persecution from state level actors, institutions, and society in general. Roma faced genocide during the Holocaust and Roma women have faced forced sterilization and removal of children. Roma, Ashkali, and Balkan Egyptians experienced suppression of language, identity, and culture, witnessed a rise in ethnic hate crimes post-Communism, and experienced high levels of forced displacement during the break-up of Yugoslavia and the ensuing wars in the 1990s.[11] Roma, Ashkali, and Balkan Egyptians continue to encounter discrimination, which has been identified as an important social determinant to health.[12]

Research comparing Roma, Ashkali, and Balkan Egyptians to other ethnic groups in their countries of residence indicates that they have poorer health-related outcomes.[13] This extends to reproductive, maternal, and child health outcomes as well. A population-based study of 8,938 non-Roma and 1,388 Roma hospitalized singleton births in the north and southwest regions of the Czech Republic found that Roma women were 4.5 times more likely than non-Roma women to have a low birth weight baby.[14] They were also 2.8 times more likely than non-Roma women to have a pre-term birth.[15] Quality of care may also be poorer among Roma women. Qualitative research in the capitals of Serbia and Macedonia, and in settlements in southeast Slovenia with Roma, has shown lack of respect and poor quality of care in their experiences with reproductive health care services.[16] In one study, Roma women stated they would like to receive more understandable information from their gynecologist and also discussed unease when accessing

gynecological care; this indicates that provider and patient communication and information sharing may be a barrier.[17] A concern of the published literature is that Ashkali and Balkan Egyptians are often not the focus, while Roma receive particular attention, especially in European Union nations.

Health system in Kosovo

Since Kosovo declared independence in 2008, it has made substantial progress in reviving the post-war health system, but the system struggles from underfunding, slow progress of health care reform, limited availability of services, a growing private sector that operates with out-of-pocket payments, and limitations in access and utilization of health services by ethnic minorities.[18]

Unlike other post-Yugoslavia countries, Kosovo did not continue the social insurance system after the dissolution of Yugoslavia.[19] A direct taxation system, without a purchaser-provider split, was established to enable basic financing of the health care system. This ensured an allocation of about 8–10% of the total Kosovo budget toward health care financing, which accounted for around 3% of Kosovo's GDP.[20]

However, Roma, Ashkali, and Balkan Egyptian communities in particular have faced substantial barriers in access to health care services.[21] In the creation of the new Kosovar state, the Kosovar government emphasized and enshrined in the constitution the creation of multiethnic state institutions and the protection of human and minority rights.[22] But this has not been smooth and has been particularly problematic in the health care sector. In Serbian communities in North Mitrovica, the government of Serbia funds and operates parallel health care facilities.[23] According to a Kosovo Women's Network report, a majority of Kosovar Serbian women seek antenatal care services in a Serbian-managed health facility, and Roma, Ashkali, and Balkan Egyptian communities reported lower quality of the patient-provider relationship as compared to Kosovar Albanian and Kosovar Serbian women.[24]

Quality of antenatal care

The World Health Organization (WHO) recommends a minimum of four antenatal care visits for women globally in order to ensure adequate antenatal care. Coverage or the proportion of women receiving four or more antenatal care visits has long been the predominant measure of antenatal care quality.[25] It was an indicator to measure progress in the Millennium Development Goals and for the United Nations Secretary General's Commission for women and children's health.[26] Although an important indicator, quantity of care does not capture the substance or content of the antenatal care visit. Research has shown that there is variation in practice quality, as measured by medical vignettes, clinical observations, and household reports, although patients may have higher frequency of doctor visits.[27] For example, research in two middle-income countries, Mexico and Indonesia, showed that patients in poorer areas received lower-quality antenatal care.[28] Das and Gertler also found that indigenous persons in Mexico received lower quality care in private sector settings and to a much lower extent in the public sector as well.[29] A 2009 UNICEF study showed that 81% of all women had blood pressure, urine, and blood samples taken during antenatal visits, while 71% of Roma, Ashkali, and Balkan Egyptian women had the same services provided.[30] However, these data only included findings primarily collected on Kosovar Albanian women; no information could be calculated for the Kosovar Serbian women because the sample size was not large enough for analytic purposes.

Displacement and health issues

Prior research has also shown that displaced and refugee women tend to receive poorer health care services in their countries of residence than non-displaced and non-refugee women.[31] During and post-conflict, support systems, such as health care, kin, and support networks become destabilized and in some cases destroyed.[32] The destabilization has long-term ramifications for the health of those displaced, particularly maternal and child health. In recent years, Western Euro-

pean governments have forcibly deported Roma, Ashkali, and Balkan Egyptian communities to Kosovo.[33] Displacement and movement, in tandem with a fractured health system, may further restrict ability to access antenatal care.

Objectives and aims

Historical contexts, pervasive institutional discrimination, and displacement during war all play important roles in disparities in maternal health care. The objectives of our study were to assess the interplay of ethnicity, displacement, and institutions and their influence on the quality of antenatal care among women of Roma, Ashkali, and Balkan Egyptian communities in post-conflict Kosovo. Our aims were to (1) examine differences in demographic and psychosocial characteristics by ethnicity among women in Kosovo; (2) explore differences in content of antenatal care services; (3) assess the interaction between ethnicity and displacement on antenatal care outcomes among women in Kosovo; and (4) investigate how ethnicity, displacement, and type of institution (Kosovar vs. Serbian government-run) all interplay to influence quality of antenatal care.

Methods

We conducted a survey in Kosovo to assess ethnic inequalities in access and quality of maternal health care. Fieldwork took place in August 2012. We approached women who had given birth in the previous two years and were 15 years of age or older in each of the three main ethnic groups of Kosovo to participate in the study.

We sampled Kosovar Albanian, Kosovar Serbian, and women from Roma, Ashkali, and Balkan Egyptian communities. We utilized multistaged cluster random probability sampling, in combination with purposive and snowball sampling, which was informed by consultation with experts in the current location of Roma, Ashkali, and Balkan Egyptian and Kosovar Serbian populations. We enumerated the sample in three ways: (1) for the Kosovar Albanian sub-sample, the 2011 Kosovo census was used; (2) for the Kosovar Serbian sub-sample, both the 2011 Kosovo census and estimates from the Kosovo Office of Statistics were used due to the fact that Kosovar Serbian populations in Northern Kosovo did not participate in the Kosovo census and; (3) the 2005 Organization for Cooperation Security in Europe (OSCE) municipal profiles were used to enumerate the Roma, Ashkali, and Balkan Egyptian population. We designed each sampling point in the Kosovar Albanian and Roma, Ashkali, and Balkan Egyptian sub-samples to have four effective interviews, and five effective interviews in the Kosovar Serbian sub-sample. The residential breakdown was 40% urban and 60% rural. In the urban areas, we first contacted the third house or address number from the starting point. In the rural areas, we utilized purposive sampling by contacting a knowledgeable person in the village (such as a village head or elderly woman) and then every *nth* household was selected (for example, if eight households were eligible and the number of effective interviews was four, then every second household was selected). If the rural sampling point could not be completed with the effective number of interviews required, a nearby village was selected and was clustered within the same sampling point. In the Roma, Ashkali, and Balkan Egyptian sample, this occurred in four sampling points, while in Kosovar Albanian and Kosovar Serbian communities, the rural sampling points were completed in one village. In the Kosovar Albanian sample, 9% of the sample was conducted via snowball sampling and 12% in the Kosovar Serbian sample. We conducted face-to-face paper and pencil interviews. Both the Kosovar Ministry of Health and the Rutgers Biomedical Health Sciences Institutional Review Board approved the project.

Variables

Predictor. The main predictor of interest was ethnicity, categorized as Kosovar Albanian, Kosovar Serbian, and the combined Roma, Ashkali, and Balkan Egyptian communities. In addition, we included displacement as an interaction variable to examine whether experiences of displacement varied by women in the various ethnic groups. Displacement was assessed using the question, "Have

you ever been displaced?" We also included type of institution (Serbian versus Kosovar-government run) as an additional interaction variable.

Outcome. For antenatal care visits, we operationalized adequate care as four or more antenatal care visits (yes vs. no). The quality of antenatal care variable was based on two guidelines. We based the physical health and examination content (for example, "Did you receive an ultrasound") on WHO guidelines.[34] We created the content on communication (for example, "Did the doctor advise you about antenatal supplements?") using the United States Centers for Disease Control and Prevention (CDC) Pregnancy Risk Factor Assessment Survey.[35] For quality of antenatal care, we summed responses to a list of 20 antenatal care services and communications received during antenatal care visits. The maximum score possible was 20. We then created a composite score that combined the services and communication scores. Higher scores indicated higher quality of antenatal care.

Statistical methods. We first conducted univariate analyses; we report means and standard deviations for continuous variables and frequencies and percentages for categorical variables. We used a chi-square measure of association for categorical bivariate analyses, t-tests for continuous variables, and analysis of variance (ANOVA) for analyses of continuous variables by categorical with three or more groups (such as ethnicity). For all findings, p-values are reported.

We performed unadjusted linear regression analyses on antenatal care quality by ethnicity. Then, we ran adjusted linear regression models of ethnicity while controlling for education and age at first birth. We included displacement and location of service in additional adjusted linear regression models. We also employed adjusted (for education and age of first birth) linear regression models with interaction variables of ethnicity and displacement, where non-displaced Kosovar Albanian women served as the referent category. We developed adjusted (for education and age of first birth) linear regression models with the three-way interaction of ethnicity, location of service, and displacement. In these models, non-displaced Kosovar Albanian women receiving care in a Kosovar institution were the reference. In the Kosovar Serbian population, only two women had less than four antenatal care visits, thus we did not conduct regression models on this outcome. We report the regression coefficient and respective 95% confidence intervals. We used Stata 13 to analyze the data.[36]

Results

Sampling outcomes

A total of 603 women participated in the study: 200 in the Kosovar Albanian sub-sample, 200 in the Kosovar Serbian sub-sample, and 203 in the Roma, Ashkali, and Balkan Egyptian sub-sample with an overall response rate of 93.3%. The response rate in the Kosovar Albanian sub-sample was 89.3%, in the Kosovar Serbian sub-sample, 92.2%, and in the Roma, Ashkali, and Balkan Egyptian sub-sample, 99%. The high response rate among the Roma, Ashkali, and Balkan Egyptian sub-sample is typical of community-based research we have conducted.[37] Of the 203 women in the Roma, Ashkali, and Balkan Egyptian sub-sample, 25% (n=50) identified themselves as Roma, 54% (n=111) as Ashkali, and 21% (n=42) as Balkan Egyptian.

Sample characteristics

Roma, Ashkali, and Balkan Egyptian women had the highest percentage of women with primary education or less (95%, n=191), as compared to 5% (n=10) of Kosovar Serbian, and 46% (n=92) of Kosovar Albanian women (Table 1). Kosovar Serbian women's income was predominantly from salaries (87%, n=174), followed by Kosovar Albanian women (71%, n=141), while 45% (n=90) of Roma, Ashkali, and Balkan Egyptian women received social assistance as their main form of income. Kosovar Albanian women comprised the largest group of women displaced, 43% (n=87), followed by 33% (n=67) of Roma, Ashkali, and Balkan Egyptian women, and 18% (n=35) of Kosovar Serbian women. Lastly, the three communities live segregated from one another. Ninety six percent (n=176) of Kosovar Albanian women lived in

exclusively Albanian neighborhoods, 99% (n=179) of Kosovar Serbian women lived in exclusively Serbian neighborhoods, and 70% (n=122) of Roma, Ashkali, and Balkan Egyptian women lived within their own communities.

Pregnancy and antenatal care characteristics

Roma, Ashkali, and Balkan Egyptian women had the lowest average age of first birth, 20.3 years (standard deviation (SD)=4.7), compared to 23.6 years (SD=3.9) among Kosovar Serbian women, and 24.1 years (SD=4.6) among Kosovar Albanian women. Of all women (displaced and non-displaced) Roma, Ashkali, and Balkan Egyptian women had the highest percentage of women with less than four antenatal care visits; 19% (n=37); while 6% (n=11) of Kosovar Albanian and 1% (n=2) of Kosovar Serbian women received less than four antenatal care visits. Roma, Ashkali, and Balkan Egyptian women also had the lowest quality of antenatal care (Table 2). Out of a total possible score of 20, Roma, Ashkali, and Balkan Egyptian women had a mean content score of 13.6 (SD=4.3), Kosovar Albanian women a mean score of 17.1 (SD=4.8), and Kosovar Serbian women a mean score of 18.4 (n=3.5). As seen in the figures, Roma, Ashkali, and Balkan Egyptian women had the lowest frequencies for receipt of various antenatal care services and communication around antenatal care issues (Figures 1 and 2).

Unadjusted analyses of antenatal care quality

In unadjusted analyses, Roma, Ashkali, and Balkan Egyptian women had received poorer antenatal care. Roma, Ashkali, and Balkan Egyptian women had a mean antenatal content score that was three [β=-3.0, CI (-3.8, -2.0)] points lower than Kosovar Albanian women's mean score (Table 3). Kosovar Serbian women's mean score was 1.5 [β=1.5, CI (0.7, 2.3)] points higher. Displaced women's mean scores were 0.83 [β=-0.83, CI (-1.6, -0.4)] lower than non-displaced women (table not shown). In adjusted models, Roma, Ashkali, and Balkan Egyptian had scores that were two points lower [β=-2.0, CI (-3.0, -0.9)], while Kosovar Serbian women had

Table 1. Sample characteristics among mothers who gave birth in previous two years, Kosovo, all women, 2012

Variable	Kosovar Albanian	Kosovar Serbian	Women from Roma, Ashkali, Balkan Egyptian communities	
	N (%)	**N (%)**	**N (%)**	**p-value**
Education				**<0.00**
Primary or less	92 (45.8)	10 (5.0)	191 (95.0)	
Secondary	79 (39.3)	138 (69.0)	6 (3.0)	
University or higher	30 (14.9)	52 (26.0)	4 (2.0)	
Income source				**<0.00**
Salary/pension	141 (70.9)	174 (87.0)	32 (16.0)	
Social assistance	15 (8.0)	9 (4.5)	87 (45.0)	
Temporary employment	24 (12.1)	5 (2.5)	43 (21.5)	
Other	18 (9.1)	12 (6.0)	35 (17.5)	
Displacement				**<0.00**
Displaced	87 (43.3)	35 (17.5)	67 (33.2)	
Not displaced	114 (56.7)	165 (82.5)	134 (66.3)	
Inclusion in financial decisions				**<0.00**
Excluded	79 (44.4)	20 (10.5)	62 (38.8)	
Included	92 (51.7)	168 (87.9)	91 (56.9)	
Sole	7 (3.9)	3 (1.6)	7 (4.4)	
	Mean (standard deviation)	Mean (standard deviation)	Mean (standard deviation)	p-value
Age	29.0 (5.1)	27.5 (4.9)	27.2 (6.0)	<0.01
Age at first birth	24.1 (4.6)	23.6 (3.9)	20.3 (4.7)	<0.00

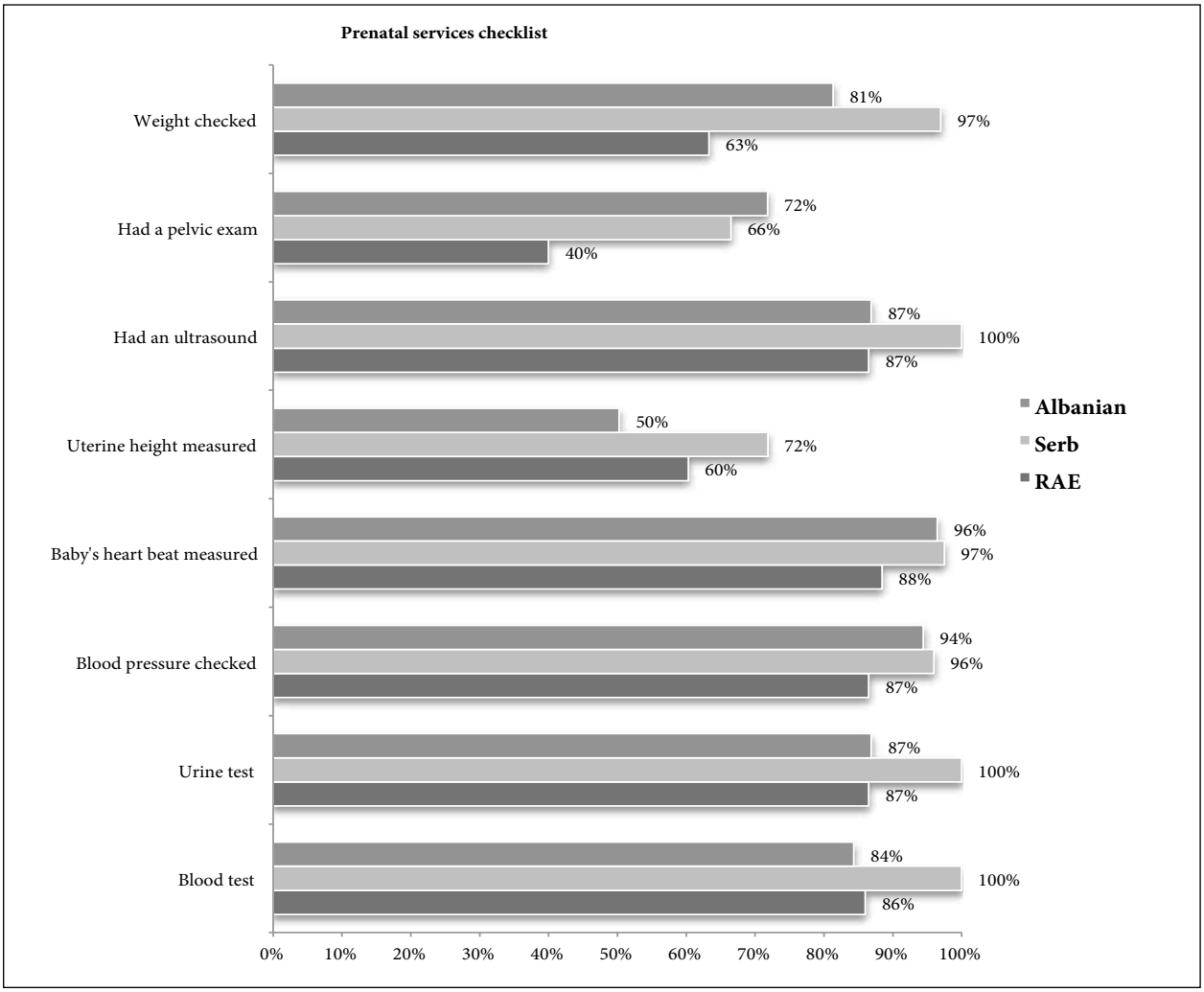
scores that were 1.3 points higher [β=1.3, CI (0.4, 2.1)]. In adjusted models (for education, age of first birth, displacement, and location of service), Roma, Ashkali, and Balkan Egyptian women's mean scores were 2.3 points lower [β=-2.3, CI (-3.5, -1.2)], as compared to Kosovar Albanian women.

Adjusted interaction analyses of antenatal care quality

In the adjusted interaction model, non-displaced Roma, Ashkali, and Balkan Egyptian women's mean score was two points lower [β=-2.1, CI (-3.5, -0.7)], as compared to non-displaced Kosovar Albanian women. Non-displaced Kosovar Serbian women's mean score was 0.8 points higher [β=0.8, CI (-0.5, 2.1)], as compared to non-displaced Kosovar Albanian women. In addition, displaced Roma, Ashkali, and Balkan Egyptian women had a mean score that was 2.4 points lower [β=-2.4, CI (-4.0, -0.90)], while displaced Kosovar Serbian women's mean scores were 1.7 points higher [β=1.7, CI (-0.1, 3.5), although not significant.

In examination of location of service, Kosovar Albanian and Kosovar Serbian women overwhelmingly sought care in institutions within their own ethnic group. However, Roma, Ashkali and Balkan Egyptian women receiving care in Kosovar institutions had mean scores that were 2.4 points lower [β=-2.4, CI (-3.5, -1.3)], as compared to Kosovar Albanian women receiving care in Kosovar run institutions. Roma, Ashkali, and Balkan Egyptian women receiving care in Serbian-run institutions

Figure 1. Receipt of antenatal care examination services among women in Kosovo, all women, 2012



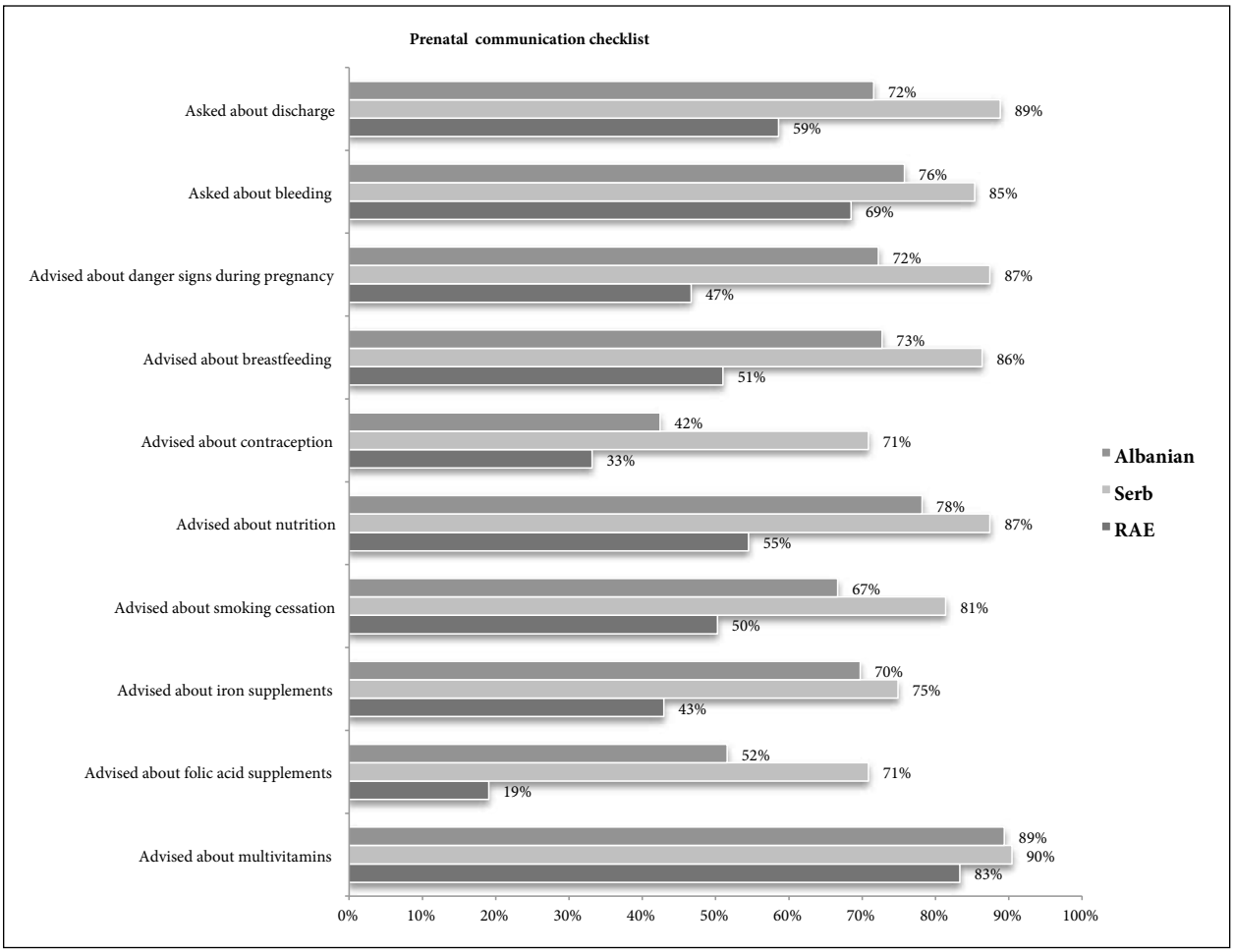
had mean scores that were not significant. Kosovar Serbian women receiving care in a Serbian-run institution had a mean score that was 0.8 points higher [β=0.8, CI (-0.09, 1.8)], as compared to Kosovar Albanian women receiving care in a Kosovar-run institution.

In the three-way interaction of ethnicity, displacement, and type of institution, Roma, Ashkali, and Balkan Egyptian women received the lowest quality of care regardless of the various interactions. Non-displaced Roma, Ashkali, and Balkan Egyptian women receiving care in a Kosovar-run institution had mean scores that were 2.1 points lower [β=-2.1, CI (-3.5, 0-0.8)], and non-displaced Roma, Ashkali, and Balkan Egyptian women receiving care in a Serbian-run institution had mean scores that were 3.3 points lower [β=-3.3, CI (-6.2, -0.4)]. Among displaced Roma, Ashkali, and Balkan Egyptian women receiving care in Kosovar-run institutions, their mean score was three points lower [β=-3.0, CI (-4.6, -1.5)], while those receiving care in Serbian-run institutions saw no difference in their scores.

Discussion

We found ethnic inequities in the quality of antenatal care among women in Kosovo. Women from Roma, Ashkali, and Balkan Egyptian communities as compared to Kosovar Serbian and Kosovar Albanian women received poorer quality antenatal care as identified by the use of antenatal care checklists. Stratified analysis indicated that women from Roma, Ashkali, and Balkan Egyptian communities received fewer antenatal examinations and, to an even greater extent, poorer quality of communication regarding antenatal care. Women from Roma, Ashkali, and

Figure 2. Completion of essential checklist items that require communication, all women, 2012



Balkan Egyptian communities that had a history of displacement during and after the conflict received even poorer antenatal care services, especially those in the Kosovar-run institutions. These findings indicate that as Kosovo develops multiethnic state institutions, specifically the health care system, improvements are needed. Particular attention should be paid in development of communication guidelines. Communication guidelines can help providers working with ethnic communities to ensure cultural humility and sensitivity, which research has shown is necessary in ensuring the right to health for childbearing women.[38]

A previous UNICEF study called attention to the need for improved antenatal care in Kosovo.[39] However, these data may mask differences in quality of antenatal care services, as the findings do not analyze specific subgroups of Kosovar Albanian, Kosovar Serbian, and Roma, Ashkali, and Balkan Egyptian women. The outdated 2011 Kosovar census was largely used to develop the clusters from which women were sampled, indicating potential concerns about representation. In addition, data on Kosovar Serbian women could not be calculated due to the limited sample. It is important to ensure that subgroup analyses are incorporated because findings from the region show that Roma, Ashkali, and Balkan Egyptian women and lower socioeconomic status Roma, Ashkali, and Balkan Egyptian women have poorer birth outcomes.[40]

Antenatal care is an important point of intervention to improve birth outcomes and child health.[41] Although most women in Kosovo deliver in hospitals, as our findings show, women from Roma, Ashkali, and Balkan Egyptian communities received poorer antenatal care services.[42] Prior research has shown that discrimination is prevalent among Roma women (focus was explicitly on Roma, as Ashkali and Balkan Egyptian are a smaller group in Europe) seeking maternal health services across Europe encounter discrimination.[43] This discrimination creates demand-side concerns, where Roma women refuse to access care due to concerns of stigma or cultural and language barriers, thus limiting access to antenatal care. Furthermore, the discrimination Roma, Ashkali, and Balkan Egyptian women experience serves to exacerbate issues surrounding acceptable and quality antenatal health services.[44]

Our findings suggest that displaced Roma, Ashkali, and Balkan Egyptian women who receive care in Kosovar institutions received the poorest-quality antenatal care. War and forced displacement disrupts the lives of those impacted, as well as all governmental systems including health and rule of law. One structural barrier for Roma, Ashkali, and Balkan Egyptian women is statelessness due to lack of government documentation.[45] Although we did not ask for documentation in our survey, it is possible that displaced Roma, Ashkali and Balkan Egyptian women were less likely to have identification documents, making it more difficult to access antenatal care. In addition, the fact that the quality of care received by Roma, Ashkali, and Balkan Egyptian women was lowest in

TABLE 2. Differences in antenatal care use and quality among women in Kosovo, all women, 2012

	Frequency of antenatal care visits			Antenatal content score	
	<4 visits	**4+ visits**		**Mean score**	
	N(%)	**N(%)**	**p-value**	**Mean (standard deviation)**	**p-value**
Variable					
Ethnicity			**0.00**		**<0.00**
Roma, Ashkali, Balkan Egyptian communities	37 (19.5)	153 (80.5)		13.6 (4.3)	
Kosovar Serbian	2 (1.1)	176 (98.9)		18.4 (3.5)	
Kosovar Albanian	11 (5.7)	183 (94.3)		17.1 (4.8)	
History of displacement			**0.646**		**<0.04**
Displaced	19 (10.4)	163 (89.6)		14.3 (4.1)	
Not displaced	31 (8.2)	348 (91.8)		15.1 (4.0)	

Kosovar institutions in particular could be due to barriers such as language and government policy. Roma tend to speak Romani or Serbian in Kosovo, while Ashkali and Balkan Egyptian generally speak Albanian. Because Kosovar institutions use the Albanian language, Serbian and Romani speakers may face language barriers in communicating with the health care staff. Furthermore, health insurance financing and ability to pay are different according to Kosovar and Serbian policies, which may alter how the institutions are run. Health insurance in Serbian-run institutions would follow Serbian law, which may allow Roma, Ashkali, and Balkan Egyptians access to health insurance by declaring they are part Roma, Ashkali, or Balkan Egyptian.[46] However, Kosovar law doesn't guarantee health insurance rights via this avenue and no social insurance is provided, thus limiting the ability of Roma to pay for services, which could influence quality of care received. Finally, displaced Roma, Ashkali, and Balkan Egyptian communities may be more likely to live in isolated neighborhoods and have lower income levels, creating geographic and ability to pay variation in quality of care that could explain our findings. We were not able to test these hypotheses in this study, but the suggestion that formerly displaced Roma, Ashkali, and Balkan Egyptian women might be most vulnerable in accessing health care might be explored in further qualitative research and during

TABLE 3. Unadjusted and adjusted analyses of antenatal care quality among women in Kosovo, 2012

	Antenatal care content score	
	β	95% CI
Model 1 (n=455)		
Ethnicity		
Kosovar Albanian	**Reference**	
Roma, Ashkali, and Balkan Egyptian communities	-2.91	(-3.77, -2.05)
Kosovar Serbian	1.50	(0.72, 2.28)
Model 2 (n=452)		
Ethnicity		
Kosovar Albanian	**Reference**	
Roma, Ashkali, and Balkan Egyptian communities	-1.93	(-2.98, -0.88)
Kosovar Serbian	1.26	(0.41, 2.12)
Education		
Primary or less	**Reference**	
Secondary	0.81	(-0.23, 1.86)
University or greater	1.31	(0.11, 2.50)
Age of first birth	0.11	(0.03, 0.19)
Model 3 (n=405)		
Ethnicity		
Kosovar Albanian	**Reference**	
Roma, Ashkali, and Balkan Egyptian communities	-2.35	(-3.47, -1.22)
Kosovar Serbian	0.52	(-1.32, 2.36)
Education		
Primary or less	**Reference**	
Secondary	0.60	(-0.52, 1.72)
University or greater	1.26	(-0.02, 2.55)
Age of first birth	0.11	(0.03, 0.20)
Primary health clinic		
Kosovar Albanian institution	**Reference**	
Kosovar Serbian institution	0.37	(-1.26, 2.00)
Displacement		
Non-displaced	**Reference**	
Displaced	0.04	(-0.75, 0.83)

needs assessment activities.

This research study is particularly important as it could support existing efforts to address the needs of Roma, Ashkali, and Balkan Egyptians with regards to antenatal care. In April 2017, the Kosovar government approved a new national strategy for Roma, Ashkali, and Balkan Egyptian communities including a section on health and with an emphasis on maternal health.[47] Health care reform processes have been ongoing since 2011 with attempts to address many structural issues within the Kosovo health care system, such as access to care, financing, quality of care, and accountability of health professionals. The data from our study could help to inform these processes and provide an opportunity to address access issues of Roma, Ashkali, and Balkan Egyptian communities in antenatal care through development or adjustment of policies and guidelines, as well as strengthening of mechanisms for their implementation. Our findings also highlight the need for accountability during these processes, particularly for vulnerable populations, and that implementation should be monitored to ensure penetration of new guidelines among all population groups. Given that strategies are under way, the Kosovar Ministry of Health should work with community stakeholders to ensure that efforts meet the specific needs of women from Roma, Ashkali, and Balkan Egyptian communities. These findings should also prove useful as Kosovo continues to strive toward implementing WHO recommendations for maternal health care.[48] Numerous barriers exist in implementing the recommendations, including fragmentation of the health care system, an urban-rural division, and limited health care infrastructure due to conflict. Finally, this research could provide direction for international stakeholders (such as Lux Development, Swiss Development Cooperation, The World Bank, UNFPA, UNICEF) and the NGO sector in Kosovo, which is active in supporting the health care sector.

A few limitations of our study should be noted. First, the cross-sectional nature of the study limits the ability to determine causality. Women from Roma, Ashkali, and Balkan Egyptian communities may have limited experiences with public services more generally, and patients from Roma, Ashkali, and Balkan Egyptian communities and the health care staff attending them may find effective communication a challenge. Other omitted variables may include low demand for health care services, which is a symptom of widespread societal and institutional discrimination, as has been shown in other research.[49] Second, we had to create a combined ethnic Roma, Ashkali, and Balkan Egyptian ethnic group in order to include all women in the analyses. However, the heterogeneity of these populations may also influence outcomes, particularly in regards to Ashkali, and to a lesser extent, Balkan Egyptians being viewed as "Albanized." However, research among Roma, Ashkali, and Balkan Egyptian communities shows that each of the three representative groups face similar issues, such as discrimination, social exclusion, poverty, and poor health due to the ethno-politics of the country and greater region.[50] Another limitation is that our displacement measure might represent a different construct for different ethnic groups. Sources suggest that majority of Kosovar Albanians were displaced during the conflict, but also have returned to their original home voluntarily. In contrast, Roma, Ashkali, and Balkan Egyptian groups have been more likely to be permanently displaced to a new location and be forced to return to Kosovo, creating many barriers to protection of their rights and access to health.[51] Self-report of antenatal care and clinical patient checklists could be another limitation, particularly for different ethnic groups across different socioeconomic indicators. A research study in Mozambique has shown that women are able to recall aspects of their care, but not all, and that socioeconomic factors are also at play.[52] In addition, "yes or no" items on a clinical checklist tell us that woman received, for example, an ultrasound, but we don't know what the ultrasound was looking for and if results were provided to women. Furthermore, the checklist assumes that providers communicate that services are being provided to their patient. However, a particular service could have been completed, but the woman never notified, further complicating issues of the right to

health. In order to improve upon our understanding of the acceptability and quality of care, patient-centered approaches and questions are needed. Items included in the WHO Responsiveness Model, such as respect, dignity, and shared decision-making may be particularly helpful in guideline development and future research efforts with Roma, Ashkali, and Balkan Egyptian communities.[53] Despite the limitations, the checklists in this study, particularly around issues of communication, are important additional pieces of information not normally included in international studies of antenatal care, and particularly among women in Roma, Ashkali, and Balkan Egyptian communities. Lastly, we do not have enough information to conjecture about why differences in quality of care exist for Roma, Ashkali, and Balkan Egyptian communities depending on the type of institution they visit (Kosovar versus Serbian-government run). The policies and guidelines in the Kosovar and Serbian institutions may be markedly different, with one following Serbian government regulations and the other the newly developed Kosovar regulations. In addition, the Kosovar health system has begun privatization, which has grown substantially over the years. As shown in prior research, greater levels of discrimination may exist in private health institutions.[54] Lastly, we understand that the use of ethnicity, particularly of Roma, Ashkali, and Balkan Egyptian communities, only serves as a proxy to the underlying and complex socio-political conditions they face in post-conflict Kosovo.

There are also many aspects of our study that lend to its credibility. We worked directly with Roma, Ashkali, and Balkan Egyptian communities and Kosovar Serbian based NGOs to ensure representation of the Roma, Ashkali, and Balkan Egyptian communities and Kosovar Serbian communities. We pilot tested the survey with women from NGOs representing Roma, Ashkali, and Balkan Egyptian communities to ensure cultural humility and sensitivity of the questions. We also conducted the study in the local languages of participants, and when possible, we completed questionnaires with women in privacy or with other women household members in attendance. We also conducted regular site visits to monitor data collection quality and ensure sampling methods adhered to the protocol. In addition, our high response rates among women in all groups help to provide confidence in the findings.

As our findings show, the most vulnerable women in Kosovo, women from Roma, Ashkali, and Balkan Egyptian communities, and in particular women from Roma, Ashkali, and Balkan Egyptian communities who have been displaced, received the poorest antenatal care services in terms of quantity and quality. A focus on equity and inclusion is necessary to guarantee that policies and guidelines ensure all women in Kosovo receive equitable opportunities to access and receive appropriate high-quality care, and that their human rights are respected, protected, and fulfilled. As Kosovo moves forward with privatization and creation of a multicultural health care system, a human rights-based and patient-centered approach will be particularly important to ensure the right to health for all women.

Conclusions

Women from Roma, Ashkali, and Balkan Egyptian communities in Kosovo receive poorer care as compared to Kosovar Albanian and Kosovar Serbian women. Furthermore, a history of displacement and where they receive their services also play important roles in quality of antenatal care. As the Ministry of Health in Kosovo continues to embark upon improving maternal health care in the country, it is important that it incorporate equity, patient-centered care, and human rights-based frameworks to ensure all women in Kosovo receive equitable access and quality of services to improve child and maternal health outcomes.

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Securing a Right to Health: "Integration Villages" and Medical Citizenship of Roma People in France

DANIEL MANSON

Abstract

A national deportation campaign targeting Romanian Roma in France has recently drawn international criticism from human rights organizations and the European Union. In this context, some French municipalities have created *villages d'insertion*—integration villages—for some of their Roma residents. Proponents of these spaces have declared that they are humanitarian solutions to the existence of Roma slums in the urban peripheries of many French cities. Yet the creation of a "healthy space" for Roma migrants in the city has also legitimated the further eviction and exclusion of people from "unhealthy slums." This article is based on ethnographic research among residents of an integration village and a number of unauthorized encampments in Strasbourg, France. This article analyzes the *village d'insertion* as a contemporary setting where the uneven medical citizenship of Roma migrants in France is being articulated in relation to wider debates about Roma inclusion in Europe. Ultimately, the *village d'insertion* is a local manifestation of state power, where the division between those deserving and undeserving of public support is reconfigured through the provision and exclusion of access to rights such as health care and shelter.

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Introduction

A Romanian Roma man in his 50s named Gheorghe sat with his left leg outstretched and his socked foot resting on top of his shoe. His foot was swollen. When he took his sock off to show me, the skin was so tight that it was almost uniformly smooth and seemed to glisten. I was standing in the middle of a group of about a dozen Roma people who recently migrated to Strasbourg from Romania. As is the case every night, they had set up temporary shelters after dark in a clearing between two buildings behind the central train station. On this night, there were eight tents, three of which were makeshift structures composed of tree branches tied together with a thin piece of opaque plastic draped over top. Gheorghe's shelter was one of these and was set up on a patch of grass in front of a tall chain link fence lined with razor wire. An old woman wearing a long flowered skirt, a thick purple jacket, and two long grey braids under a bright teal head scarf caught my glance. She told me, "You know that wire was put there for us." The conversation returned to Gheorghe's foot and I offered to drive him to the hospital. Gheorghe smiled from underneath his black fedora and shrugged, "*mon français… pas bon*,"—"my French… not good." He said that his foot had been like this for some time now but that he didn't know where to go. Marc, a French-Romanian who had come to distribute some warm clothing, mentioned that Gheorghe can receive a medical exam free of charge and that he would be willing to accompany him to translate. We agreed to pick him up first thing in the morning. When Marc and I returned, though, a city truck was parked where the camp was set up the night before. Two workers in reflective vests were using long poles to pick items up and place them in garbage bags. A woman from the camp told us that the police had evicted everyone from their tents early in the morning. When we asked what happened to the tents and their belongings, the woman simply took a puff of her cigarette and pointed to the truck. I asked where Gheorghe was. She shrugged, telling me that the police had taken him and perhaps he was being sent back to Romania. I never saw him again.

The most remarkable part of this scene is that it took place across the street from Quartier, a *village d'insertion*—"integration village"—that the city of Strasbourg set up for a portion of its Roma migrant population. Over the past decade, a number of French municipalities have implemented *villages d'insertion* aimed at "integrating" local Roma populations from unauthorized urban encampments using the same logic. These projects typically involve the transfer of a portion of a city's Roma population to a state-operated site in order to facilitate social and economic "incorporation." In contrast to the street, where eviction and contact with the police are a constant reality, the residents of this place live in a cluster of used caravans provided by the city. Quartier residents have access to a team of full-time social workers who are instrumental in helping them navigate French bureaucracy and access social support. Social workers also arrange visits to doctors, specialists, and register residents to receive free state-funded health care. Roma at Quartier and in makeshift settlements are eligible for state medical assistance—*aide médicale de l'état*—which extends emergency and basic preventive health care to all people residing in France, regardless of legal status.[1] Coupled with EU directives that entrench rights to health as a fundamental part of European citizenship, the French health care system is often touted as an example of humanitarian European norms. Yet Gheorghe's experience demonstrates that on-the-ground access to these rights is complicated by the "evictability" of the places where some Roma live.[2]

Anthropologists have analyzed the ways that health and illness have become central to collective claims of belonging and access to rights made by "non-citizens" in France. Fassin has analyzed the ways that humanitarianism and politics have blended to produce new residency permits for migrants within a climate of deepening anti-immigrant sentiment.[3] Similarly, Ticktin argues that asylum seekers with HIV are seen as non-political and therefore more deserving of French aid than other migrants.[4] These studies point to the ways that the deliberation of health rights has become a

crucial terrain for the arbitration of citizenship and to the governance of migrant populations in Western Europe.[5] This article examines how the creation of a *village d'insertion* in Strasbourg transforms the ways that a group of Roma people accesses health and other rights of EU citizenship. The Romanian Roma I worked with in Strasbourg are EU citizens, and therefore entitled to reside in member states beyond an initial three-month period if they are: actively employed, students, or possess adequate funds to support themselves. Nevertheless, EU states can restrict these rights if individuals are deemed a threat to public policy, security, or health.[6] Gheorge's story illustrates how national and municipal laws allow some EU citizens to be treated like foreigners.[7]

Health plays a crucial role in both the residence of Roma in the *village d'insertion* and in their eviction from other places in the city. Though the majority of Roma people in the city have regular jobs and do not live in poverty, local politicians commonly invoke the presence of Roma living in "unhealthy slums" to legitimate their eviction and exclusion from social services.[8] The highly selective nature of these projects has been widely criticized. For example, the selection process has in some cases involved "screening" potential residents to assess their ability to integrate.[9] The invocation of "problem" Roma populations in Europe is certainly nothing new.[10] Yet proponents of *villages d'insertion* like the one in Strasbourg have claimed that they are a novel alternative to deportation and eviction. I argue that these sites are settings where the French state arbitrates what Mark Nichter terms "medical citizenship," that is, the forms of entitlement that "articulate what we deem to be the basic rights of a citizen, what human rights are recognized for undocumented immigrants and who is excluded or sacrificed when health resources are rationed or restricted."[11] Ultimately, Quartier is a local manifestation of state power, where the division between those deserving and undeserving of public support is reconfigured through the provision and exclusion of access to rights like health care and shelter.

Research methods and setting

I arrived in Strasbourg in January 2016 and spent the next year attempting to understand how a group of Romanian Roma people is being affected by an ongoing national deportation campaign. The crux of my research involved participant observation of the everyday routines of people living at Quartier and the informal settlement across the street. I observed interactions of residents with social workers, security guards, and NGOs, as well as city workers and police officers that operate in these places. I witnessed a marked difference between the ability of Quartier residents and the Roma who lived across the street to access health care in the city. I spent time with residents in both places as they traded stories about accessing health care in the city and dealt with illnesses in their families. I also accompanied them as they interacted with nurses, doctors, and pharmacists while seeking treatment through the local health system. I conducted several life history interviews to gauge how they viewed the evolution of their health treatment before and after moving to Strasbourg. The names of all people in this article and the insertion space where they live are pseudonyms.

The city of Strasbourg has an urban population of approximately 276,170, though including the entire metropolitan area this number is approximately 491,516.[12] There are an estimated 400 Romanian Roma who live in uncertain housing conditions, which is considerably lower than other major French cities. However, there is no shortage of state, international, NGO, and, public interventions targeting Roma. Strasbourg is the official seat of the Council of Europe, European Parliament, and the European Court of Human Rights, and is also the legislative capital of the EU. Strasbourg is a central hub in Europe for the legislation of Roma rights policies and initiatives. Additionally, there are a number of NGOs that have until recently operated in the informal settlements to provide basic health care and other social services, often in cooperation with the municipal government. Of these, the most active is Médecins du Monde (MdM), an independent charity that provides regular health

care and other social services via a mobile health team of doctors and social workers.[13] Since the opening of Quartier, the municipal government has asserted control over the distribution of public services while simultaneously dismantling the informal settlements that depend on NGO assistance.

Strasbourg is also home to around 500 Manouche—Roma of German and French origin—many of whom have been living in permanent subsidized housing or mobile caravans in the southern district of Polygone since the 1960s.[14] Other Manouche people residing in caravans live in a constellation of municipal *aires d'accueil*—welcome sites—around the city. According to the Council of Europe, the population of Roma people in France is between 300,000 and 500,000, the overwhelming majority of whom live with regularized legal statuses and whose living situations are not likely to make the news.[15] While the vast majority of Roma and Manouche are French or EU citizens with legal rights to reside in France, public authorities tend to refer to the Roma, Manouche, Travellers, and other groups interchangeably, which reinforces the idea that all members of these groups are migrants.[16] Furthermore, the visibility of Roma people living in makeshift urban encampments contributes to a homogenizing public perception that all Roma are poor or choose to live on the fringes of society.

State medical aid and the non-use of rights

The French health care system has been internationally recognized for its relatively liberal extension of the right to health to all people residing within its territory. In 1999, the French government passed the "universal health coverage act"—*couverture maladie universelle* (CMU)—which recognizes the rights of all residents in France, including foreign nationals, to receive health care and social security benefits. In 2001, the government passed a second bill, "state medical aide"—*aide médicale de l'état* (AME), —which extended the right to access health care to all people who cannot afford health insurance and also to undocumented persons.[17] Under these laws, social security pays for all medical treatments and patients are not responsible for any up-front fees when visiting the doctor. This represents a significant departure from some Western European states, where irregular migrants in particular may only access emergency health care services and run the risk of being reported.[18] In contrast, AME covers a wide range of preventative and routine health services including doctor visits, prescriptions, and childbirth.[19] Furthermore, in 1998, the French government implemented the so-called "illness clause," which allows people to claim legal residency if they are declared unable to receive treatment in their own countries.[20]

While most advocates agree these developments are beneficial for marginalized populations in France, the bills have been the subject of ongoing debate and reform. Critics claim that coverage is too expensive, vulnerable to fraudulent claims, and marks France as a destination for medical tourism.[21] Recent studies have proven these allegations to be unfounded, yet the association of migrants with fraud and economic drain stigmatizes those who depend on these programs.[22] Furthermore, the division between CMU and AME in the current system is based on the legal status of individuals and therefore limits the universality of the bills.[23] This is critical given that the number of beneficiaries of AME is well below the estimated population eligible to receive these benefits.[24] In France, the issue of *non-recours aux droits*—non-use of rights—has become a prominent topic of academic and political debate. Philippe Warin claims that there are three principal reasons why people may not claim rights they are entitled to: (1) they have incomplete knowledge of their rights; (2) they are aware of their rights but decide not to claim them; or (3) their claims are rejected.[25] Larchanché adds that irregular migrants experience "intangible factors" such as stigmatization, fear of being targeted for expulsion, and precarious living conditions that prevent undocumented persons from accessing health services through the AME scheme.[26] In Quartier, social workers help residents register for state-funded health care, yet those living across the street often told me that they were unaware they are entitled to receive health care or that they preferred not to draw attention to themselves. However, this

was not always the case. When I visited Strasbourg for the first time in 2013, health care was being provided to the informal settlements in the city though a mobile unit operated by Médecins du Monde. When I returned in 2016, almost all of the unauthorized settlements had been dismantled and MdM was no longer responsible for distributing health care to Roma in the city. An acquaintance from the mobile health unit explained that since the evictions of most other settlements, "most Roma migrants now receive health care through the French system." Quartier had become a central node for accessing the right to health.

Securing health for Roma

In August 2012, the newly elected French government of François Hollande made international headlines following a wave of police raids on "illicit encampments" of Roma people in the cities of Lyon, Lille, Paris, and Marseilles. The evictions reopened a bitter debate that had erupted in 2010 when then-President Sarkozy publicly initiated a Roma deportation campaign, explicitly linking immigrants to criminality. EU and human rights groups condemned Sarkozy's attempt to dismantle over half of the 539 known Roma settlements in France as xenophobic.[27] Though Hollande vehemently opposed the deportations during his election campaign, the expulsions have increased under his leadership.[28] Hollande's government has defended its own use of deportation by citing a latent "public health risk" posed by the unsanitary conditions in the settlements. In distinction with the ethnic motivations of Sarkozy, the current expulsions take advantage of ambiguities in the wording of EU legislation that allow for deportation of EU citizens on grounds of "public policy, public security, or public health."[29] The reference to "public health" to legitimize the eviction of Roma from similar situations has been documented across Europe.[30] Recent studies suggest that stigma towards the Roma in France is declining in relation to other minorities, yet homogenizing images of poor Roma living in makeshift settlements continue to inform public and political discourse.[31] For example, in 2016, more than half the French population thought Roma do not want to integrate and believed they make a living through theft and human trafficking.[32] Despite the fact that the overwhelming majority of Roma in France have a permanent residence, over 70% of the French population believes that all Roma are nomadic.[33] These perceptions contribute to legitimizing eviction in cities like Strasbourg.

Recent estimates suggest that there are around 15,600 Roma people living in "squats or slums" in France, mostly having emigrated from Romania, Bulgaria, or the former Yugoslavia.[34] While many Roma arrived in France in the 1990s following the dissolution of socialism in Eastern Europe, the relaxation of Schengen visa requirements for Romanians in 2001—allowing three-month stays—prompted sustained temporary migrations.[35] The accession of Romania and Bulgaria to the EU in 2007 theoretically entrenched the legality of these migrations. All citizens of the EU are entitled to freedom of movement and may reside in member states longer than three months if they attain a residency or work permit.[36] However, the majority of EU member states imposed "transitional measures" restricting access of nationals from these countries to national job markets. In France, these measures were in effect until January 1, 2014, and prevented Romanians and Bulgarians from taking employment in 150 trades.[37] The restrictions included significant levies on employers wishing to sponsor individuals to gain work permits, which are necessary to legitimate long-term residence in France.[38] Unable to secure legally sanctioned work, many people have taken up residence in places designated by the state as "illicit encampments" in the urban peripheries of cities like Strasbourg.[39] The French state has also since 2004 reserved the right to expel EU citizens who pose an "unreasonable burden" on the social system.[40] Despite having EU citizenship, Romanian and Bulgarian Roma living in informal settlements can be deported based on the purported threat they pose to the French social system and to public security.[41]

Roma rights advocates argue that forced evictions of Roma people in France exacerbate health issues by propelling people into increasing precar-

iousness, thus violating European human rights norms.[42] Hollande's government strove to distance itself from the previous administration by highlighting its concern with humanitarian issues. In response to a 2012 Amnesty International report, for example, Hollande declared it,

> *necessary to support those who take the path of integration and to avoid leading them down the path of the most precarious populations. I wish that when an unsanitary camp is dismantled, alternative solutions are proposed. A policy of support in all areas (welfare, education, housing, health and employment) will also be necessary to ensure that these populations live in dignified conditions.*[43]

In the past decade, several French cities have created *villages d'insertion* using the same logic. Strasbourg's first *village d'insertion,* Quartier, was initiated in 2011 to house 130 Roma people who were then living in what the city called its largest *bidonville*—slum. Following successive evictions of other settlements, Quartier was expanded in 2013 and now houses just over half of the estimated Roma living in uncertain housing. This produces a sort of "cream-skimming" effect, where those not selected for inclusion have become the target of renewed efforts to evict all non-official settlements in the city.[44] Quartier is thus tightly bound to the processes of eviction that both necessitated its creation and to the continued dismantling of all other settlements in the city.

Quartier: Shelter and (better) access to rights

Stela, a 31-year-old Roma woman, has been living at Quartier since 2013 with her husband and three children. One day, Stela invited me to have lunch with her family in their caravan. She bounced her youngest daughter, Viena, on her knee as we waited for a pot of *ciorba*—Romanian stew—to finish cooking. Viena had a persistent nasal infection for almost the entire time I knew her. Stela told me that Viena was undergoing a corrective operation later that week, "She's little. It makes me sad. But the doctor told me it's a short operation." When I asked about visiting the doctor in Strasbourg she told me that it was very easy for her. "The doctor is very good. He is very nice. I couldn't afford it in Romania." Before moving to Quartier, Stela's family lived with about 50 other Roma people in a forest settlement until they were evicted. "Life was harder then," Stela told me, "we had no water. I had to find water and carry it back to the tent where we stayed. We lived for two years like that." Many people contrasted conditions at Quartier with the day-to-day difficulties of living without access to heat, water, and electricity in the settlements. Alain, a middle-aged man, told me, "It was the rats. There were always rats! It's bad for your health!" Alain's remark is striking because French officials likewise cite the presence of rats as a health risk when publicly defending camp evictions. Almost everyone I knew felt that Quartier lessened the sense of physical and social precarity associated with the urban settlements.

Almost a quarter of the people living at Quartier have illnesses that require various forms of medical intervention.[45] For many of these people, the transition to the *village d'insertion* enables a more direct connection to the formal medical system in Strasbourg through the provision of onsite social workers. Once, while visiting with Nicoletta, who suffers from bouts of depression, she pulled a number of prescription bottles from a shelf above her stove. She related that she had been diagnosed in Romania but until coming to France had received prescriptions only when she was hospitalized. She told me that the staff at Quartier helped her to find doctors and prescriptions for her illnesses free of charge. Florin, who had recently had both of his legs amputated because they had become gangrenous, told me, "I was a mechanic before. Now work is impossible. What would I do in Romania?" Prescriptions like Nicoletta's, serious medical treatment like Florin's, and routine operations like Viena's are all covered under AME. Residents told me that before coming to Quartier, they relied on their social networks to find treatment or waited for the mobile health unit to visit them. It would therefore seem that for these people "the problem is

not the lack of social rights but of gaining access to these rights."[46]

This improved access to rights comes at a price. The notions of "integration" attached to such places are contradicted by administrative rules that separate Roma from the general community and tightly control their daily lives.[47] First, the city chose to house residents in caravans, despite the fact that Romanian Roma typically live in sedentary lodgings. The city cites the temporary and inexpensive nature of the project, but the caravans also evoke stereotypical notions of nomadism commonly attributed to Roma.[48] Quartier's location in a non-residential region of the city spatially reinforces the social and economic invisibility of the residents. More disconcerting are the presence of tall fences around the sites and the surveillance by full-time security guards. Though the city suggested that both measures are for the protection of the residents, they give the impression of a closed space that is not open to non-Roma interaction. More than once after 8:00 pm, a guard escorted me off the property and told me that residents are not permitted to have non-resident visitors after this time. As in other *villages d'insertion*, Quartier residents are contractually bound to learn French, demonstrate an active search for employment, and send their children to school.[49] NGOs have pointed out that these obligations ignore structural constraints like the transitional measures that prevented Romanians from taking certain kinds of employment.[50] Many people still relied on informal employment and sometimes panhandling in order to support themselves. Some critics view the constant presence of the social workers along with the guards as a patronizing force as these actors have the ability to limit entry and to evaluate the "progress" of integration.[51] These measures are part of a broader process of "contractualization" of welfare provision in Europe that purportedly aims at reincorporating working-age beneficiaries of social services.[52] The imperatives of surveillance and control over the daily routines of Quartier residents illustrate that the provision of social benefits can also become a mode of governance over those who access them.

"If I can't buy food, what good is an ambulance?"

Anica left Romania about 10 years ago with her husband and has lived at Quartier since it opened in 2011. Her husband had since passed away and Anica's health began to deteriorate. She developed high blood pressure, diabetes, kidney stones, and a blood platelet disorder, and she needs a walker to get around. When I met Anica, she was enduring complications from surgery to remove her kidney stones. She often complained that her abdomen hurt and even a short walk would put her out of breath. Anica has been hospitalized numerous times in the period that I have known her. Each time, an ambulance was summoned to Quartier and she was taken to the university hospital to be examined and prepared for surgery. Then she would be transferred to the city hospital and would inevitably spend a day or two for the surgery and recovery before being sent home. Anica occasionally forewent the ambulance ride back to Quartier and asked me to pick her up. Typically, we would sit in the hospital café chatting before heading home. The most recent time, Anica asked me to take her to the CAF—*caisses d'allocations familiales*. This government department distributes social assistance monies for a number of qualifying conditions. When I first met Anica, she had told me angrily that a monthly subsidy she received from this office due to her inability to work had been cut off. Anica believed that this had been a mistake, but now that her condition had worsened she assumed that she was eligible for an allowance for adults living in France with debilitating illnesses.

Anica was worried about her future because lately she felt too unwell to go far from home and had been struggling to make money. Like a number of other women at Quartier, Anica sells goods at the bi-weekly market in the center of Strasbourg. In her case, she gathers and sells used clothing. On market days, Anica piles her wares into a stroller and pushes them to the market, which is about 20 minutes away. Sometimes Anica told me that she was in too much pain to make the trek, or to stand for the duration of the market. As Anica's health

deteriorated, she began to miss more and more market days.

We arrived a few minutes later at the CAF building. Anica was still wearing her hospital gown over her skirt, she told me cheekily, "In case they don't believe that I was at the hospital!" We walked inside and were eventually called to a booth where a woman asked for our ticket through the small hole in the window. I explained that Anica was hoping to have her case re-examined. The woman asked for Anica's passport and began entering information into a computer. A moment later she remarked, "Ah, yes… it seems that madame does not have the required conditions to receive this benefit." The woman explained that Anica must have resided in France for more than five years to be eligible. Anica protested, telling the woman that she has been here for more than 10 years. I added that Anica has been living in a state-funded *village d'insertion* space since it opened five years ago. The woman replied, "I am sorry again, but this does not qualify her for these rights. She has an address, but we have no record of employment." I explained that Anica is self-employed and sells wares at the market in town. The woman interrupted, "Yes, but this benefit is for people who have the right to stay in France permanently. Madame does not have this right. Her work is not recognized by any official document. I cannot help her." Tugging at her hospital gown, Anica told the woman that she just came from the hospital and that she would work if she could. The woman behind the counter ended our conversation by suggesting that we talk to Anica's social worker.

Tears began to roll down Anica's cheeks as we got in the car. "The doctor said I need to eat well. How can I get healthy? They want me to eat at the soup kitchen? Never! I will die before I do that. It's not real food!" We returned to Quartier in relative silence. I walked Anica to her caravan. She opened the door, and posted on the inside was a message explaining that an ambulance would pick her up next week for a follow-up exam at the hospital. Anica scoffed, "If I can't buy food, what's the point of the ambulance?" Anica's story exemplifies the limits of the types of "medical citizenship" afforded to Roma people living in places like Quartier.[53] She was aware that her "suffering body" could be used to leverage better social and economic inclusion.[54] However, the transitional measures imposed on Romanian nationals in France were in place until 2014, making it almost impossible for Anica to have worked, in 2016, for five years in a recognized trade.[55] Anica worked at the market because this was one of the few options available to her during this time. Anica's experiences also illustrate a number of things about the nature of Quartier as a technique for facilitating "integration." First, Quartier is, like all *villages d'insertion*, a temporary and experimental policy instrument that is designed to funnel a small portion of Roma into more stable living situations. While a number of residents have found employment and long-term housing in the city, most of the original inhabitants continue to live at Quartier. For people like Anica who have complicated health concerns impeding their ability to find employment, the possibility of leaving Quartier is even lower. Secondly, as Quartier ties access to shelter and social support to the site itself, residents are ultimately dependent on this institution. Anica had asked me to take her to the CAF because she wanted to access her rights herself, without the mediation of her social worker. Insofar as Anica had secured a right to health, it seems that these rights were tied to her living in Quartier.

Conclusion

On September 27, 2016, Strasbourg publicly declared that it had closed all of the illicit encampments of Roma people within its municipal territory. The mayor, Roland Ries, detailed the city's efforts to close the 14 known sites.[56] He proudly affirmed that the city provided alternate housing for some of the evicted Roma at Quartier and another *village d'insertion* located a few miles outside the city. According to city officials, those who had not been offered lodging, approximately 112 people, had "chosen to leave."[57] Some NGOs have likewise cited the "success" of Strasbourg's insertion project for "reabsorbing" its Roma slums.[58] Yet the mayor was also quoted as saying, "We cannot accept new populations of Roma. We have done the job. National

solidarity must play its full part."[59] Ries suggested that the humanitarian generosity offered by the city had reached its limit and called for similar projects across France.

For Gheorghe, the ill Roma man whose story introduced this article, the realities of this alleged success story are much different. Only 15 steps across the street from Quartier, another group of Roma people continues to set up camp each night, only to be evicted the next morning by the police. The daily eviction of their camp recreates a sort of microcosm of the periodic larger-scale evictions of Roma camps across Europe. The claim that the city has cleared all "illicit" Roma slums is spatially reinforced by the green metal chain link fences that prevent anyone from entering these places. The city's efforts to eliminate all illegitimate Roma spaces intensified after the construction of Quartier. These integration spaces are not just alternatives to eviction and securitization, but may actually accelerate these processes under a humanitarian veneer. One effect of this acceleration is that people like Gheorghe get pushed into further precariousness.

The declaration of the mayor of Strasbourg articulates a particular kind of medical citizenship envisioned for Strasbourg Roma. Inclusion and exclusion in Strasbourg are based not on healthy bodies but increasingly on a division between healthy and unhealthy Roma spaces.[60] Like other *villages d'insertion,* Quartier combines housing and access to social support under a mandate of "Roma integration."[61] This has a number of effects for the residents of Quartier and those that live outside its boundaries. First, it frames the existence of urban slums as a problem of public order rather than the product of successive public policies. The only two types of residence envisaged for the Roma are the slums and the *village d'insertion*, both of which contribute to dominant ideas about Roma people as nomadic people who choose to live outside society.[62] The city has declared the provision of health care to informal settlements redundant despite the fact that not all Roma who need social assistance live at Quartier. Slums are a response to the legal instabilities wrought by national policies like the transitional measures that make it difficult for some Roma to gain long-term residence in France.[63] Furthermore, the spatial and administrative controls imposed on Quartier residents signal that access to these rights are provisional and contingent on the ongoing demonstration of their potential to "integrate." In a context where access to health care is guaranteed under national and EU human rights laws, the provision of these rights is in practice constrained to the *village d'insertion.* These measures ironically reproduce the marginality of the Roma in Strasbourg by naturalizing their poverty and obscuring the role that the French state has played in producing Roma precarity.[64] Without rethinking the forms of securitization that prevent Roma people from realizing their rights as EU citizens in the first place, it is perhaps too early to sound an end to Roma slums in Strasbourg.

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Inconvenient Human Rights: Water and Sanitation in Sweden's Informal Roma Settlements

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Abstract

Following an increase in Roma migration under the European "freedom of movement" laws, Swedish municipalities initiated more than 80 evictions of informal Roma settlements on the grounds of poor sanitation between 2013 and 2016. These evictions echo policies from earlier in the 20th century, when Roma living in Sweden were often marginalized through the denial of access to water and sanitation facilities. The recent Swedish evictions also follow similar government actions across Europe, where Roma settlements are controlled through the denial of access to water and sanitation. However, access to water and sanitation—central aspects of human health—are universal human rights that must be available to all people present in a jurisdiction, regardless of their legal status. The evictions described here violated Sweden's obligations under both European and international human rights law. More positive government responses are required, such as providing shelters or camping sites, setting up temporary facilities, and directly engaging with communities to address water and sanitation issues. The authors conclude by providing guidance on how states and municipalities can meet their human rights obligations with respect to water and sanitation for vulnerable Roma individuals and informal settlements in their communities.

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Introduction

Access to water and sanitation are fundamental human rights central to human health. Limiting access to water and sanitation are key means by which governments control the movements of marginalized people, deter their inclusion in the community, and undermine their well-being. In this study, we explore the ways in which limitations on water and sanitation access have been used to control the movements of Roma by examining Swedish municipal evictions of informal Roma settlements between 2013 and early 2016. Although Swedish authorities are prohibited from keeping records of ethnicity, records of official communications, reports from the media, and accounts from eye-witnesses confirm the Roma identity of the inhabitants of the affected sites. Among the official records analyzed for this study are the notes of officials discussing the evictions, which include the following comments: "we have problems with various bums/Roma," "there were sleeping Roma in the cars," "it is very hard for us to determine the identity of EU-emigrants," and "we have issue in an area where there are Romanians."[1]

This article proceeds as follows. Following this introduction, the second part sets out information on the legal status of water and sanitation, including for informal settlements, under European and international human rights law. The third part provides general information on access to water and sanitation in informal Roma settlements in Europe and Sweden. Part four presents our data regarding municipal evictions of Roma from informal settlements in Sweden based on sanitation grounds. Part five reviews ways in which Swedish municipalities might begin to meet human rights standards. We conclude by highlighting that access to water and sanitation remain key tools for controlling Roma individuals in Sweden, despite human rights norms that extend the human rights to water and sanitation to all.

Both European and international human rights laws protect water and sanitation access for informal settlements

Water and sanitation are independent human rights protected by European and international human rights law.[2] These rights extend to people living in informal settlements and homeless people, and they are not conditioned on legal status.[3]

The fundamental nature of the rights to water and sanitation

In the European Union (EU), the human rights to water and sanitation have been repeatedly recognized. Provisions of the EU's Charter of Fundamental Rights protect the rights to dignity and life, implicitly encompassing the rights to water and sanitation.[4] The relationship between water and Roma integration was explicitly identified by the Council of the European Union in 2013, when it recommended that member states "take effective measures to ensure equal treatment of Roma," including "access to public utilities (such as water electricity and gas)."[5] The first successful European citizens' initiative addressed these rights even more specifically and urged that "EU institutions and Member States be obliged to ensure that all inhabitants enjoy the right to water and sanitation."[6] Answering this petition, the European Commission endorsed these basic rights and urged member states to "step up their own efforts to guarantee the provision of safe, clean and affordable drinking water and sanitation to all."[7] In 2015, the European Parliament urged the commission to take aggressive steps to implement the initiative while also calling on member states "to ensure non-discrimination in access to water services, ensuring their provision to all, including marginalized user groups."[8]

The Council of Europe has also recognized the human rights to water and sanitation. Implicit protections are found in the "right to life" enshrined in the European Convention on Human Rights and Fundamental Freedoms and in the European Social Charter's protections for the rights to health and housing.[9] Water was addressed directly when, in 2001, the Council of Europe's Committee of Ministers adopted the European Charter on Water Resources. Paragraph 5 of the charter states that "[e]veryone has the right to a sufficient quantity of water for his or her basic needs," including "a mini-

mum quantity of water of satisfactory quality from the point of view of health and hygiene."[10]

The rights to water and sanitation have likewise been recognized internationally. In 2002, the United Nations (UN) Committee on Economic, Social and Cultural Rights stated that the rights to water and sanitation are protected under the International Covenant on Economic, Social and Cultural Rights. According to the committee's General Comment 15, "The human right to water is indispensable for leading a life in human dignity. It is a prerequisite for the realization of other human rights."[11] Further, states have a duty to "ensure that *everyone* has access to adequate sanitation, which is crucial to protecting the quality of the water supply" (emphasis added).[12]

In 2010, the UN General Assembly confirmed the fundamental nature of the human rights to water and sanitation in its Resolution 64/292. The resolution stipulates that each member state should enable "access to drinking water for the most vulnerable persons and those living in informal settlements."[13] In 2015, the UN General Assembly adopted, by consensus, a resolution explaining that the right to sanitation is an independent human right.[14]

As with other economic, social, and cultural rights, states' obligations regarding water and sanitation are to "respect, protect and fulfill" these rights by promoting their "progressive realization."[15] States must immediately meet the minimum core obligation of the rights in order to meet their basic commitments under the International Covenant on Economic, Social and Cultural Rights. For water and sanitation, commentators suggest that states must guarantee the minimum standard that is indispensable for human survival and dignity.[16] Moreover, a state may not take deliberately retrogressive measures to hinder the realization of these rights.[17]

States are further obliged to avoid discrimination in securing the rights to water and sanitation.[18] This obligation goes beyond eliminating formal inequalities and requires states to address substantive inequality as well.[19] In particular, states parties must "immediately adopt measures to prevent, diminish or eliminate" de facto discrimination, including by "ensuring that all individuals"—including those living in informal settlements—"have equal access to adequate housing, water and sanitation."[20]

The rights to water and sanitation of informal settlements

The rights to water and sanitation belong to all, including those residing in informal settlements or otherwise without regular legal status. The United Nations Human Settlements Programme defines informal settlements as residential areas where

> *1) inhabitants have no security of tenure vis-à-vis the land or dwellings they inhabit, with modalities ranging from squatting to informal rental housing, 2) the neighbourhoods usually lack, or are cut off from, basic services and city infrastructure and 3) the housing may not comply with current planning and building regulations, and is often situated in geographically and environmentally hazardous areas.*[21]

In Sweden, Roma settlements affected by municipal evictions typically fall within this definition.

The human rights to water and sanitation, and the state obligation to ensure those rights, extend to such settlements. The Committee on Economic, Social and Cultural Rights indicates that "access to water services and protection from forced eviction should not be made conditional on a person's land tenure status, such as living in an informal settlement."[22] Further, the committee has stated that "[d]eprived urban areas, including informal human settlements and homeless persons, should have access to properly maintained water facilities. No household should be denied the right to water on the grounds of their housing or land status."[23] The committee has specifically called on states to take the "necessary steps to ensure Roma nomadic groups or Travellers camping places for their caravans, with all necessary facilities."[24]

In sum, the rights to water and sanitation are well established in both European and international human rights law. These rights unequivocally extend to informal settlements and homeless individuals, and require that states take affirmative steps to assure minimum standards of water and sanitation.

Roma and access to water: The European context

Many Roma across Europe lack access to adequate water and sanitation, a symptom of both poverty and social marginalization.[25] In Romania, for example, an estimated 60% of Roma live in segregated communities without access to basic services.[26] Similarly, experts estimate that about 70% of the Roma settlements in Serbia are informal.[27] Because of these conditions, Roma often lack access to acceptable water and sanitation. The European Union Agency for Fundamental Rights reports that one in three Roma families lives in housing without tap water.[28]

Persistent anti-Roma bias has also been well documented.[29] The European Roma Rights Center has recently documented biases that result in the disproportionate denial of water and sanitation access, with local governments using this as a basis for eviction or to otherwise control Roma settlements.[30]

In some respects, Sweden has been proactive in addressing the historic discrimination against Roma populations. Swedish law recognizes Roma as a distinct national minority protected by national non-discrimination laws.[31] In addition, the government's 2014 study titled *The Dark Unknown History* (hereafter the white paper) and a national commission supported the development of an ambitious plan to fight Roma discrimination.[32] While these measures focus on historic Roma populations in Sweden rather than recent arrivals, they acknowledge persistent discrimination against members of the Roma ethnic group—a history of bias which cannot be fully disentangled from the situation of more recent Roma migrants.[33] Significant for our study, the ways in which the human rights to water and sanitation access have been, and still are, manipulated to control Roma is an under-recognized aspect of this pattern.[34]

The lack of access to water and sanitation for Roma settlements is particularly striking in Sweden, where household water and sanitation facilities are accessible to virtually all residents. Yet vulnerable EU citizens residing in Sweden, principally Roma, are often unable to access water and sanitation in ways that meet Sweden's international human rights obligations.

Water, sanitation, and Roma settlements in Sweden

The legal status of vulnerable EU citizens

Citizens of EU member nations, including Roma, are legally entitled to reside in EU countries in accordance with the EU's freedom of movement laws.[35] The freedom of movement of EU citizens within the EU is a fundamental principle of EU law, provided for in both founding EU treaties and in the Free Movement Directive.[36] Citizens of the EU are permitted to reside in other EU member states for up to three months provided they are in possession of a valid identity card. EU citizens have a prolonged right of residence in a member state following the initial three months if they are working (employed or self-employed), actively seeking work with a genuine chance of being hired, studying (with sufficient resources and health insurance), in possession of sufficient funds (and health insurance), or a family member of anyone meeting the aforementioned requirements.[37]

In Sweden, the prolonged right of residence is not granted through any form of registration, application, or decision by a public authority.[38] EU citizens in Sweden have an immediate right of residence when they meet one of the above criteria. If an EU citizen abuses the Swedish welfare system, the Swedish Migration Board has the right to expel that person from Sweden.[39] However, monitoring is limited, and it is rare that EU citizens are expelled.[40]

In the past five years, thousands of Roma migrants from elsewhere in Europe have utilized the free movement laws to enter Sweden, where they are generally referred to as "EU migrants" or "vulnerable EU citizens." Many of these individuals are without resources; they subsist on begging and odd jobs and live in informal settlements.[41] One study found, for example, that 86% of beggars surveyed in Stockholm identified as Roma.[42]

Sweden's extensive social support system is well known. Acute homelessness and visible poverty were previously rare; a national survey in 2011 found fewer than 600 people in the entire country sleeping in tents, caravans, or in the rough.[43] This changed with the influx of vulnerable EU citizens,

since the social welfare system provides only limited assistance to these new arrivals. Under the Swedish Local Government Act, municipalities cannot provide more social support than is stipulated in national legislation. While the Social Services Act provides that municipalities are responsible for meeting social welfare needs, support can be granted only as far as there is basis in national legislation.[44] Applying this principle, the Supreme Administrative Court ruled in 1995 that assistance to individuals not belonging to the municipality in question is limited to aid for acute emergency situations. The individual can be given aid only in exceptional cases with regard to food, accommodation (up to five nights in a shelter), and repatriation to his or her domicile (a bus ticket home).[45]

The Social Services Act has been updated since the 1995 judgment, so this restrictive interpretation may be susceptible to challenge.[46] More importantly for the purposes of this study, water and sanitation fall outside of these domestic restrictions on social welfare assistance. Unlike social assistance, the administration of water and sanitation is squarely within the competence of Swedish municipalities, and municipalities can be guided by human rights norms in responding to these needs.

Evictions of vulnerable EU citizens on sanitation grounds, 2013–2016

In order to retrieve eviction orders made by the Swedish Enforcement Authority, we contacted all of Sweden's 290 municipalities and relevant subunits (304 jurisdictions total) to inquire regarding evictions of individuals with Romanian or Bulgarian identification. We sought eviction data in two phases. In the first phase, we sought information for the dates between January 1, 2007 (the date of Romania's and Bulgaria's accession to the EU), and October 23, 2014; the response rate from municipalities was 84%. In the second phase, we sought information from the responding municipalities for eviction orders between October 24, 2014, and January 27, 2016; the response rate from this subset of municipalities was 85%. After receiving data from the municipalities, we obtained the eviction applications and orders from the Swedish Enforcement Authority; these documents constitute the material used in this study. Additional information regarding these evictions, including the underlying documents, is available at http://maps.nulawlab.org/view/map-rebuild.

We found no municipal evictions prior to 2013. A possible explanation is that Romania and Bulgaria acceded to the EU in 2007, but Romanian and Bulgarian citizens were granted full freedom of movement to all EU countries only in 2014.[47] However, during the period from January 1, 2013, through January 27, 2016, Swedish municipalities initiated at least 83 evictions of groups of vulnerable EU citizens holding a right of residence in Romania or Bulgaria. These evictions generally met the following criteria: (1) they concerned EU citizens identified as Romanian or Bulgarian who were not in the Swedish population register, (2) the land occupied belonged to a municipality, and (3) the municipality applied for assistance from the Swedish Enforcement Agency. It is important to note that our data is limited in that not all municipalities responded to our query. Additionally, evictions under the aegis of the Swedish police are not included.[48] Thus, the 83 evictions documented here likely represent a fraction of the true number.

Of the 83 applications for eviction examined, almost all cite sanitation hazards and littering as grounds for eviction. Interestingly, the sanitation hazards are treated as equally severe regardless of the number of respondents being evicted. For example, between the issuing and implementation of an eviction decision concerning forty-nine respondents in Högdalen (April 2015), the Stockholm Land and Premises Maintenance Office discovered that two new respondents had moved to the site. Applying for assistance for the eviction of these two respondents, the municipality did not alter its argument regarding the significant adverse effects on the environment. Though the newcomers numbered only two and had arrived just days before, the city argued that "the areas around the settlements are exposed to great environmental effects … the settlements generate waste and latrine in the nature which will risk affecting the property both short-term and long-term."[49]

Twenty-five evictions were directed at six or fewer respondents in settlements that had existed for less than three months. Though these small settlements were of short duration, "extensive inconveniences" in terms of sanitation costs were cited in each decision. This was the case in a 2013 decision in Stockholm involving only two respondents, where the municipality argued that

> *the area around the settlement is subjected to great environmental impacts. Large amounts of waste and latrine have been dumped on the ground around the settlement … Furthermore, this littering will lead to sanitation inconveniences for the surroundings and an increased risk for spreading diseases etc.*[50]

Applications for Swedish Enforcement Authority assistance often cited municipal responsibility. Several applications initiated by Uppsala asserted the municipality's "responsibility towards the community, surrounding residents and towards those who wish to use the area for its intended purpose, for the adversities the occupation leads to."[51] At the same time, Uppsala did not acknowledge any responsibility for ensuring that residents of this informal settlement had access to water and sanitation. On the contrary, the respondents were characterized as a nuisance, with the municipality stating that "every day the settlement stays it risks being perpetuated and legitimized."[52]

In some instances, municipalities did show a concern for the sanitary situation from the respondents' perspective. For example, in Stockholm Skarpnäck in June and September 2014, the municipality's eviction papers acknowledged concerns about the health of people and animals "when large amounts of litter and latrine are dumped in the woods without any further management."[53] But although the municipality recognized the risks to the informal residents, eviction was the response.

Some applications simply cited the assumption that the settlement would lead to sanitation hazards. Such was the case in an eviction in Tensta in 2016, where the municipality asserted that "it can be assumed that latrine . . . is being dumped."[54] A similar municipal claim was challenged in Sollentuna, where the city sought to evict 45 individuals on sanitation grounds. Respondents countered that the alleged environmental hazards were improbable, as volunteers had helped set up garbage disposals and portable toilets.[55] But the appeal was dismissed by the court, and the city proceeded to evict based on the mere assumption of environmental impacts.

We did find one example of a municipality explicitly showing consideration for the respondents' situation despite requesting their eviction on grounds of sanitation. In Skara in 2015, the municipality asked that eight individuals be evicted at a time when the Social Services could be present to offer support to the respondents.[56]

In conclusion, the vast majority of decisions to evict vulnerable EU citizens from informal settlements were based on grounds of sanitation. These grounds generally did not vary according to the number of respondents or how long the settlement had existed. Some consideration for the health of the evicted was shown, but with no recognition of their human rights to water and sanitation. Where municipal responsibility was identified, the discussion focused on the municipality's responsibility toward the community rather than any obligation to the people living in the informal settlements.

Decades of Roma settlements seeking access to water and sanitation

Water and sanitation access for recently arrived Roma in Sweden cannot be understood without reviewing the historic discrimination against Roma populations. The Swedish government's white paper on rights abuses against Roma in the 20th century compiles this record in detail, providing an important context for examining Roma's water and sanitation access in recent years.[57] While the white paper does not explicitly focus on water and sanitation, it is clear that these have been central components of discrimination against Roma over the decades.

As travelers in the early 20th century seeking work, Roma necessarily settled where water and sanitation were available. When Swedish municipalities sought to deter Roma from settling, controlling their access to water and sanitation was

often a means to that end. This approach not only frustrated Roma efforts to drink, cook, and maintain hygiene but also further stigmatized these individuals in a society where frequent bathing and cleanliness is the norm. As the white paper notes, municipalities frequently identified Roma settlements with "sanitary or 'hygienic' issues," using these labels to marginalize Roma encampments.[58]

Reviewing the literature through the lens of water and sanitation access reveals this undercurrent, demonstrating the ways that Roma experiences in Sweden have been shaped by their efforts to gain access to these basic human rights. The white paper describes several occasions when the city of Stockholm controlled water access as a means to discourage Roma settlements. In the 1940s, for instance, Stockholm public authorities argued that "there was no point in arranging for electricity and water as the Roma would soon be moving on again anyway."[59]

Recent Roma arrivals in Sweden continue to face these challenges. For example, the city of Gothenburg stipulated in 2014 that it would not provide washing facilities for Roma camping within the city's jurisdiction, arguing that doing so would encourage permanent settlement.[60]

When municipalities refuse to address these issues, private businesses often come forward, but private actors alone cannot be depended on to accommodate Roma individuals needing access to water and sanitation. Even when businesses make an effort to help, they often find it unsustainable to provide services indefinitely.[61] Further, the low-income neighborhoods where individuals are most likely to need access to public restrooms are those most likely to lack such facilities.[62]

Implementing the human rights to water and sanitation for Roma settlements

The national responsibility for human rights compliance persists even when, as is the case with water and sanitation, domestic laws locate significant policy responsibility with municipalities. Giving administrative leadership to municipalities has the benefit of increasing community input concerning issues like water that are central to local well-being and that may be supported by local taxes. However, the delegation of authority to a local government does not modify the state's obligations to the international community. Under international human rights law, it is up to the state to ensure compliance, and the state must secure local governments' cooperation in that effort.[63]

Nevertheless, while the national government bears ultimate responsibility, it is not accurate to say that it bears the sole burden of human rights implementation. As cogently stated by Thomas Hammarberg, the former human rights commissioner of the Council of Europe:

> *While governments and national parliaments ratify international treaties on behalf of the state, the day-to-day work of implementing human rights standards often rests on the shoulders of local and regional authorities. They too are bound by these agreements.*[64]

In the case of water and sanitation, municipalities have an obligation to support the national government in addressing these needs from a human rights perspective. Municipal failure to progressively realize these rights can put the national government in default of its human rights obligations. At the same time, the fact that Swedish municipalities exercise primary responsibility for water policy ensures that they are able to take concrete steps to fulfill their role in implementing these human rights.

Local governments have every reason to take leadership in implementing human rights. It is at the local level that the burden of human rights failures is most acutely felt. When a municipality fails to provide water and sanitation to vulnerable populations, local businesses, organizations, and private residents bear the burden. In the case of vulnerable EU citizens in Sweden, local gas stations, stores, and churches have come forward to help, providing a patchwork of services to vulnerable individuals, often at their own expense. Yet without adequate access to sanitation, the informal camps where Roma often reside can soon raise legitimate public health and environmental concerns, impinging on

the rights of all in the community, creating a crisis for the municipality, and incurring even greater expenses in evictions and clean-ups.

By the same token, local governments also benefit most from policies that honor human rights. For example, when local governments provide informal settlements with access to water and sanitation, these costs are spread evenly rather than unfairly imposed on a few businesses and nongovernmental organizations. Accessible water and sanitation enables vulnerable EU citizens to devote more time to activities such as education and work. By managing waste, accessible sanitation diminishes the risk of public health and environmental crises in areas occupied by informal settlements.

To date, Swedish municipal authorities have carried out scores of evictions on sanitation grounds without addressing their own obligations to ensure the human rights to water and sanitation of the residents of these informal settlements.[65] Yet some Swedish municipalities have taken steps to progressively realize the human rights of the vulnerable EU citizens who have joined their communities. Several of these are described below.

Public-private partnerships

Across Sweden, public-private partnerships have often been successful in ensuring that vulnerable EU citizens have access to basic water and sanitation. Such partnerships have been established in Lund, Malmö, Linkoping, and Gothenburg, among others.

Public-private partnerships typically involve the municipality, religious bodies, social service agencies, and affected individuals in developing solutions to the situations of vulnerable EU citizens living in unstable housing situations. In some communities, other institutions such as universities are involved. Central to the success of these partnerships is the willingness of the municipality to recognize that repeated evictions are ineffective and contribute to serious human rights violations in the long run.

In Sweden, because water and sanitation are almost always provided as part of housing, housing-based approaches to addressing the water and sanitation needs of vulnerable EU citizens are particularly appropriate. In many instances, public-private partnerships have provided group shelters for vulnerable EU citizens that include water and sanitation access. An example of this approach is a seasonal shelter in Linkoping, upheld against an administrative challenge.[66] In some communities, shelters are provided by individuals who come forward to offer apartments for vulnerable citizens.[67]

Extending stable housing options to vulnerable EU citizens has many positives. In addition to providing for water and sanitation, a stable home can help its inhabitants access other social services. The year-round sheltering system in Lund has had several success stories of this type—for example, Roma individuals who, after gaining the stability provided by access to water, sanitation, and housing, were able to secure jobs and move into independent living situations.[68]

The cost and lack of available housing may make such solutions prohibitive in some communities. As an alternative, some localities have explored the provision of campsites that include water and sanitation access.

Municipalities often own property with accessible water and sanitation facilities. Caravans or tents may be established at the sites without any significant modifications. These settings provide some of the same benefits as more formal housing. They can serve as a place for social welfare interventions that can lead to more stable work situations, and at the same time, they protect against environmental impacts since the sites are designed for habitation.

Some Swedish municipalities have tried this approach. In April 2015, for example, the city of Helsingborg relocated vulnerable EU citizens from rough camps in the downtown area to a municipal campsite which provided showers, water, and communal kitchen space. Though this campsite operated for almost a year, it was ultimately dismantled by the city in March 2016. The alternative offered was limited to a bus ride back to Romania—no alternative accommodations in Sweden.[69]

Focused solutions to provide water and sanitation access

Accessible and affordable public toilets are another incremental approach. A number of Swedish cities have experimented with providing public toilets in tourist-heavy areas. For example, Gothenburg installed 15 free public toilets in critical areas around the city in 2012.[70] In 2013, Gothenburg was also the first Swedish city to install "pop-up" public urinals that emerge only at night in areas of high usage.[71] Similar innovative approaches near informal settlements could help alleviate the sanitation issues in these settings.

Household water may also be provided in ways that target residents of informal settlements. In an urban area with an existing water infrastructure, repurposing existing connections to serve an informal settlement may be easily accomplished.[72] Alternatively, portable water sources can be located near informal settlements on a temporary basis to ensure access to water until longer-term solutions can be devised.

Affordability and access are key to making these targeted approaches consistent with human rights standards. While water and sanitation services need not be free for informal settlements, there must be a realistic assessment of affordability in light of the important human rights at stake.

Currently, most public toilets in Sweden require payment of 5 to 10 SEK. Taking into account that healthy individuals use the toilet up to 10 times each day, this fee can take a percentage of a vulnerable EU citizen's daily earnings far above the 3% figure recommended by the United Nations Development Programme.[73] These costs can represent a serious deterrent to using the facilities.

Indeed, this deterrent effect influenced Gothenburg's decision to install free public toilets. The city found that such toilets were more likely to be used and would therefore contribute to the goals of increased hygiene and decreased environmental stress.[74]

Access is also a critical issue. Public toilets and water sources in tourist areas are not likely to be accessible to Roma living in informal settlements in other parts of the city. Further, many public facilities do not have evening hours.[75] Public facilities will not meet human rights standards unless they take these practical considerations into account. If, on the other hand, a municipality places accessible water and sanitation facilities in locations where informal settlements can be tolerated, it can further minimize the pressures that might lead to eviction.

The guidelines of the UN High Commissioner for Refugees for water and sanitation facilities in refugee camps provide a touchstone for minimally acceptable levels of accessibility. These guidelines state that in non-emergency situations, there should be no more than 100 people per water tap, and 20 people per latrine. The distance to a water point should be less than 200 meters, with a safe and secure route between a dwelling and its water source. The distance from a dwelling to a latrine should be less than 50 meters.[76] As the UN Special Rapporteur has observed, "shared or public toilets that are well maintained, safe and hygienic, may be accepted as short-term solutions in those conditions where the alternative is to provide no toilet at all."[77]

Community participation

The participation of affected individuals is critical to the success of any of these approaches.[78] Given the personal and often intimate nature of water and sanitation usage, only through engagement with the affected individuals can municipalities develop approaches that will fulfill human rights and alleviate stresses on the environment and surrounding communities. Once a municipality ensures that realistic, human rights-based solutions to the dilemmas of water and sanitation access for informal settlements are in place, the locality could then be justified in proceeding against individual residents should they abuse the facilities provided. However, community participation in the development of these solutions is the best way to minimize failures of this kind.

Conclusion

Our study demonstrated that Roma living in informal settlements in Sweden face barriers to accessing

water and sanitation—including eviction—that are similar to other barriers faced by Roma for decades and that violate their human rights to water and sanitation. While the issues raised by the migration of EU citizens are complex in many respects, the human rights to water and sanitation are straightforward and apply to everyone within a jurisdiction.

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Doubling Syndemics: Ethnographic Accounts of the Health Situation of Homeless Romanian Roma in Copenhagen

CAMILLA IDA RAVNBØL

Abstract

This study investigates health concerns and access to health services for Roma from Romania who live in homelessness in Copenhagen, Denmark. They collect refundable bottles and call themselves "badocari," which in Romanian refers to "people who work with bottles." Homeless Roma in Denmark have not previously been studied through ethnographic research. The study stresses the importance of a syndemic approach towards understanding badocari health concerns. Syndemics is understood as co-occurring diseases, which unfold within contexts of social injustice. The case of the badocari is argued to be a case of "doubling syndemics" since the co-occurring diseases are further multiplied and enhanced by an ongoing mobility between dual contexts of precarious livelihoods in Romania and Denmark, respectively. The study complements the approach to syndemics with a perspective on human rights. It sheds light on the limited possibilities that exist for addressing health concerns of the badocari, both in Romania and in Denmark, and argues that the universal human right to health is not realized in the everyday lives of destitute EU migrants such as the badocari. Rather, they experience lack of access to adequate medical treatment and follow-up care, both as citizens of a member state and as co-citizens of the European Union.

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Introduction

Cornelia sits nervously at the doctor's office in the Red Cross clinic for undocumented migrants. Her husband, Tudor, is with her. The doctor arrives and explains that Cornelia and Tudor have both tested positive for the MRSA bacteria (Methicillin-resistant Staphylococcus aureus). She underlines that MRSA is a serious condition that can have consequences if they would need antibiotics or surgery in the future. Furthermore, they risk transmitting the bacteria to their children home in Romania. The doctor explains the treatment for MRSA, which they have to follow. They need to shower and wash their hair on a daily basis using a disinfecting soap. They should change their bath towels daily, wash their sheets twice a week, and smear an ointment around their nostrils three times daily. Cornelia and Tudor listen attentively to the doctor, but the usually very talkative couple remains silent. The amount of information appears to be overwhelming. The doctor frowns in a concerned look, and asks if they understand what MRSA is and how they should treat it. They nod. There is an awkward silence. The doctor looks at the couple with a thoughtful look in her eyes, pauses and says, "Well, this is, of course, more complicated to do when you are homeless…" They nod again. We leave and exit into the street. It is a warm summer day in Copenhagen. Cornelia is now her talkative self again and explains that they have to leave immediately. They are anxious to start their working day of collecting refundable bottles from garbage bins around the city. I ask if I will see them tomorrow at the shelter where they can shower with the disinfecting soap that the doctor gave them. Cornelia and Tudor smile without replying. They discuss how to incorporate showers into their daily routines of rough sleeping and collecting bottles. It appears unlikely that Cornelia and Tudor will make it to the shelter tomorrow to shower and even less likely that they will change their towels and sheets daily. In fact, they have no towels or sheets to change. They only have a few blankets and one sleeping bag that they share at night when they go to sleep at a street corner in the city center.

This study addresses Roma migrants' health concerns and access to health services within the European Union (EU) from a perspective on Romanian Roma who live in homelessness in Copenhagen. It brings forward the experiences and perspectives of women and men who are destitute EU citizens that do not fulfill criteria to register as EU workers under Danish law. Instead, they live as unregistered EU citizens, who sleep rough and have minimal contact with the Danish health care system. This group of Roma travels continuously between Denmark (where they live and work in the street) and Romania (where their young children and other relatives are left behind). Their mobility is directed towards a constant search of income opportunities to support the household in Romania.[1] The situation of continuous migration presents several health concerns, which are the focus in this study. The study introduces the concept of syndemics to address co-occurring health concerns as being exacerbated by the social context.[2] It argues that the case of the badocari is a case of doubling syndemics since they experience co-occurring and mutually enhancing diseases within dual contexts of precarious livelihood and social exclusion. These dual settings include growing up in poverty and social exclusion in Romania and then migrating into circumstances of homeless livelihood in Denmark. The study complements the syndemic approach with a perspective on human rights. It approaches health as a human right and discusses the barriers and complexities that the badocari experience in accessing health services in Copenhagen. It argues that the case of badocari presents a litmus test not only to the outreach of the Romanian and Danish health care systems but also to the European Union project of realizing the right to health of all EU citizens.

Research design

In the period April 2014 to January 2015 and September to November 2016 (13 months), I carried out extensive anthropological fieldwork. I followed 40 Romanian Roma closely in their everyday lives as homeless in the streets of Copenhagen, and visited them in Romania when they returned home to spend time with their families. I continue in close contact with many of my interlocutors at this

time. The majority of my interlocutors come from the same local Roma community in Romania and mostly make a living by collecting refundable bottles in Copenhagen. They call themselves badocari, which is a Romanian term that refers to "people who work with bottles." Badocari is, therefore, not a broadly applied ethnonym for a particular Roma group in Romania. Rather it is a self-defined and self-ascribed plural term used by my interlocutors with reference to their current occupation in Denmark. In this study, I adopt the emic terminology of my interlocutors and refer to them as badocari.

The data material in this study draws on parts of my ethnographic material from the fieldwork. It consists of participant observation and informal conversations as well as semi-structured interviews and document analysis. The data has been triangulated and names of the Roma community and my interlocutors have been anonymized and replaced with pseudonyms. It is an anthropological study, which takes the point of departure in selected empirical cases, which are representative of the general situation of my interlocutors.[3] It is the aim that through the thick descriptions of the situation of a few, general tendencies can be understood in a new and more nuanced light.[4] For this reason, but also for matters of ensuring anonymity, the health trajectories of the individuals in the selected cases are not unique. Rather, they represent a few among many similar health trajectories (such as being diagnosed with MRSA, diabetes, and heart diseases) that I witnessed during my fieldwork and that my interlocutors shared with me.

Intersecting research fields

The study learns from, and contributes to, several fields of research. Firstly, it introduces the concept of syndemics as an analytical lens that allows for insight into the complex health concerns of homeless Roma in Copenhagen. It complements the syndemic approach with a human rights perspective in order to shed light on broader structural barriers of social exclusion. Secondly, the study contributes to health research fields concerning Roma, undocumented migrants, and homeless populations, respectively. The limited scope of this study does not allow for an exhaustive overview of literature within all these large research fields. Rather, examples of selected publications are referenced throughout the study.

Analytical perspectives: syndemics and human rights

The term syndemics was introduced by the medical anthropologist Merrill Singer in the 1990s as a concept to address human health as a biosocial process.[5] It serves to address situations where the health status of a population is significantly affected by interrelated and mutually enhancing health problems that unfold within contexts of noxious social and physical conditions. Singer defines syndemics as "the concentration and deleterious interaction of two or more diseases or other health conditions in a population, especially as a consequence of social inequity and the unjust exercise of power."[6] The concept has, since the 1990s, been applied in a broad array of studies that examine the relationship between comorbidities and the social context.[7] Inspired by the work of Paul Farmer as well as Sarah Willen, Michael Knipper and César. Abadía-Barrero et al., who argue for the importance of viewing complex health trajectories of poor communities from a human rights perspective which underline state responsibilities to address the comorbidities and adverse living conditions, this study complements the focus on syndemics with a perspective on human rights.[8] It approaches health from a human rights perspective, which regards health as essentially concerning the enjoyment of human rights.[9] The principle of non-discrimination and equal access to all human rights is primary, particularly rights to preventive health care and medical treatment. It is regarded as essential to have equal access to a range of social and economic rights in order to realize adequate health standards, including access to adequate housing and environmental conditions, education, employment, and social benefits.[10]

Roma health as a field of research

This study takes inspiration from health studies concerning Roma as well as undocumented migrants and homeless populations. The study of the

health situation of Roma populations throughout Europe is a growing research field, though there remains a lack of larger sample studies as well as epidemiological data.[11] Examples of studies on Roma health are referenced in the below section, which discusses Roma health disparities in Europe.

Given that my interlocutors not only reside in Romania but are also engaged in an ongoing mobility to Denmark, it is relevant to look to studies on migrant populations' health. This is another vast area of research, which contributes to both migration studies and health studies. In this study, I draw on two contributions which concern the access of undocumented migrants to health care in Denmark.[12] Whereas undocumented migrants have in common limited legal rights of residence, they are heterogeneous in regard to their housing opportunities. Hence, the social contexts that they inhabit may be slightly different, depending on which standards of housing they are able to access. In contrast, my interlocutors travel to Denmark with an initial legal right to enter and reside for a limited period of time, as will be explained later. They also have in common that they live in the street and sleep rough, and hence engage with a broader homeless environment in Denmark. I argue, therefore, that it is important to have insight into the implications that a homeless livelihood has on health conditions of the badocari. Homeless populations' health is studied broadly within academia and selected examples of relevance to this study are referenced in the section concerning the health status of the badocari who live in homelessness in Copenhagen.

Comorbidities and social exclusion among Roma in Europe

Despite methodological limitations of lack of ethnic data and larger sample studies, existing research indicates that marginalized Roma communities in Europe have higher rates of morbidity and premature mortality compared with non-Roma populations. The average life expectancy is five to 20 years lower than that of non-Roma, depending on the country, and infant mortality is also estimated as higher among the Roma.[13] Research points towards a tendency that marginalized Roma populations across Europe are at higher risks of a range of diseases, including infectious diseases such as Hepatitis A, B, and C; measles; meningitis; and tuberculosis (TB).[14] Studies indicate a higher prevalence of major chronic diseases such as diabetes, cardiovascular diseases (including hypertension), and asthma and their associated complications among Roma populations.[15] Research also points to lower immunization uptake among Roma populations in some European countries.[16] Studies show that Roma women are particularly at risk because they additionally experience maternal health risks that are enhanced by poor and stressful living conditions.[17] Notably, poor maternal health has a wide range of antenatal health consequences including e.g. newborn morbidities and mortalities as well as low birth weight.[18]

The health situation of Roma in Romania largely reflects the above described concerns at European level. The average life expectancy for Roma is 12 years lower than for non-Roma populations. Available data suggest that 45.7% of Roma children did not receive all the vaccinations included in the National Immunization Program.[19] In theory, Romania complies with European Union law, which establishes the rights to access health care.[20] Health care is declared to be free of charge, but in practice, patients are still expected to pay certain percentages of their treatment if they do not have medical insurance. Medical insurance is in general tied to employment status, but persons who receive social benefits and children under 18 are officially insured.[21] Emergency health care is provided free of charge for three days, and thereafter patients are requested to pay partial or full costs. Research shows that the Romanian health system is significantly underfunded and corruption is prevalent. Consequently, whereas health care may be officially free (for some), other costs are often requested by all patients, such as costs for medicines, medical supplies used during the hospital treatment (such as gloves and injections), as well as consumables for

patient and hospital staff. Corruption includes informal payments requested by health professionals for their services in public hospitals.[22]

This study argues that Roma health can with benefit be understood as a case of syndemics. The causes for which marginalized Roma populations have higher prevalence of a range of morbidities and premature mortalities are multiple and often compounded.[23] Barriers are generally associated with social exclusion due to poverty and ethnic discrimination. It is important to complement the perspective on syndemics with a perspective on human rights, in order to understand the broader structural barriers, which contribute to syndemics and hinder Roma in Europe in realizing their rights to health. In most European countries, Roma experience structural discrimination on the grounds of their ethnic origin, which manifests itself in exclusion from health care services and in poorer attendance and discriminatory treatment by medical staff.[24] Discrimination is not limited to the health care sphere but pervades every aspect of public life of Roma across Europe. This includes discrimination in accessing services such as quality education, social housing, welfare, and insurance schemes. As a consequence of discrimination and social exclusion, which further enhance poverty, many Roma live under precarious housing conditions in isolated areas with limited access to clean water, sewage systems, heating, and electricity, as well as limited access to health services, health insurance, and health care information. Furthermore, family generations' multiple experiences of poverty and social exclusion impact attitudes toward personal health and compliance in health self-care. Families who experience poverty and social exclusion are more prone to behavioral risk factors such as smoking, poor nutrition, and alcohol consumption.[25]

Badocari livelihoods and health concerns in Romania

The badocari experience health situations in their home community in Romania which in many ways reflect the poor health situation of marginalized Roma populations in Europe. The badocari come from a community in Romania which is situated geographically within the margins of a larger city, yet they are deprived from accessing a broad range of services and possibilities that (non-Roma) Romanians can access. For example, my interlocutors' children experience segregation at school, where they sit at the back of the classroom. They experience bullying by teachers and students on grounds of their Roma origin. Furthermore, only one part of the community has access to the sewage system and running water. The inhabitants generally have a low-income level and the majority live in poverty. Most are unemployed, and particularly the younger generations have never held a job with a working contract. Poverty is enhanced by the fact that only a few families have access to social benefits. Revenue is generated primarily from informal work in other EU member states, including, for example, the badocari engagement with refundable bottle collection in Denmark. Most households can afford basic daily needs such as food and clothing, but have limited possibilities of saving money, paying off debt, or investing in their future. However, many families also live in extreme poverty in shacks on the outskirts of the community, with no access to running water, electricity, or a sewage system. They cannot afford three daily meals, winter clothing for the children, or primary school expenses. Many have no health insurance since they are unemployed and do not receive social benefits. Even if medical treatment were free of charge (such as for children and those on benefits), the families cannot afford related medical costs for medicine and medical equipment used during hospital treatment. The badocari experiences of poor health are closely associated with economic scarcity due to their poverty. However, they are particularly affected by an additional dimension of economic expenditures: bribery from health professionals. This is the case for Vasile:

> *Cristian, 14, falls ill with stomach cramps. His father, Vasile, rushes him to the emergency room and it turns out that the son has appendicitis. The doctors inform Vasile that the son needs immedi-*

ate surgery. However, they also tell him that the surgeon has to be paid, in cash, 250 Romanian Lei (RON, approximately US$59) and the anesthesiologist must be paid 150 RON (approximately US$35). They place Cristian on a bed in the corridor of the hospital while waiting for the money to be paid. Vasile hurries home and borrows money from relatives to pay the formal and informal hospital expenses. After payment is made, Cristian is brought straight to surgery. He recovers well after the surgery, but Vasile now has a debt for hospital and medical expenses.

This empirical example of Vasile, whom health officials bribe even in a situation of acute child health risks, stands in contrast to the official health strategy of Romania, which formally establishes free health care.[26] It is merely one out of numerous stories of such bribery requests shared by the badocari concerning their contact with medical services as well as other public services such as the educational system. The practice of bribery has been noted in studies that argue it originates largely from underpayment of public officials such as hospital staff and school teachers.[27] While bribery is requested from both Romanians and Romanian Roma, it has a disproportionate effect on poor families who are unable to fulfill these requests.

From a human rights perspective, the empirical data illustrates how the badocari experience discrimination and unequal access to a broad range of economic, social, and cultural rights established in international conventions ratified by the Romanian state.[28] Poverty, adverse livelihood conditions, social exclusion, and discrimination exacerbate poor health outcomes for the badocari. They experience prevalence of health problems and comorbidities common among poor Roma communities, including chronic illnesses, infectious diseases, low immunization, and maternal health risks. Many of the badocari's children experience frequent illness with chronic illness such as asthma, or infectious diseases such as appendicitis. Several interlocutors lost a child, either at childbirth or during the child's first five years of life.

Cornelia and Tudor illustrate how the un-realization of a range of human rights, not only rights to health care, contribute to a noxious social context that enhances comorbidities. Cornelia grew up in significant poverty. Her parents were unemployed, and Cornelia and her siblings never went to school. She explains that since she was young, she had problems with stomach pains and worms, but never received treatment since her parents could not afford medical costs. She met Tudor and had her first child at 17. The couple lives with their four children in a small two-room dwelling that they have built themselves. The children range from eight to 14 years old and take care of themselves while Cornelia and Tudor are in Copenhagen. The money that the couple makes on bottles is transferred home to the children to pay for daily expenditures. Cornelia and Tudor explain that they struggle to keep the children in school, and work in Denmark to earn money for school costs. Their daughters, however, talk about being bullied at school by teachers and students because they are Roma. Since Cornelia and Tudor are unemployed and do not receive social benefits, they have no health insurance. Cornelia experiences health problems including worms, severe stomach pains, and weight loss and was recently infected with MRSA while living in Copenhagen (I return to discuss this aspect later). As is the case in all other families that I followed, the children are not immunized. Cornelia explains that her youngest daughter also has worms and is underweight. However, just as the majority of my interlocutors, this family only consults a doctor in emergency situations. Their children are officially entitled to free health care but the parents cannot pay the costs. As a consequence of the lifelong experiences with poverty and social exclusion, Cornelia and Tudor tend to self-medicate or even neglect health concerns. They have a low awareness of health risks and the implications of their high tobacco intake. The example of Cornelia and Tudor is not unique. Rather, it is a common picture of the complex health situation for badocari, in which comorbidities arise out of adverse social contexts characterized by discrimination and lack of access to a broad range of human rights. The lack of medical insurance and formal and informal medical

costs create a context where most of the badocari only seek health specialists in emergencies. Many self-medicate or do not take life-saving medicine such as medicine for hypertension and diabetes. Consequently, this enhances complications that can lead to more severe diseases such as heart attack or stroke.

Furthermore, poverty and self-financing of health care and medical treatment is a contributing cause of migration for the badocari. Many families explain that a family member travels abroad to work in order to support another family member's costs of medical care in Romania. For example,

Alexandru is 50 years old and has been traveling to Denmark to collect bottles and scavenge trash since 2008. His wife, Daniela, explains that she used to travel with Alexandru but now stays home in Romania because she suffers from type 1 diabetes and pancreatic cancer. Daniela explains that her condition got worse while she was living on the streets, and that she was diagnosed with hepatitis C while in Denmark. She returned to Romania to get treatment for her multiple diseases but has to cover medical expenses herself since she has no health insurance. Alexandru elaborates: "And let me tell you, I go there [to Denmark] for her. I go to make money and buy her medicine! If I get sick, we will die here, both of us; then there is nobody to help us. But as we are now, there is one who is sick and one who is strong and has the power, and the strong one works to support the sick one."

Six months after this interview, Alexandru explains that Daniela's health deteriorated and she died during surgery. Their case illustrates not only how comorbidities are enhanced by adverse social contexts but also how health-related expenses are a motivating factor for migration to Denmark. However, at the same time, the example shows that the migration to Denmark is an enhancing factor in the deterioration of Daniela's health condition. In other words, and even paradoxically, health problems are not only incentives for migration but also consequences of processes of migration. Many of my interlocutors experienced this paradox, and they constantly have to weigh the necessity of travel to pay for health care costs against the risk of getting (more) sick during migration. A frequent statement among the badocari is: "When you go to Denmark, you come back sick." The following section discusses health risks as consequences of migrating to Denmark in a broader argument for approaching the case of the badocari as a case of doubling syndemics.

Doubling syndemics: "When you go to Denmark, you come back sick"

The previous section described how the household economy of the badocari in Romania is premised upon a constant migration to Denmark. This section explores the health-related implications of a constant mobility between inadequate housing standards both at home in Romania and in Denmark. Everyday life for the badocari in Copenhagen takes place in the street and is contingent on the weather. They sleep rough (unsheltered) for various reasons related to an expensive and inaccessible housing market and limited availability of shelters that allow entry to unregistered EU citizens and undocumented migrants. Police immediately demolish shanty towns, shacks, and other forms of destitute housing.

Most of the badocari initiated their migration to Denmark and other EU member states following Romania's 2007 accession to the EU. Whereas some are new to Denmark, others have been travelling regularly for many years, including Cornelia and Tudor, who arrived in 2007, and Alexandru, who arrived in 2008. Many tried unsuccessfully to find work and accommodation but failed because they did not speak English or Danish and had no education and previous work recommendations. Hence, Danish law prevented them from registering as EU workers. Such a registration would have given them rights guaranteed under the EU framework of free movement, including a Danish social security number that is needed to access social services including health services, help with job searching, and housing.[29] My interlocutors explain that since they are not registered with a Danish social secu-

rity number, no one will hire them or rent them a place to live. Without a job, they are unable to afford the rent. In this way, one barrier enhances the other; without a formal working contract and a home address, it is impossible to obtain a social security number, but without this social security number it is difficult to access work and housing. The badocari instead turn to the informal market, including rough living and the income option of collecting refundable bottles and scrap collection. Studies of Roma migrants' health in Europe have highlighted health concerns in migrant campsites and shanty towns.[30] However, as described previously, the badocari do not even have access to these substandard camp options. Rather, the badocari sleep rough and move in social contexts with other homeless persons. In other words, they are exposed to environmental and social hazards of rough sleeping as well as diseases already prevalent among homeless populations. This begs questions about what happens when syndemics are doubled, in the sense that health concerns and precarious social and physical conditions relating to homeless livelihoods are coupled with health concerns of poor and marginalized Roma communities.

Research has shown that homeless people have higher rates of morbidity and premature mortality compared with the general population.[31] This includes higher prevalence of infectious diseases such as hepatitis C, tuberculosis (TB), HIV/AIDS, scabies, and body lice.[32] They are also at higher risk of infection with MRSA, which is estimated to enhance morbidities and premature mortalities.[33] Homeless populations have higher rates of morbidity and mortality from cardiovascular diseases, for reasons relating to limited access to care for early cardiac risk factors (hypertension, diabetes, elevated cholesterol) and higher rates of behavioral risk factors (high intake of drugs, tobacco, and alcohol).[34] Several studies indicate a higher prevalence of psychiatric diseases in homeless people compared with general population estimates.[35] Homeless people also experience low self-esteem due to their poor social status and poor hygiene.[36] One study from Copenhagen showed increased comorbidity between mental illness and substance dependency.[37] Furthermore, homeless individuals experience age-related diseases such as cognitive impairment and functional decline 10 to 15 years earlier than the general population.[38] The health of homeless populations is another area of public health that is best approached from a syndemic perspective. Homeless persons experience severe economic and social inequality and live in dangerous and poor conditions. They are exposed to safety and environmental hazards, including violence, drugs, and alcohol, as well as harsh weather conditions. Hence, they have higher rates of behavioral risk factors such as drug and alcohol abuse. Thus, the health of homeless populations is syndemic since it is shaped by interrelated and mutually enhancing health problems in contexts of adverse social and physical conditions.[39] In a human rights perspective, homeless populations experience exclusion from health care due to poverty and discrimination on the grounds of their low social status as well as unequal access to a broad range of rights, including adequate housing, social services, health care, and health information.

Many badocari struggle with illnesses as those identified as more prevalent among homeless persons. Cornelia and Tudor, for example, are diagnosed with MRSA and experience difficulties, difficulties in treating MRSA on similar terms as many other homeless, since they cannot change bed sheets or shower daily. However, Cornelia and Tudor experience more barriers to their treatment than Danish homeless, since they are unregistered EU citizens and do not have access to a range of health care services. This limited access to medical treatment is explored in the next section.

Daniela was diagnosed with hepatitis C, another infection for which homeless persons are at high risk. Other badocari experience problems with bug bites such as from body lice and scabies. Both scabies and body lice are frequent concerns for homeless persons due to their precarious living conditions.

Substance dependencies prevalent among the homeless have also become common for the badocari. While an overwhelming majority used tobacco before arriving in Denmark, they all say

that their consumption has increased since they started living in the street. They use tobacco to calm stress and depression related to their precarious livelihoods and are also more exposed when living in a street environment where everyone smokes. My male interlocutors express similar tendencies with alcohol abuse. Many badocari, particularly the men, started drinking more heavily after traveling to Denmark, and I witnessed this development during the period that I followed them from 2014 to 2016. By now, many of them have developed severe alcohol abuse problems, and some have started using drugs. One example is a young man called Doru, who is in his early 20s. Prior to his arrival, he had worked with begging in France and lived in a Roma camp close to Paris. He travelled to Denmark to search for work. After a while he began to drink and use drugs since he sleeps rough in a part of town known for its exposure to drugs. He befriended other young men who experiment with drugs. Doru explains that he had never tried using drugs before arriving in Denmark. The last time I meet Doru before he is arrested for petty theft, he is highly intoxicated. Doru's experiences are caused largely by exposure to a social street context which is marked by precariousness and substance abuse.

The badocari women express health concerns relating to pregnancies and gynecological problems that are worsened by their living conditions in Copenhagen. Sleeping rough and not having easy access to showering is particularly problematic for the expectant mothers, but women who are not pregnant talk about abdominal pains that have worsened during the stay in Denmark. This includes infections in the abdomen and bladder related to sleeping and living under harsh weather conditions and lacking access to showers and toilets. Many of the women explain that they experience stress- related symptoms and some struggle with depression. For some, the psychiatric conditions have worsened because of the hardship of living and working in the street as well as the long-term absence from their children at home. However, since they come from an impoverished community where mental health treatment is expensive and traditionally surrounded by stigma, most go untreated. These examples sketch out a syndemic tendency where one vulnerability couples with and potentially enhances the other.

The above examples illuminate complexities of doubling syndemics. In terms of comorbidities, the badocari are exposed to a range of health risks associated with homeless livelihoods, and their health condition is already compromised from growing up in poor conditions in Romania at higher risks of various diseases and associated health risks. Also, the badocari may neglect or misinterpret their health situation and health needs in Denmark as they tend to do back home, due to experiences with inaccessible and unaffordable health care in Romania. In this way, poor compliance in personal health care continues in Denmark. Importantly, they risk exposing their young children at home with diseases from a Danish homeless environment, such as MRSA, TB, body lice, and scabies. TB is a major concern since it is frequent among homeless populations, but none of my interlocutors' children have received TB vaccinations and are therefore at high risk. Whereas scabies is less likely to be transferred between parents and their children under circumstances of standard housing conditions, the poor living conditions that the badocari have at home increases this risk since poor families often have to share the same bed. Scabies, caught in homeless circles in Copenhagen, can thereby be transferred to young children in Romania.

One of the defining elements in a syndemic approach is that health concerns are largely caused by as well as exacerbated by adverse social contexts. The above discussions illustrate that the badocari experience not only syndemics caused by co-occurring health concerns within social contexts of exclusion and marginalization in their home country Romania. In fact, their case is syndemic also in Denmark since they become subjects who live in precarious livelihoods as homeless. The syndemics are in this sense doubling. Reaching this conclusion, however, opens up questions about state responsibilities to disrupt such circumstances of syndemics. This requires holistic approaches to rights realization, beginning with implementing rights to access health care.

Unregistered and destitute EU migrants' rights to health care in Denmark

The international human rights framework establishes "the rights of everyone to the enjoyment of the highest attainable standard of physical and mental health."[40] States must ensure timely and appropriate health care as well as healthy and safe occupational and environmental conditions.[41] Furthermore, states' legal obligation also concerns access to health care for undocumented migrants and asylum seekers.[42] At the European level, access to health services falls within the scope of the European Social Charter and has also been interpreted by the European Court of Human Rights to fall within the scope of the European Convention on Human Rights.[43] At the level of the European Union, all member states are legally bound to the European Union Charter of Fundamental Rights, which establishes the "rights of everyone to access preventive health care and to benefit from medical treatment" (article 35). However, article 35 is conditioned on national laws and practices, and the European Court of Justice also generally approaches health as a national matter.[44] The EU has developed strategies and policies on health care. Nevertheless, it is legally largely up to the individual Member States to interpret how the right to health should be realized.[45] EU citizens also have rights to access health care under the status of "tourists" if they have an EU health insurance card. The card is intended to be issued free of charge by the national health insurance provider and gives access to unplanned medically necessary state-provided health care during a temporary stay.[46] However, many countries, Romania included, have as a precondition that medical insurance depends on a working contract and hence the EU health care card is only accessible for Romanian citizens with formal employment.

Health care in Denmark is based on tax finances and ensures free universal coverage to national citizens. Furthermore, Denmark has ratified the above mentioned international and regional framework for protection of the rights to health. However, two studies illustrate that undocumented migrants are only granted access to emergency health care in Denmark.[47] An executive order on the right to hospital treatment notes that non-residents have rights to emergency treatment in cases of sudden illness, delivery, or aggravation of chronic illness.[48] Denmark has not developed official policies or guidelines for health professionals concerning undocumented migrants' rights to access health care. The absence of relevant polices transfers the responsibility to the health professional to determine whether or not an undocumented patient is suffering from an acute illness.[49]

In Denmark, citizens from EU member states have rights to access public services, including free health care and treatment, depending on a status as "EU workers" or "students" enrolled at a higher educational institution. The Danish State Administration assesses each case individually, but in general adheres to case law by the European Court of Justice. On this basis, the state administration defines the status of "EU worker" as dependent on "effective and genuine employment" for more than 10-12 hours weekly for a minimum of 10 weeks.[50] If criteria are fulfilled and EU working status is granted, the EU citizen receives a Danish social security number and a yellow health card, which grants free access to all forms of health care and treatment. EU citizens also have rights to access health care under the status of "tourists" if they have an EU health insurance card.[51]

In order to address the large need for health services to undocumented migrants, the Red Cross opened a volunteer-based medical clinic for irregular migrants in Copenhagen in 2011. The Red Cross clinic directs itself primarily to persons who do not have access to Danish public health insurance (based on the social security number) or private health insurance. It offers treatment to adults and children for diseases usually treated by GPs in the primary sector. However, the nonprofit clinic is limited in size and scope, and is entirely dependent upon private funding and volunteer health professionals.[52] The staff attempts to follow up on patients, but has no established outpatient clinic and cannot follow up on patients they have sent to a hospital for

emergency treatment. The clinic can at times transfer patients to clinical examinations, such as X-ray, ultrasounds, and further complex diagnosing.[53]

Badocari access to health care services in Denmark

The badocari are neither registered as EU workers in Denmark nor are they employed back home in Romania, which would grant the EU health card. They are unregistered EU migrants who have legal permissions to stay for a period up to three months (which is expanded to six months for job-seeking individuals). The badocari access to health care and medical treatment while in Denmark is therefore limited. Legally, they only have access to acute emergency health care on similar terms as undocumented migrants. What is defined as an "emergency" depends on an individual medical audit but in general concerns acute medical conditions. For example, medical treatment for non-acute chronic diseases or terminal illnesses is excluded from treatment including diabetes, hypertension, and cancer. Furthermore, pregnancy screenings are excluded from treatment, and pregnant women can only access the hospital free of charge if they are in labor.[54] Hence, many badocari turn to the Red Cross clinic for undocumented migrants.

The badocari experience the consequences of the doubling syndemics on their health conditions as well as legal barriers to accessing health care in a variety of ways. Daniela, for example, was admitted to the hospital during an acute aggravation of her diabetes a few years prior to her death. While admitted, she was further diagnosed with hepatitis C. The possibilities that Daniela had for receiving treatment in Denmark only concerned the acute circumstances of her disease. The long-term medical treatments and follow-ups that Daniela needed remained inaccessible.

Cornelia and Tudor's MRSA diagnosis is another case that highlights the barriers the badocari experience in accessing health care. While Cornelia and Tudor receive treatment for the MRSA in the Red Cross clinic, they have no possibilities for follow-up treatment, which is crucial to ensure that the medical treatment has worked, but mainly to ensure patient compliance with the treatment. Furthermore, their case shows how civil society ends up lifting a health care responsibility that generally lies on the state.

Cornelia, Tudor, and Daniela are far from alone in experiencing exclusion in terms of health care in Denmark. Rather, their cases are exemplary illustrations of a situation in which most of my interlocutors experience health problems which deteriorate in Denmark and for which they cannot receive adequate treatment as unregistered EU citizens. The situation is particularly critical for pregnant Roma women. Half my interlocutors are women aged 17-50. They all have three or more children, and most had their first child when they were 15-19 years old. Most continued migrating to Denmark or other EU countries during their pregnancies. From a syndemic perspective, these women and their unborn children are particularly at risk due to compounded health concerns related to growing up and living in an impoverished Roma community as well as rough sleeping in Copenhagen. However, given their unregistered status, the women do not have access to maternal health visits in the public health care sector in Denmark. The Red Cross clinics offer maternal health visits with a midwife, however, if the volunteer midwife suspects complications that require hospital treatment, she/he can only direct the women to the hospital if it is an acute emergency. If it is not "acute," but rather a complication that requires longer treatment, the state may request payment for the service granted at the hospital.[55] For example, follow-up treatment is not accessible for pregnant women with diabetes or early age (maternal age of 14-17 years) high-risk pregnancies, which are two very common risk factors among my interlocutors.

The legal limitations for accessing follow-up health care and treatment are particularly evident in psychiatric care. The badocari who experience depression and psychiatric disorders also share experiences of limited access to treatment in Romania particularly due to unaffordable treatment but also

due to stigma concerning mental health disorders within many families. They have low compliance levels with taking medicine, and struggle with substance abuse on similar terms as Danish homeless who experience psychiatric disorders. They require long-term care and follow-up with specialized professionals. However, in comparison with nationals or persons with status as EU workers, the badocari do not have access to follow-up or long-term treatment. The only treatment they can access is that of acute emergency psychiatric care at the hospitals, or access to a volunteer psychiatrist at the Red Cross clinic.[56] This was the experience of one of my interlocutors, Dorian, who struggled with mental illness prior to his arrival in Denmark. He explains that travelling is a way for him to tackle his illness. However, Dorian experiences a deterioration of his mental health after a period of rough sleeping in Copenhagen. He explains that he sees and hears visions and sometimes forgets where he is. The Red Cross clinic offers Dorian meetings with a volunteer psychiatrist, but they cannot refer him to non-acute psychiatric treatment or follow up.

The cases illustrate that one major barrier for the badocari accessing health in Denmark is the limited access to non-acute medical treatment as well as follow-up. The Danish state does not interpret international obligations for fulfilling the rights to health to concern undocumented and unregistered migrants. Civil society (in this case, the Red Cross) does not have the legal and financial ability to take over the state's responsibilities and meet all such needs. These limitations not only hinder adequate medical treatment but also make it even more difficult to address cases when patients do not comply with their treatment or neglect health needs. Noncompliance and neglect of health are also social consequences of syndemics, where the badocari experiences with marginalized livelihoods and in-access to health care in both Romania and Denmark are mutually enhancing. Not only do they experience limited access to medical care in Romania due to poverty, corruption, and discrimination, which influence many to self-medicate or neglect their own health, but the experiences of exclusion continue in Denmark when they are excluded from primary care, further "non-acute" medical referrals, and follow-up medical treatment.

Studies of undocumented migrants' health in Denmark illustrate how formal legal barriers combine with other informal barriers within the health care system.[57] This also appears to be the case for the badocari, who, for example, experience language barriers in communicating with Danish health staff. They lack knowledge of the functioning of the Danish health care system. Furthermore, health staff in the emergency sector may be biased or have difficulties in understanding this patient group due to lack of awareness, stereotypes, or even discriminatory perceptions of Roma. These informal barriers couple with the already existing legal barriers and have a mutually enhancing effect. The effect is again strengthened since experiences with formal and informal barriers within the Romanian health care system influence how the badocari approach the Danish health care system.

The analysis has shown how syndemics concerns comorbidities as well as inequity and injustice in the social contexts. In this regard, the badocari situation is argued to present a case of doubling syndemics, since they experience social injustices in two social contexts. The exclusionary context must be understood in broader terms as also including the legal barriers to access health care. The doubling syndemics is arguably enhanced by the limited rights status that they have despite the fact that both Romania and Denmark are signatories to international and to EU legal frameworks which establish the right to health.

Recommendations

At the European Union level:

- promote implementation of EU health policies at national levels through concrete state interventions, and,
- ensure that the EU Blue Health Card is universally accessible and not conditioned upon national requirements such as employment status or housing registration.

At the state level, in Romania:

- ensure de facto free health care including coverage of expenses related to medical treatment;
- disseminate information about the EU health card at the national level, with a particular focus on poor households. If health care is officially free, EU Blue Health Cards could be issued in a similar process to ID issuance;
- combat corruption, including informal payments requested by health professionals, as well as officials in other public domains;
- strengthen efforts to combat discrimination against Roma within public institutions;
- develop efforts to ensure marginalized and poor families' access to health care, including families who remain out of scope of social benefits; and,
- ensure access to other human rights, including social benefits, housing etc.

At the state level, in Denmark:

- develop polices and guidelines for health care for undocumented migrants and unregistered EU migrants as well as concrete guidelines for health professionals;
- consider the financial benefits of providing non-acute health care and follow up to undocumented migrants and unregistered EU citizens in comparison with costs for emergency health care for these target groups when their health issues go untreated; and,
- ensure access to health care for undocumented migrants and unregistered EU citizens by increasing support to civil society.

Conclusion

This study has illustrated how the badocari experiences of "when you go to Denmark, you come back sick" are not isolated experiences of health concerns in one country. Rather, the badocari represent a case of doubling syndemics, where diseases are co-occurring, caused by, and enhanced by precarious social contexts both in Romania and Denmark. Health risks and diseases associated with living in homelessness seem to enhance problems for already vulnerable and exposed populations. Furthermore, children and elderly people at home in Romania, who are not immunized and are at high risk of disease, risk further exposure to diseases common in Danish homeless contexts. The study has shed light on badocari experiences with accessing health services in Romania and Denmark and ultimately how the universal human right to health is manifested in a badocari everyday life in the street. The reality is that access is limited. As unregistered EU citizens and unemployed in their home country Romania, the badocari neither have rights to Danish public health care nor can they obtain an EU medical insurance card (EU Blue Health Card). They can only access medical treatment in emergency situations or at the volunteer-run Red Cross clinic for undocumented migrants. The long-term medical treatment and follow-up that this population needs is inaccessible. This underlines the doubling syndemic nature of the health status of the badocari since they do not only experience co-occurring diseases but these are largely caused by (and particularly enhanced by) social inequity and exclusion in two contexts of Romania and Denmark, respectively.

The study complements a syndemic approach with a perspective on human rights. The empirical findings raise a range of questions as to the realization of the European Union project on access to health for all EU citizens when it comes to destitute EU co-citizens. The badocari are Romanian citizens but experience limited access to medical care in Romania due to poverty and ethnic discrimination. Services that are officially free of charge in Romania are in practice unattainable, due to the requirement of formal employment and/or to formal and informal medical costs. In fact, national limitations on access to health care come to impact EU rights, since persons who are unemployed in Romania cannot access an EU Blue Health Card. Having such health insurance would significantly alter the legal rights to health care that the badocari

have in Denmark or in any other EU country. The badocari have legal rights to reside in Denmark but no legal rights to health care and medical treatment apart from emergency situations. The non-acute treatment and follow up treatment that this group needs remains inaccessible.

In sum, the empirical case of the badocari illustrates how the EU right to health does not match the reality on the ground. In fact, certain populations appear to be excluded from enjoyment of this human right. These are destitute populations who, in their everyday lives within the European Union, cannot access adequate health care and medical treatment both as citizens of a member state and as citizens of the EU at large. The case of the badocari can therefore be regarded as a litmus test of the *de facto* realization of the rights to health of all individuals as established in international conventions and in EU law.

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Dedicated Caravan Sites for French Gens du Voyage: Public Health Policy or Construction of Health and Environmental Inequalities?

LISE FOISNEAU

Abstract

In France, *gens du voyage* ("people who travel" or "travellers") is a term used by the government to categorize various itinerant populations, the majority of which are diverse Romani groups. People categorized as *gens du voyage* are legally required to reside in particular locations called "dedicated caravan sites." Parliamentary debates about these dedicated caravan sites have clarified that one of the objectives of such sites is to help fulfill the *gens du voyage*'s right to health. However, there is a significant gap between the officially stated goals of such sites and the reality of life within them. This paper draws on research finding that the conditions in most dedicated caravan sites do not conform with the rights of *gens du voyage* to acceptable sanitary conditions and other underlying determinants of health.

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Introduction

In France, a dedicated caravan site (*aire d'accueil*) is a site reserved for caravans and camping-cars that belong to people whom the French government calls *gens du voyage* ("people who travel" or "travellers"). A caravan site is a fenced-in area, somewhat like a parking lot, completely paved with asphalt, and with a gate controlling access. Alongside the gate is a cement administration building. The state and local councils are legally obligated to construct these caravan sites and therefore they select their location and design.[1]

The legal definition of *gens du voyage* is rather broad, and includes "all persons having had neither home nor fixed residence for more than six months in a member state of the EU."[2] In reality, nearly all people defined in that way belong to Romani groups that have been traveling around France for several centuries.

One of the officially stated purposes of placing obligations on local councils to provide caravan sites is to reduce social and sanitary inequalities experienced by *gens du voyage*. Their life expectancy is 15 years less than the total French population.[3] Parliamentary debates about these dedicated caravan sites have clarified that one of the objectives of such sites is to help fulfill the right to health of *gens du voyage*. However, there is a significant gap between official discourse and the reality of life within these sites. Most dedicated caravan sites are located in distant suburban areas alongside industrial parks, highways, or railroads. Consequently, residents are exposed to high levels of pollution of many sorts, including noise, dangerous chemical products, and traffic.

This paper presents research that identifies a disconnect between the intention of relevant legislation—improving the health conditions of *gens du voyage*—and the reality of residents' lives in the dedicated sites. It suggests that the very design of most dedicated caravan sites leads to violations of *gens du voyage* human rights entitlements. The research applies a critical analysis of the administrative and legislative requirements that *gens du voyage* stay in these degraded sanitary environments, thereby denying them their right to the highest attainable standard of health.[4]

European scholars have used three main lenses to analyze environmental inequalities: research-action studies, publicly or privately funded, which have justified the public policies; political theory studies exploring the nature of environment inequalities; and critical analyses of environmental normativity.[5] The present paper is a contribution to the latter approach, and it includes analysis of historical documents, legal and otherwise, as well as direct observations of the current living conditions.

This paper begins by providing an interpretation of international and national texts related to the health conditions of *gens du voyage*, because these texts have provided legitimacy to particular treatment of people on dedicated caravan sites. In the following section, the paper draws on observations of the sites made by the author over a 22-month research period. In the third section, the paper presents analysis of historical sources from various departmental archives which show that dedicated caravan sites, although a relatively recent phenomenon, are in fact a further development of a century-long history of indirect forced settlement.

From international discourses to local interpretations

Most political decisions regarding *gens du voyage* are health-oriented: the justification of a new dedicated caravan site on a local community territory is thus, most of the time, to achieve a higher standard of health conditions for its inhabitants. How are such justifications articulated with public policies aiming at controlling Romani groups?

The health of gens du voyage from a World Health Organization perspective

In 2009, the World Health Organization (WHO) and the *Réseau français des Villes-Santé* [RFVS; French Healthy Cities Network] published a guide entitled *The health of gens du voyage: Knowledge and action*. Throughout the guide, the terms "*gens du voyage*" and "gypsies" ["*tsiganes*"] are incorrectly assigned

to the groups. Furthermore, the guide states that "*gens du voyage*" and "gypsies" are of Indian origin, although they do not form two homogeneous groups.[6] In fact, the French phrase "*gens du voyage*" has no anthropological basis at all; invented by the French government in 1969, it classified a subgroup of citizens and replaced the term "nomad" that had previously been used in French law.[7] Both categories, "nomad" and "*gens du voyage*", allow the government to characterize a small minority of the French population without using racial terms—to do so would be contrary to French republicanism.[8] The *gens du voyage* category includes Catalan Gypsies, Yeniches, itinerant merchants, and Roma. The only common feature they share is their inclusion in the category; that is, they live an itinerant life as defined by a circulation booklet, which for a long time deprived them of a proper French identity card. The groups travel not because they cannot afford a house but because they want to travel. Indeed, their caravans and camping-cars are often very expensive. The French government treats them differently simply because of their choice of lifestyle.

The WHO-RFVS guide explains that the French government has no specific public health policy related to *gens du voyages*, but it identifies "actions in the general framework of struggle against poverty or related to dedicated caravan sites and housing."[9] It states that

> *on the basis of the danger associated with their conditions of housing and their way of life gypsies can be considered as a 'risk population', along with 'young people having difficulties in finding their place in society', 'persons under justice surveillance or coming out of prison', and 'illegal immigrant[s].'*[10]

"Gypsy" housing and way of life are thus considered a source of health problems; indeed, health problems among *gens du voyage* would be "associated with the combined effects of precarity and mobile housing."[11] It suggests that frequent pathologies affecting *gens du voyage* are due to "the promiscuity of caravan residents" and to "[bad] professional habits" of their inhabitants. In particular, infectious respiratory disease is said to be due to overcrowding and lack of air circulation in caravans.[12] This WHO-sponsored guide attributes the ill health of the "*gens du voyage*/gypsies" to their habits and, in particular, to living in caravans. The guide suggests that dedicated caravan sites include "a building aimed at collective activities so that inhabitants can get together in a room larger than a caravan," a recommendation representing a series of misunderstandings.[13]

Health evaluation and public actors

Two influential documents demonstrate the negative way in which the health of *gens du voyage* is presented. In 2001, *Médecins du Monde* (Doctors of the World) and a regional association published a report entitled *A community health diagnosis of the gens du voyage population*. In 2010, a transcript was published following a conference in Guyancourt on the health of *gens du voyage*.

The Doctors of the World report states: "living in a caravan has a direct impact on human health."[14] Due to its "contiguity," caravan life increases the number of "domestic incidents," "respiratory problems," "sleeping difficulties," "unruly behavior of children," and the "overeating and stress of mothers."[15] Furthermore, it claims that "traditional activities" have health impacts, citing metal collection, which exposes the collectors to toxic substances.[16] The report concludes that the habits of *gens du voyage* are the main cause of their poor health. These public health observations refer only briefly and very cautiously to the risks that the settlement of caravans on unhealthy sites ("*l'environnement insalubre*") could represent for human health.[17] One of the speakers at the 2010 Guyancourt conference, a general practitioner, stresses that, according to his analysis, the main causes of sickness among *gens du voyage* are consanguinity, addictions, and unhealthy food. He writes: "I have observed pathologies due to consanguinity that can only be seen in medical books."[18] The speaker appears unaware that his stated observations are a repeat, with little change, of racial stereotypes widely circulated in the late-19th century that led to 20th century persecutions of the Roma. These reports support the ill-informed view that dedicated

caravan sites will allow a higher standard of health conditions for their inhabitants.

Dedicated caravan sites: Legally required but unwanted

Between legislative direction and practice

French authorities generally refer positively to the "Besson law," passed on July 5, 2000, noting that it enables local councils to fulfill their legal obligations for hosting and housing *gens du voyage*. These include allowing *gens du voyage* to pass through, or to host and provide decent housing for the families that want to adopt a more settled lifestyle.[19] The law obliges all towns with more than 5,000 inhabitants to build a dedicated caravan site for *gens du voyage*. However, a reading of the legislation suggests the burden of obligation rests only on the side of local authorities who must welcome, host, and provide the caravan site. In this paper, it is observed that there is also an obligation placed on the *gens du voyage*, who are no longer free to choose where they can park their caravans as they could before the enactment of the Besson law. Under this law, they are obliged to gather in specific places reserved for *gens du voyage*.[20]

Because residents in many French towns do not want dedicated caravan sites near their own homes, the sites are usually placed in areas not favored by property developers. For example, the caravan site La Chaberte, in the territory of the *Toulon-Provence-Méditerranée*, was built on the outskirts of Toulon, in an industrial area between a major highway and a departmental road. It opened in 2014. The site is not served by public transport, and it is too remote for the inhabitants to walk to town, which leaves cars as the only means of transport. This is typical as dedicated caravan sites are nearly always in suburban areas, surrounded by national roads, highways, or a railway, if not all three together. They are also placed alongside industrial parks, exposing the inhabitants to pollution. Several caravan sites in the suburbs of Lyon have been set up near refineries and factories which the European Commission has associated with high industrial risk levels as identified by the Seveso Directives (named after the 1976 explosion of the Seveso chemical plant in Italy). Those directives place obligations on dangerous industrial sites to adopt measures to prevent pollution and accidents. Caravan sites built in smaller communities are not necessarily any better; those near Aubagne and Sisteron are located remotely, distant from the small communities, but near noisy major roads.

Administrative practices and architectural features result in further burdens for people living in dedicated caravan sites. Since the end of the 1990s, private enterprises have specialized in building and managing the sites. The New Public Policies (NPP), creations of neoliberal inspiration, have favored public service being delegated to the private sector. In the case of dedicated caravan sites, it created a new public market which is now in the hands of a few private enterprises. One such company, Vago, has outlined its "four commitments" in creating new sites: more respect, less degradation, less conflict, and no unpaid bills.[21] Architecturally, dedicated caravan sites built by companies like Vago are comparable to low-category parking lots: the ground is all asphalt, there are no trees and therefore no shade in the summer. Bathroom facilities are rudimentary at best and designed simply to limit any degradation.

Case study: Marseille

In order to better understand the environmental and health conditions on dedicated caravan sites, I now turn to the findings of my fieldwork. This fieldwork was conducted for a PhD in anthropology at Aix-Marseille University (AMU). There has been some published research on dedicated caravan sites based on interviews with inhabitants, but I used a participant observation methodology, spending 22 months on various dedicated and non-dedicated caravan sites within my own caravan.[22] I therefore had direct experience of the challenges of living on such sites, notably in matters of health and hygiene. My research received the ethics approval of my PhD committee at AMU.

Marseille's dedicated caravan site, which can host up to 24 families, is located in the industrial area of Saint-Menet between a highway, a railway, and a power station. There is a large chemical plant

less than 500 meters from the boundary of the site. The chemical plant is hazardous, as evidenced by its Seveso category, and it is managed by Arkema, the company that managed the factory that burned in Texas after the 2017 Hurricane Harvey.

The layout of the caravan site matches the harsh environment: it has rectangular grounds surrounded by a fence, and looks onto the power station, which is surrounded by barbed wire. There is only one entrance to the site, so it would be difficult for all inhabitants to exit quickly in an emergency. In the center of the site, there is a building for administrative and social staff; its windows have iron bars, and staff can survey the entire site from this building. On both sides of an asphalt road, each lot has an individual sanitary block with squat toilets and a basic shower hose. Inhabitants must pay a EUR60 deposit, plus a EUR2 fee per day, but this does not include charges for water and electricity.

The dedicated caravan site is located in the most-at-risk part of the Seveso-rated area. This means if there is an explosion, the inhabitants and their caravans would experience direct thermal effects, as well as the impact of the explosion itself. The consequences were well-documented following the explosion that destroyed the AZF site in Toulouse in 2001.[23] Despite the EU's adoption in 1982 of the Seveso regulation that bans housing in most-at-risk areas, Marseille authorities kept this site at Saint-Menet, which had been built in 1977. The minimum safety standards require the site to include a confined room for shelter of all inhabitants in case of chemical emergency. The onus of this obligation lies with the local authorities and the management, Vago. France Nature Environnement, a French association specializing in environmental protection identified the lack of this safety feature in 2016. Their report notes "insufficient shelter conditions, for not even half of the persons who would be impacted, and this shelter [that is, the administrative building] is only open during business hours."[24]

During my time on the caravan site in Saint-Menet between April 2015 and February 2016, Arkema had agreed to a containment scheme and was putting a containment room for shelter within every house inside the perimeter of the Seveso area. But when I inquired as to whether the caravan site was included in the scheme, they said no, and they confirmed that there were no plans in place to ensure protection to inhabitants in case of a chemical emergency.[25]

There are other unpleasant aspects of this site. It is close to the highway so the noise level is high, and there is an ever-present smell of gas.[26] The nearby power station means some of the inhabitants live only a few meters from high-tension power poles. The sanitation blocks are in a state of poor repair; the clogged drains from the toilets and showers frequently overflow. When I asked for the blocked drains to be cleared, the management informed me that the inhabitants had deliberately thrown little stones in the pipes. These unsanitary conditions attract rats and people living on the site claim they are often scratched by the rats.

Health services on the site

Where, in such conditions, could we observe actions that would fulfill the stated objectives of the legislative to improve the health and living standards of the *gens du voyage*? In the administrative building where medical staff work. Several times a month, nurses, and occasionally doctors, are on site to implement compulsory vaccination campaigns and health promotion measures, particularly for children.

However, my research found that inhabitants of the site prefer to consult their own doctors. The *gens du voyage,* like other French citizens, are included in a social security system that allows them to consult, without a fee, general practitioners and specialists anywhere in France. I observed that when inhabitants took their children to the nurses and doctors on the caravan site, they visited their own family doctor afterwards.

When I asked a neighbor about this arrangement, she explained that she did not want her present living arrangement in a contained area to prevent her from using normal public services like county primary schools and local doctors. She added that it would not be wise to trust the doctors designated for you by an administration that forces you to live in degraded environmental conditions. Since France has a non-discriminatory health system—anyone is entitled to equal and free health

care—why should the *gens du voyage* renounce the benefit of free choice of doctors? By consulting their own family doctors, my neighbors clearly demonstrated their understanding of their rights entitlements as French citizens to benefit from a common social security system and to be treated equally with the "sedentaries," as they sometimes call French citizens who do not live in caravans.

Most inhabitants regard dedicated caravan sites as segregated places with unhealthy environments. By extension, they also consider the sites' health services not as social services but as measures of social restraint. They were aware that French public policies concerning *gens du voyage* are not implementing the right to live in a healthy environment, or the right to health care, but to the contrary, the sites bring about environmental injustices. The right to health is not only a right to access equal care but also a right to live in a healthy environment. However, on the Saint-Menet caravan site, those arguments are only aired privately—I was aware of them because I was a resident—but I never heard them expressed to the managers of the site.

Women's protest

Inhabitants are aware that managers of dedicated caravan sites could ban them if they complained about their living conditions.[27] And if they could no longer access dedicated caravan sites, the only option left to them would be to park in illegal locations, which would place them under constant threat of expulsion by police forces. Under such circumstances, their silence on their poor environment is understandable.

Nevertheless, some inhabitants have organized protests about their degrading environmental and health conditions. Women living in the Hellemmes-Ronchin dedicated caravan site in the suburbs of Lille formed an association in 2014. One of the women described the site as "stuck between a cement-plant, a stone-breaking company, and fields with regular spreading of pesticides and other toxic products."[28] She added that "children and elderly people are more affected [than others] since they remain there constantly, and therefore breathe ceaselessly the cement dust in the caravans and in the atmosphere." She observed that children made up the majority of inhabitants.[29] These women assert that facilities were poorly designed: there are no closing doors and no heating in the sanitation blocks, which makes it difficult to take showers in the winter. The association observed that the gate controlling access to the area was not big enough to allow fire trucks to enter the area.[30]

Hellemmes-Ronchin in Lille and Saint-Menet in Marseille are not isolated cases. The Besson Law has resulted in a market for dedicated caravan sites, with potential for good revenue for companies such as Vago. There is no incentive for a company to spend funds on creating a pleasant environment. Indeed, the less it spends on improving or maintaining the site, the greater its profits. A human rights accountability mechanism should review this public policy to ensure that profit is not made at the expense of inhabitants' rights.

In this paper, I contend that authorities and commissions have been blind to the historical discrimination against Romani groups in France that the Besson Law perpetuates. I now consider this law in its historical context.

History of the dedicated caravan site policy

Hygienic surveillance of the "nomad"

The vagueness in the use of the terms "*gens du voyage*" or "gypsy" is not limited to the WHO guide discussed above.[31] As early as the end of the 19th century, members of the Third Republic discussed the possibility of passing a specific law for bohemian populations, as Romani population used to be called. However, there were difficulties identifying the population concerned in the legislation. In 1907, the Chamber of Deputies (the lower level of parliament) queried: "What are the signs according to which a gypsy can be identified?"[32] There is no evidence that the question caused any concern, even though it is equivalent to asking by what stigmas a gypsy can be stigmatized. One member answered: "Gypsies can be identified with the following characteristics: there is first of all a racial criterion that you know as well as I."[33] It took until the adoption

of a July 16, 1912 law for the members to elaborate a "proper" administrative category, "nomad," that focuses on the supposed nomadism of gypsies ["*romanichel*"] without using racial criteria explicitly. But this Republican "omission" of a racial characteristic is replaced by another dangerous concept, namely, the "precise idea that a nomad is, almost always, a criminal."[34]

Christophe Delclitte observes that the administrative category of "nomad" is "a central element in the understanding of the fact that there is a continuity in the way the [French] legislative, administrative, and police institutions have treated gypsies during the 20th century."[35] The "nomad" category ended in 1969 but was immediately replaced by the new category of *gens du voyage*.[36] It is also worth noting that the 1912 legislation provided a legal framework for the detention of gypsies in France during the Second World War.[37]

The "hygienic surveillance" of the gypsy population was one of the intentions of the July 16, 1912 law, which obliged all "nomads" to carry with them an anthropometric leaflet.[38] Nomadic populations were considered responsible for the spread of disease, so surveillance of the individuals was considered essential. The last pages of the anthropometric leaflet concerned health. This health section [*carnet de santé*] started with smallpox [*antivariolic*] vaccination and following pages included "prophylactic measures that can be applied to disease." The leaflet mentioned whether the nomad had been in isolation or had been hospitalized, and also outlined whether "disinfection" measures had been applied, or if "destructions of contaminated objects" were required. This focus on hygiene is an ongoing feature of all policies relating to "nomads" or *gens du voyage*; indeed, it is used to justify increased health surveillance of specific populations.

First steps of a politics of settlement

In 1960, a few years before the abrogation of the 1912 law, the French Ministry of Public Health and Population launched an inquiry into "the conditions of life of populations having a nomadic origin."[39] The inquiry led to a new law, passed in 1969, and helped generate new ideas on the best way to "hasten the evolution in the sense of settling the Nomads."[40] One of the most successful ideas was "to create in all important cities halting areas with facilities."[41] That is the first occurrence, at a national level, of a system of caravan sites under the supervision of local councils. The report says that "the halting areas for Nomads are liable to help the settlement and the social insertion of those populations."[42] The centers were to have "specialized" schools, because "if the young nomad is clever, he is used to an unconstrained life," and workshops "that would encourage the transformation of itinerant jobs." The centers were also to have a system of surveillance allowing "better public security (end of thefts, improvement of hygiene)."[43] The inquiry led to the laws and decrees that created the "dedicated caravan areas." A historical study of this project shows that the initial target was not to allow a peaceful coexistence of two ways of life but to speed up the settlement of nomads.

Environmental injustices

Gradually, over the last 50 years, national and local authorities have implemented a system assigning special halting places to a certain category of people. Some areas that had already been known to *gens du voyage* were chosen by local authorities. In those cases, the spots had been chosen because, being far from city centers, they would be beyond easy reach by police forces. Often neglected by local authorities, those areas were very poorly kept and had degraded sanitary conditions. It was on those unhealthy grounds that some local authorities had decided to have dedicated caravan sites built. The state appears to have funded projects in these unsanitary areas than in newer, more pleasant areas.[44] As an example, Labarde in Bordeaux, also known as the "Andalous village," was first a proper slum, then a camp occupied by various people, and eventually an area that local authorities rehabilitated, adding small houses for residents. In 2001, after recognizing extremely high lead levels in the blood of children living in the area, local authorities decided to relocate those families.[45] But the official statement from local authorities said that the lead poisoning in the children was the result of their parents' professional activities, dealing with

metals. However, the parents had not worked with metals for many years, and Doctors of the World established that the cause of the lead poisoning was definitely environmental.[46]

Other cases show that local authorities have sometimes chosen unhealthy spots with no connection to a "gypsy" background. A report of the advising committee of the Bouches-du-Rhône department (May 5, 2003) says that the proposition made by Gardanne, a local community, to have its dedicated caravan area "close to a Péchiney plant" must be subject to the results of a study on "risks afferent to the presence of two heavy oil tanks located at 60 meters from the area."[47] The same report observed that the city of Arles had decided to have its dedicated area in a flood zone and that "a specific scheme of alert and emergency should be realized for the rapid evacuation of caravans."[48] Similarly, the towns of Berre-l'Étang, Velaux, and la Fare-les-Oliviers have suggested that their respective caravan sites are located in most-at-risk areas, all in earthquake risk zones. The advising committee of the Bouches-du-Rhône department said it was not opposed to the choice for two other dedicated areas, in Fos-sur-Mer and Port-Saint-Louis-du-Rhône, each within a Seveso area.

Conclusion

The *gens du voyage* have been forced to stay for longer or shorter periods in areas supposedly intended to provide them with better health conditions. We have seen that the reality is extremely different from the stated intention of the legislation: the so-called *aires d'accueil*, literally in French "welcoming areas," more closely resemble home residency, where inhabitants experience social discrimination, and poor health and environmental conditions. People staying in spots such as Saint-Menet (Marseille) or Hellemmes-Ronchin (Lille) inhale and ingest pollutants present in the environment and suffer diseases resulting from toxic environments. Although the inhabitants are sometimes being held responsible for their own illnesses, with blame placed on their professional activities or unsanitary habits, there is evidence to show the causes are environmental.

The creation of dedicated caravan sites in which *gens du voyage* must live has enabled authorities to keep surveillance on these people. The stated purpose of the sites is to improve the health of *gens du voyage*. But the evidence and history suggest otherwise: such arrangements simplify the surveillance of populations who have suffered discrimination from the beginning of the Third Republic onwards, through the official acceptance of their 'bad reputation": dangerous people, thieves, and vector of epidemic diseases.

This restriction of the rights of *gens du voyage* is not unique: it is analogous to the restriction imposed on other marginalized social groups' rights, including, most recently, illegal immigrants. Sociologist Michel Agier has forged the word "encampment" to describe this general phenomenon of surveilling people through restricting their liberty of movement.[49] There are various ways in which to practice this encampment. One of the observations of my study is that French administration has invented a new form of encampment that I suggest calling "nomadic encampment," consisting of leaving people free to circulate between dedicated areas.

By a perverse use of language, with the notion of *gens du voyage* evoking a choice of lifestyle associated with traveling, the category created by legislation aimed eliminating this way of living. In another perverse use of language, the health goals associated with the Besson Law—improving the health of *gens du voyage* thanks to medical services—are an illusion: the reality is that exposing the *gens du voyage* and their children to environmental toxins serves to curb their desire to continue to live on the road. The paper has shown the connection between today's sanitary policies and a long history of administrative control and surveillance of 'nomads'. It has also shown the unpleasant and dangerous consequences of contracting out public responsibilities to private enterprise.

There are immediate actions available to improve this situation for *gens du voyage*: dedicated caravan sites in the vicinity of industrial sites and highways could and should be closed. A second measure would be to listen to what *gens du voyage* have to say, and to address their concerns. Indeed,

when it comes to deciding what policies are needed to avoid major sanitary risks, people living in the areas need to be consulted so they can participate in policy development, as is their human right. This approach gives priority to the testimony of *gens du voyage* and helps shape changes in practices that would enable their rights to health and a healthy environment to be fulfilled.

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The Impact of Legal Advocacy Strategies to Advance Roma Health: The Case of Macedonia

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Abstract

Across Europe, Roma face exclusion and obstacles in access to health services, resulting in poorer health. While there are legal and policy frameworks for Roma inclusion, implementation often lags behind. Increasing the grassroots capacity of Roma to advocate for accountability in health care and against systemic impediments has been a central focus of Open Society Foundations (OSF) support. This analysis discusses the impact of an OSF-supported legal advocacy project on Roma health rights in Macedonia. The paper uses qualitative indicators to measure the capacity of nongovernmental organizations, accountability for violations, changes in law and practice, and impact on communities. The methodology for assessing the impact of legal advocacy was developed over the course of OSF's legal advocacy project and used to calculate the baseline and conduct the follow-up assessment to track progress across four strategies: legal empowerment, documentation and advocacy, media advocacy, and strategic litigation. Results show that legal advocacy has led to a notable increase in Roma awareness of their health rights. The number of lawsuits has risen dramatically, and cases are increasingly more sophisticated. Although accountability in health care is still the exception rather than the rule, blatant violations have been reduced. Some structural barriers have also been tackled. At the same time, new challenges require continuous and adaptable legal advocacy.

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Introduction

The poor state of health in Roma communities is prevalent—and ignored—across Europe. Some Roma are completely excluded from health care, while most face hostility and discrimination within health care settings. Improving the overall health of Roma communities requires addressing a host of underlying factors, some of which have already been recognized in domestic and international initiatives. For instance, the European Union—to which several Southern and Eastern European countries continue to aspire to join—attends closely to the situation of Roma, devoting a special section of the European Commission's annual progress report to Roma rights in European Union accession candidate countries.

However, more work is required to breathe life into formal regulations and policies on Roma in order to see meaningful improvements in their health. While regional nongovernmental organizations (NGOs) have been working diligently on human rights issues as they pertain to Roma populations, they tend not to focus directly on health, and their resources are often insufficient to sustain legal advocacy for the benefit of Roma.

The past two decades have also witnessed unprecedented attention to systemic abuses of Roma rights. In order to build on this momentum, Open Society Foundations (OSF), through its Public Health Program, has supported legal advocacy for Roma health rights by Roma-centered NGOs. This paper explores the impact of OSF-supported legal strategies, outlining the current state of legal advocacy for Roma health rights in Macedonia.

Methodology

This paper uses the methodology developed in the course of the OSF initiative. In 2010, two OSF programs—the Law and Health Initiative and the Roma Health Project—commissioned a needs assessment in several focus countries, which included Macedonia, in order to guide grant making and capacity building for the advancement of Roma rights. The assessment tailored existing initiatives on Roma human rights to a health care context and consisted of a survey of NGO needs and donor engagement opportunities. As a result of that assessment, OSF identified two guiding objectives for future initiatives: (1) increased accountability for violations of Roma rights in health care settings, and (2) a resolution of systemic impediments to Roma access to health care. Attached to each of these objectives were concrete implementation strategies.

The initial (baseline) evaluation of 2012 took "snapshots" of the situation on the ground prior to the launch of the NGO initiatives, to establish a point of reference for subsequent evaluations.[1] A follow-up assessment in 2015 then recorded the changes that had occurred and explored the extent to which those changes could be attributed to legal advocacy interventions.

Given the lack of official statistics and other current, comparable, and reliable quantitative data, which is broadly recognized as one of the challenges in assessing the state of Roma health rights in the region, the methodology deploys a set of qualitative indicators to measure the impact of NGOs' legal advocacy initiatives (see Table 1). Specifically, it assesses impact in four categories: legal empowerment, human rights documentation and advocacy, media advocacy, and strategic litigation. The assessment is conducted on four levels: NGO capacity, accountability for violations, changes in law and practice, and effects on Roma communities.

The present analysis relies on various sources, including the following: written questionnaires and surveys that collected responses from Roma-centered NGOs in Macedonia to the questions in the methodology grid (Table 1) at the beginning of the initiative and then again after three years of implementation; semi-structured interviews conducted during two rounds of field visits with Roma community leaders, Roma health mediators, Roma paralegals, health professionals, and other key stakeholders; information gleaned from OSF grantees' annual implementation reports and publications; and secondary sources on the socioeconomic factors underlying poor health in Roma communities and rights violations against Roma in health settings.

OSF is the principal donor for legal advoca-

cy specifically focused on Roma health rights in Europe. This makes it easier to trace and attribute emergent changes in the field of health rights advocacy to OSF-supported NGO interventions. However, because Roma health is informed by multiple determinants—including access to documentation, insurance, housing, employment, and education—changes in access to health services among Roma populations may sometimes be byproducts of other initiatives addressing such factors. We take this into consideration when assessing the impact of the initiative.

We selected Macedonia as the case study for this paper because it was the country where the most systematic support was provided to build the capacity of Roma rights NGOs and where a substantial number of activities were carried out within the framework of the project. The Macedonian case thus offers empirical evidence of the concrete impact of legal advocacy strategies on Roma access to health care.

Background

Roma health in Europe

There is a body of research devoted to analyzing the status of Roma communities' health in Europe. Studies have consistently found that Roma health is worse than the health of the majority populations or other ethnic minority groups. Estimated life expectancy for Roma is consistently lower—in some cases up to ten years less—than corresponding national averages. Infant mortality among Roma is estimated to exceed national averages by several percentage points.[2] Roma are less likely to be covered by health insurance.[3] Roma do not appear to enjoy preventive health care on equal footing with non-Roma and instead are more likely to rely on emergency services.[4]

Scholars and advocates identify inadequate living conditions, poverty, limited education, and pervasive discrimination against Roma by health care professionals and the public as the key reasons for the poor health of Roma.[5]

The lack of accountability for rights abuses—due to a low awareness among Roma of their rights vis-à-vis the health system—means that neither systematic nor individual rights violations are challenged, despite legal and policy reforms over recent decades aimed at ameliorating the situation of Roma in Europe.[6] Accordingly, the legal empowerment of Roma communities at the grassroots level appears to be a key variable to break the impasse.

TABLE 1: Assessment methodology

ADVOCACY AREA / INDICATORS	Legal empowerment	Documentation and advocacy	Media advocacy	Strategic litigation
Level I: NGO capacity	Can NGOs educate and empower Roma on health rights?	Can NGOs document health rights violations and draw on them in their legal advocacy?	Do NGOs integrate media into their legal advocacy?	Do NGOs use legal frameworks to address health rights violations?
Level II: Enforcing accountability	Do Roma know and claim their health rights?	Do documentation and advocacy bring about greater enforcement of Roma health rights?	Does media advocacy bring about greater enforcement of health rights by exposing rights violations against Roma?	Are those responsible for health rights violations against Roma brought to justice?
Level III: Changing law and policy	Do authorities engage with Roma to address systemic barriers to Roma health rights?	Have there been changes in law and policy as a result of documentation and advocacy?	Does media advocacy influence decision-makers and bring about systemic changes in law and policy?	Do legal norms and policies improve as a result of strategic litigation?
Level IV: Effect on communities	Do Roma participate in broader legal advocacy for their health and human rights?	Has Roma access to health care improved as a result of documentation and advocacy?	Does media advocacy result in better information on Roma health rights and in the public becoming more positive toward Roma?	Have illegal practices in health care been reduced or deterred?

Macedonia: The national context

The situation in Macedonia is similar to that of many other European countries where Roma have faced systematic exclusion and poor health conditions. In Macedonia, Roma are disproportionately affected by unemployment, poverty, and precarious living conditions, and they face multiple barriers in accessing health rights.[7] Roma without formal documentation are particularly disadvantaged because they are rendered effectively and legally invisible and are denied access to public services, including health care. An estimated 4,000 internally displaced Roma from the former Yugoslavia live in Macedonia without papers. Of those who have Macedonian citizenship, as many as 50% lack health insurance.[8]

Macedonia's economy is in a dire situation, which translates into limited resources for social services, including health care, while the legal and policy framework concerning health often lacks proper implementation mechanisms and remains underutilized in practice. For example, the 2008 Patients' Rights Law lacks protocols and procedures and is thus not fully functional. Awareness of the law is limited, even among health professionals. Most patients are not aware of the law at all—and since patients do not invoke it, health professionals often conclude that there are no patients' rights violations in Macedonia.[9] Likewise, the country's 2010 antidiscrimination law is rarely used, and even among legal professionals there is only marginal awareness of legal instruments to defend Roma rights.

Furthermore, claiming rights in Macedonian courts is difficult for most people without financial means or without a supporting organization behind them. Since its inception, the Law on Legal Aid has proved inadequate for people who could benefit from its assistance. It is now being revised, leaving people in need of free legal assistance in limbo. Although civil society organizations were invited to provide suggestions on how to improve the law, the reform process appears devoid of transparency, and there is little hope that the new law will bring significant improvement or be a useful resource for strategic litigation.

In this context of virtually nonexistent accountability in health care settings, violations of Roma rights have been commonplace.[10] Such violations have included the denial of health services, including for pregnant women; provision of substandard care; negligent treatment; requirement of illegal payments for services that are free; extortion of bribes; confiscation of identity documents and false imprisonment for failure to pay hospital fees; verbal and physical assaults; violations of specific patients' rights (for example, to medical information and informed consent); and racial discrimination.[11]

OSF's approach

The legal empowerment of Roma has been a central part of OSF's strategy to use legal advocacy to advance Roma health rights in Macedonia.

At the end of 2010, OSF assigned several pilot grants to NGOs to enable them to engage in legal advocacy for Roma health rights. As a result, the Skopje-based Association for Emancipation, Solidarity and Equality of Women (ESE), which promotes women's rights and human rights and social justice in general, started working with three Roma-centered NGOs—the Humanitarian and Charitable Association of Roma (KHAM), the Initiative for Development and Inclusion of Communities (formerly the Roma Resource Center), and the Centre for Democratic Development and Initiatives—to train paralegals. The goal of this paralegal pilot project was to empower Roma and advocate for better health services for Roma communities in several Macedonian municipalities.

Another grantee was the Prilep-based Roma SOS, whose mission is to build capacity among Roma activists, particularly Roma women. Roma SOS used its grant to establish a health advising center to promote human rights awareness among the local Roma community and advocate for Roma rights before health authorities at different levels. The organization also developed a legal department responsible for identifying strategic litigation opportunities and initiating cases. Roma SOS counts among its victories an anti-discrimination case that led Macedonia's Health Insurance Fund to amend its administrative procedures so that Roma would

no longer be indirectly excluded from obtaining health insurance.

In 2011, OSF issued a call for project proposals on legal advocacy for Roma health rights that advanced one or both of the aforementioned guiding objectives. Previous grantees saw their projects extended through further funding, and several new grants were also provided to NGOs in the focus countries.

For example, the Skopje-based Health Education and Research Association (HERA), which aims to advance Roma women's enjoyment of reproductive rights in Suto Orizari, documented and challenged violations of Roma women's reproductive rights, such as the outright denial of health care, extortion of bribes or other illicit payments, and discriminatory treatment. HERA implemented a series of initiatives, including legal submissions to the Ombudsperson's Office, the State Commission for Anti-Discrimination Law, and other human rights bodies, following up where appropriate with strategic litigation.

Another grantee, Healthy Options Project–Skopje, sought to advance the health rights of Roma who use drugs, in particular their right to drug dependence treatment and their access to justice in cases of rights violations. This project, which was subsequently extended, also mapped the situation of Roma with regard to their enjoyment of the right to health.

Yet another grantee, the Skopje-based organization known as LIL—whose mission is to protect Roma women and children, particularly those who lack identification papers—focused on advocacy to help undocumented Roma obtain papers in order to access public services, including health care. LIL monitored the implementation and documented violations of Macedonia's Law on the Protection of Patients' Rights and other relevant legal frameworks and, in partnership with other Roma-centered NGOs, engaged in strategic litigation and conducted media campaigns to address systemic rights violations of and barriers to Roma access to health care, such as improper birth registration, discrimination, excessive health care fees, denials of reimbursement, and detention in health care facilities resulting from an inability to pay.

OSF's next challenge was to develop a framework for assessing the effectiveness and impact of its support for these NGO interventions and, if necessary, revisit the strategies originally selected. A dearth of "hard" data precluded a quantitative impact assessment of Roma rights—and, in any case, the very nature of legal advocacy called for a qualitative analysis. Since the OSF initiative aimed to enable Roma communities to claim and defend their health-related rights, increased human rights reporting, viable lawsuits (even if unsuccessful), and expanded coverage of Roma health issues in public fora should be considered signs of success with regard to Roma legal empowerment and health rights advocacy. Hence, OSF developed a set of qualitative indicators to measure whether and how the Roma health rights situation would change by the next assessment as a result of OSF-supported legal advocacy (see Table 1).

As mentioned earlier, in 2012, prior to the start of the project, OSF conducted a rigorous assessment to record the state of Roma health, the relevant legal and policy frameworks, the patterns of Roma rights violations in health care settings, public attitudes, and the level of legal advocacy (or capacity for engaging in such advocacy) among Roma centered-NGOs in Macedonia.[12] This was followed by an assessment in 2015 using the same indicators and levels of evaluation. Below we discuss the outcomes of these assessments.

Results

Legal empowerment

Legal empowerment is defined as the transfer of power from the usual gatekeepers of the law—lawyers, judges, police, and state officials—to ordinary people who can make the law meaningful on a local level and engage the agency of disadvantaged populations.[13]

At the beginning of the OSF initiative, the capacity of grassroots community-based organizations to empower Roma on health rights was limited. The main challenge they faced was insufficient knowledge of health and human rights legal

frameworks among Roma-centered NGOs. After OSF supported specialized capacity building and training, the NGOs' familiarity with and ability to deploy legal redress mechanisms has improved considerably, and they have been able to impart this knowledge directly to the communities.[14]

In the process, Roma-centered NGOs have started to challenge legal and administrative provisions that place disproportionate burdens on Roma communities. Some organizations have advanced to the point that they have been able to start building the legal capacity of other organizations in Macedonia and abroad, ensuring the sustainability and expansion of the initiative.

The improved availability of legal services and increased rights awareness, in turn, have begun to deter blatant human rights violations: NGOs report that paralegal assistance and mediation, where available, have lessened the open and outright abuses of Roma rights by health professionals.[15]

Previously, Roma were apprehensive about filing complaints and had little faith in the system to protect them. But since the project's launch, the number of legal and administrative complaints brought by or on behalf of Roma has increased considerably. Moreover, the follow-up assessment shows that claims brought by Roma have increased in sophistication, maturing from requests for help with filling out official forms to concrete patients' rights claims.

The most dramatic effect of legal empowerment has been felt among Roma communities, with Roma increasingly seeing themselves not just as victims but as advocates speaking for their community. For example, in Prilep and Bitola municipalities, the grassroots Roma movement has evolved into an informal Roma "Civic Parliament," where Roma leaders, activists, and advocates share experiences, identify priorities, brainstorm, and formulate joint positions toward Macedonian state bodies.[16]

The empowerment of Roma has started to put pressure on local governments and health authorities to engage with Roma on the policy level.

Human rights documentation and advocacy

Human rights documentation refers to collecting evidence of rights violations—in the form of victim and witness testimonials, official data, audio and video recordings, and other materials—in order to raise awareness of abuses and hold perpetrators accountable.

At the start of the project, Roma-centered NGOs had a limited ability to conduct or use documentation of rights violations, with many unable to recognize the difference between preparing legal cases and documenting human rights violations. The follow-up assessment shows improved NGO capacity for human rights documentation and advocacy. NGOs have formed collaborations to document cases and engage in domestic and international legal advocacy. Several NGOs (specifically ESE and its partners) have developed rather sophisticated documentation systems to monitor and evaluate the effectiveness of their own projects, as well as to capture the changing patterns of health-related human rights complaints.

Reports outlining patterns of Roma rights violations are now regularly presented to the national authorities in charge of health and social policy matters, as well as to international and regional human rights monitoring bodies, as recommendations and criticism coming from outside the country often carry more weight with Macedonian authorities than domestic NGO advocacy.[17] Some of the NGO reports have helped address structural impediments. For example, persistent advocacy by LIL on behalf of undocumented Roma has led Macedonian authorities to recognize the lack of documentation among Roma as an institutional problem. The Ministry of Labor and Social Affairs set up a task force to build a database of undocumented persons, and up to 500 persons managed to obtain their documents.[18]

However, the outcomes in enforcing accountability have been mixed, and even well-documented instances of Roma rights violations have not always resulted in the perpetrators being held accountable. Reporting of discrimination cases—outside of those detected by grassroots Roma-centered NGOs—is still extremely low in Macedonia. This finding suggests that the documentation of human rights violations alone is not sufficient and that it

needs to be combined with other types of advocacy to be effective.

Strategic litigation

Strategic litigation involves "identifying and pursuing cases on critical human rights issues which if successful are likely to have a high impact at the national, regional or international level. Successful litigation can establish important legal precedents or effect changes in legislation, policy or practice. It can also positively influence public opinion."[19]

The capacity of Roma-centered NGOs to engage in litigation, which was very limited at the beginning of the initiative, has improved. Initially, only a handful of NGOs had both the expertise and motivation to challenge Roma rights violations in courts. Now, each NGO engaged in legal work handles hundreds of Roma-related cases per year. Not all of the cases pertain to health or result in court proceedings, but the increase indicates a fundamental shift in attitude. For example, Healthy Options Project–Skopje observed a three-fold increase in complaints in the first few months after its legal services became available.[20] HERA recorded an increase from just 4 individual complaints about unlawful fees charged by gynecologists in 2015 to 24 such complaints in 2016. Roma SOS documented 340 legal complaints between 2012 and 2015, of which 4 were chosen for strategic litigation and subsequently won on behalf of Roma clients, with countrywide legal and policy implications.[21] Roma paralegals currently deal with up to 400 cases per year; while the number of cases has stabilized, the complaints themselves show a degree of knowledge among Roma of specific patients' rights that did not exist in the beginning of the initiative.

NGOs also use non-court remedies—such as the Ombudsperson's Office and specialized commissions on patients' rights and discrimination—much more actively than before. Although not all decisions by these bodies are legally binding, they carry important political weight. In this way, NGOs can achieve the objectives of better access to health and social rights for the Roma community while avoiding the burdens inherent in the traditional legal process.

Given the inverse relationship between accountability and human rights violations, highly publicized legal victories have led not only to a marked improvement in awareness of rights and increased assertiveness among Roma but also a noticeable reduction in the blatant denial of health services and somewhat more courteous treatment of Roma by health care professionals. The change has been palpable, although localized in the areas where Roma-centered projects are implemented.

Some barriers to Roma access to health care have been removed as a result of strategic litigation. For example, in late 2014, Roma SOS successfully advocated to remove a requirement to provide an income statement from the previous year as a condition for renewing health insurance coverage.[22] This provision indirectly placed a disproportionate burden on Roma since, as mentioned earlier, many Roma lack documentation, are not formally employed, or work seasonally, and therefore cannot procure an official income statement. Easing paperwork requirements has benefited not only Roma but all unemployed individuals who lack proper documentation or steady income; they can now have continuous health insurance coverage.

Furthermore, several high-profile cases have shed light on medical negligence and discrimination, establishing important precedents of compensation for victims of patients' rights violations.[23]

Media advocacy

Media advocacy is the strategic use of mass media to promote public debate and generate community support to advance changes in social norms or public policies.[24]

The capacity of Roma-centered NGOs to engage with the media was uneven at the beginning of the project; many organizations lacked the skills to make effective use of the media. In 2013–2014, OSF provided selected NGOs with media advocacy training, including components such as communication and public relations; debate and argumentation; visualization; audio and video advocacy; internet activism; and media advocacy strategies.

The follow-up assessment revealed impressive NGO media advocacy activities. Most have excelled

in using traditional as well as new media, especially social media networks, to raise awareness of the Roma health situation and advocate for Roma health rights. For example, KHAM has produced three videos based on "storytelling" that try to discredit the mainstream media's predominantly negative portrayal of Roma. HERA has successfully engaged journalists in raising public awareness of unlawful practices, such as making Roma women pay for free antenatal health services. Moreover, Roma-centered NGOs now regularly participate in television debates and media interviews to explain their work and educate the public on the plight of Roma communities in Macedonia.

Compared to the status quo at the beginning of OSF's legal advocacy initiative, when media coverage was permeated with prejudice and Roma issues were covered almost exclusively in the context of criminality, there is now more coverage of Roma rights violations in health care settings, and Roma are presented as examples of vulnerable patients. This shift has been helpful in conjunction with strategic litigation efforts and indicates a gradually changing narrative.

Some advocates express concerns that in the current political climate, Roma rights are no longer a priority and that NGOs critical of the government are often presented in the official media as enemies. Despite these difficulties, the public has become more aware of corruption, extortion, and other human rights abuses in health care because of coverage in the mainstream media. Therefore, media advocacy continues to be an important tool for promoting Roma health and human rights.

Discussion

An analysis of the outcomes of OSF's initiative supporting legal advocacy on behalf of Roma health rights shows mixed results, with greatest progress achieved in the area of rights awareness and more limited progress (and at times regression) in ensuring that the Macedonian state fulfills its legal obligations to guarantee Roma health and human rights. The positive outcomes have also been largely limited to the regions where the projects were implemented. However, the example of Macedonia demonstrates that empowered Roma communities at the grassroots level are key to improving respect for Roma rights in health care settings and to removing systemic barriers to Roma health rights.

Good practices

The empowerment of marginalized communities has been the most palpable change, as evidenced by two paralegal initiatives. The first project, led by ESE, has been implemented by several grassroots Roma organizations—KHAM, the Centre for Democratic Development and Initiatives, and the Initiative for Development and Inclusion of Communities—in Delcevo, Pehcevo, and Suto Orizari since 2010. The project's objective is to prepare paralegals to provide appropriate and accurate information on health rights to Roma communities so that individuals themselves are empowered to assert their rights. The project has taken place on three levels: providing rights literacy to the communities and paralegal assistance in cases of health rights violations; conducting advocacy before local authorities and health care providers; and conducting national advocacy in partnership with other NGOs or state bodies.

The second paralegal project has been spearheaded by HERA, in partnership with grassroots Roma NGOs Ambrela and Initiative for Development and Inclusion of Communities. Initiated in 2014, the project focuses on supporting Roma women's reproductive health rights. Roma women activists, trained to work as paralegals, conduct outreach to local Roma women to build awareness of reproductive health rights; collect evidence and document cases; and, when necessary, escort Roma women to local health care institutions to mediate conflicts. Paralegals also mobilize Roma women to conduct community monitoring of health services, using periodically developed community scorecards. HERA uses the scorecard results to pressure health authorities to provide missing health services to Suto Orizari, which is the only majority-Roma municipality in Macedonia. Strategic outcomes include the establishment of a community task force on reproductive and gynecological health and the

development of an advocacy action plan, which targets the National Committee for Safe Motherhood, the Ministry of Health, the Macedonian Health Insurance Fund, and associations of general practitioners and gynecologists in order to promote systemic changes.

Participants in these paralegal initiatives attest overwhelmingly to their success. For example, the ongoing evaluation by ESE shows that over 70% of Roma community members are satisfied with the paralegals' work.[25] This is not to suggest that Roma no longer face violations of their health and human rights. According to a recent survey conducted by ESE in ten Macedonian localities with substantial Roma populations, 34.6% of Roma still report "unkind treatment" by medical specialists, versus only 5.3% of non-Roma. In addition, 9.8% of Roma report being insulted by doctors, versus 1.6% of non-Roma. Up to 2.3% of Roma women visiting gynecologists said they were hit at least once; for the non-Roma women the number is 0%.[26] However, as the more aware and assertive Roma communities have begun to claim their health rights and call for accountability, power dynamics in the health system have started to shift, and Roma are no longer perceived as helpless and unaware persons. Continuous dialogue with health professionals has also resulted in greater awareness among doctors and nurses of the needs and problems faced by Roma patients.

As a way to create synergy, the NGOs have started to merge legal empowerment approaches with social accountability strategies. As a result, Roma have progressed from merely asking for access to the health system to demanding a say in the development of local policy to improve Roma health indicators. Roma paralegals from KHAM have also started providing capacity building in other countries, such as Romania, where local Roma organizations have expressed interest in adopting this initiative. Such international exchange and peer learning and mentoring fosters the continuity and sustainability not just of the paralegal pilot itself but of Roma legal empowerment more broadly.

Furthermore, engagement with local authorities has helped tackle structural barriers that previously seemed insurmountable. For example, at the beginning of the initiative, a vast majority of Roma settlements were officially unauthorized, with the result that such settlements were excluded from urban planning and did not benefit from public investments or services. Habitat for Humanity, an international NGO with branches in Macedonia, spearheaded a project to legalize Roma settlements and provide grants to cover administrative (registration) fees, based on the 2011 Law on Proceeding with Illegally Built Objects. Several Roma-centered NGOs previously trained by OSF (specifically the National Roma Centrum in Kumanovo and Roma SOS in Prilep) have participated in this initiative by offering legal counselling and other kinds of support.[27]

As a result, an estimated 50% of Roma settlements across Macedonia have been legalized and, following NGO advocacy, included into urban planning.[28] The fact that no Roma home demolitions were reported and local authorities were forthcoming can be attributed in large part to increased Roma awareness of their rights and the capacity of NGOs to support them in claiming those rights. Legalization means that residents of the formerly illegal Roma settlements can now expect and demand the provision of public services, including, but not limited to, new health centers.

Emerging challenges

Along with successes, the follow-up assessment noted challenges to legal advocacy for Roma health rights. If some constraints (such as limited expertise with legal frameworks and lack of technical skills with media advocacy among NGOs) have been addressed, other problems that did not receive sufficient consideration at the beginning of the initiative have come to the fore.

One of these constraints is the continuous changing of laws and administrative regulations, which can make NGO expertise obsolete if advocates are unable to keep abreast of legal developments. This factor entails the need for ongoing legal training, which places additional burdens on the already limited resources of NGOs that lack access to continuous legal capacity building.[29] For example, Roma-centered NGOs reported that the recent

rollout of electronic insurance cards contributed to confusion among many users of health services and placed extra burdens on Roma, especially those who lack identity documentation or who lack sufficient education to understand new requirements and procedures.[30]

Furthermore, progress in the area of legal empowerment is often offset by the lack of progress on the part of the state to fulfill its human rights obligations, both toward minorities and toward the public at large. Legal personnel and professionals, as well as community activists, note that while the ability of persons to access health services has improved, the quality of the services offered has declined precipitously. Many qualified doctors and nurses have either left the public health sector in favor of private practice or left the country altogether. There is also an apparent shortage of equipment, medications, and supplies.[31] But national authorities do not seem to recognize the extent of the problem and attempt to quell criticism from those who do by branding them as "subversive." Occasionally, the state has blamed its lack of resources on the "global economic crisis," although resources are readily available for new monuments and architecture projects, which signals that authorities may be out of touch with the real needs of the Macedonian population. Human rights NGOs that openly criticize the government for its policies, especially those that receive external funding (such as from OSF), face harassment and pressures in the form of audits and negative media coverage aimed at stifling their activism. Some Roma activists report receiving thinly veiled economic threats, such as the prospect of family members losing their jobs, and even threats of violence if they continue participating in rallies and demonstrations.[32]

However, the Macedonian government has implicitly recognized the value of Roma-centered NGO initiatives.[33] Some of the most successful pilots—such as the provision of Roma health mediators—have been partially adopted by Macedonian authorities (for example, the Ministry of Health) and touted as state achievements in promoting Roma integration within the framework of the Decade of Roma Inclusion (2005–2015).[34] This leaves a glimmer of hope that other good practices, such as the paralegal pilot projects, could also be institutionalized in time.

Conclusion

An assessment of legal advocacy initiatives in Macedonia shows that after just a few years of NGO interventions (from 2012 to 2015), there has been progress in bridging the gap between law and practice for Roma access to health care.

The capacity of Roma-centered NGOs to carry forward this work has increased considerably. Roma communities are more aware of their health rights and are less afraid to complain when rights violations occur. The increase in legal and administrative complaints brought by or on behalf of Roma has resulted in a reduction of violations of their rights in health care settings and has deterred some previously common abuses. Newly found assertiveness among Roma has also helped achieve cooperation with local authorities in tackling systemic problems, such as the lack of personal documentation and unauthorized housing. Although accountability in health care is still more of an exception than a norm, strategic litigation and human rights advocacy, accompanied by media campaigns, have led to a few concrete changes with regard to reducing structural impediments to accessing health care.

Therefore, on the whole, the strategies of community empowerment, human rights documentation, media advocacy, and strategic litigation continue to be valid and effective approaches in contexts where Roma and other vulnerable groups face exclusion and barriers to exercising their right to health. This finding shows promise for other countries with similar issues. Ongoing evaluation of these efforts remains important.

At the same time, new challenges have arisen that require continuous and adaptable legal advocacy. Changes in legislation strain the already scarce resources of NGOs by requiring them to retrain continuously. A deteriorating political environment and occasional hostility toward civic activism mean that Roma-centered NGOs struggle to make

their voices heard. Finally, without the political will to embrace and support civil society initiatives, the scaling up of successful pilots (such as that of Roma paralegals) is unlikely. Accordingly, the overall impact of NGOs' legal advocacy remains limited to just a few localities, and the sustainability of the progress achieved to date is far from ensured.

Despite these challenges, a national health care system that is inclusive, accountable, and respectful of patients' rights benefits all members of society, irrespective of their ethnic or other minority background. That goal is a strong argument for continued legal advocacy on behalf of Roma health and human rights.

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FOREWORD

Harnessing the Power and Promise of Human Rights to End AIDS by 2030

MICHEL SIDIBÉ

The HIV epidemic and response are at a critical juncture. Our advances against the epidemic have been impressive, with unprecedented numbers of people accessing antiretroviral treatment, especially in low- and middle-income countries, and a global reduction in new HIV infections.

However, the epidemic is not over, and the challenges ahead are significant. More than 15.8 million people are still awaiting treatment, while an estimated 11 million people do not know their HIV status. Globally, adolescent girls and young women account for approximately 7,000 new HIV infections every week. These figures represent an indefensible injustice: millions of people worldwide are being denied their right to health.

Common to these challenges are stigma, discrimination, gender inequality, denial of services, violence, and human rights violations against people living with HIV and those most vulnerable to the epidemic, including women, young people, sex workers, prisoners, people who use drugs, transgender persons, and gay men and men who have sex with men.

In all regions, and regardless of the nature and level of the epidemic, vulnerability to HIV is linked to inequality and disenfranchisement; and women and those at the margins of society remain underserved by health services, including HIV prevention, treatment, care, and support services. This special section of *Health and Human Rights* comes at an opportune moment to describe and reflect on our progress to realize human rights as an imperative for health. It allows us to reflect on how, in the past decades, the AIDS epidemic has transformed our understanding of the structural, legal, and social determinants of health and the approaches to address them. The epidemic has also revealed the power of those living with and affected by the disease, who came together to break the conspiracy of silence, challenge exclusion in access to treatment, and demand the protection of human rights. It comes at a time when we are facing unprecedented challenges that curtail efforts against exclusion and marginalization—including growing conservatism, contestation of multilateralism and the rule of law, and shrinking of civil society space.

The power of mobilization from our shared history tells us that today's challenges can and must be overcome. As the contributions in this section remind us, we have a transformative global agenda for sustainable development grounded in social justice and the rule of law that sets a vision for ending the AIDS epidemic as a public health threat by 2030. We have powerful scientific and medical tools, and innovative

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partnerships that bring together governments, civil society, scientists, international organizations, and other stakeholders. There is indeed great hope that the world can deliver on its promise to make the AIDS epidemic a thing of the past, but much more needs to be done, as the UN Secretary-General pointed out in his recent message for the 2017 World AIDS Day.

The question is: do we have the courage to do what is necessary to reduce vulnerability to HIV and expand access to health services for all? I believe the lessons from the AIDS response give us the opportunity to shape policies and practices aimed at empowering the "global health citizen," as an individual who knows her rights and can voice her concerns, challenge injustices, and hold decision makers accountable.

Together, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and I have joined our voices to call for the "empowerment of the global health citizen," and upon stakeholders to popularize participation, democratize data, and eliminate discrimination.

Indeed, building on rights-based and community-led approaches that have been essential to our achievements in the AIDS response, we must open up health programs and policies to meaningful public engagement. As the UN Secretary-General also reminded us, "Closing gaps in service coverage requires the empowerment of populations that are often left behind: women and girls, young people, key populations and people living with HIV. All national AIDS programs require a strong community empowerment element and specific efforts to address legal and policy barriers."

To address systemic corruption in the health sector we need institutional support, information, and tools to demand more firm and concerted action for good governance and transparency, improve "legal" empowerment, fund civil society organizations, and reinforce legal mechanisms for holding governments accountable.

Also, as this section reminds us, progress is needed in transparency and access to data for every community. Guaranteeing the right to health will require far more independent advocacy and accountability, which the UN and civil-society groups are in a strong position to provide. Commitment from states and donors to create and preserve an enabling legal and policy environment that allows and supports civic engagement is critical.

Finally, many of the papers in this section remind us that eliminating discrimination in health care settings and law enforcement—among many contexts where discrimination is pervasive—must become an international priority. The central promise of the SDG agenda is to leave no one behind. Discrimination creates *de facto* barriers to universal health coverage, health-seeking behaviors, and prevents many from accessing health services of any kind.

The underlying message in this special section is that we have a moral and legal responsibility to act. We must build on the rights-based lessons of the past and find innovative ways to expand protections, to promote gender equality, to support civil society and community engagement, to strengthen accountability, and to close the inclusion gap between those who have and those who do not. As the UN High Commissioner for Human Rights reminded us at the 2017 Human Rights Council Social Forum: "When human dignity and equality are placed strongly at the core of policy, they unlock better outcomes."

EDITORIAL

Learning from the Past: Confronting Legal, Social, and Structural Barriers to the HIV Response

LUISA CABAL AND PATRICK EBA

The first special issue on HIV and human rights published by this journal in 1998 highlighted emerging concerns that structural, legal, and social barriers were at the core of vulnerability to HIV.[1] It called attention to the specific challenges and human rights violations faced by women, gay men and men who have sex with men, people who use drugs, and persons with disabilities, and stressed the need to address these challenges.[2] Nearly 20 years later, significant transformations and progress have occurred in the global AIDS epidemic and our response to it. In 1998, less than 500,000 people worldwide had access to antiretroviral therapy. Today, 21 million people receive highly active antiretroviral therapy, the majority of whom live in low- and middle-income countries.[3] We now have better understanding of the epidemic, and of the approaches and tools for successful HIV prevention, testing, treatment, and care.

However, many of the human rights, social, and structural barriers described in the 1998 special issue continue to hinder the HIV response. The historic achievement in expanding access to treatment has not been matched with the commensurate commitment and courage to tackle the underlying determinants that continue to fuel the epidemic among the most marginalized.

This December 2017 special section offers critical observations on the past, present, and future of human rights in the response to HIV, and in efforts to realize better health for all within the Sustainable Development Goals agenda. The history of the HIV response is marked by hard-fought victories of inclusion, human rights, and accountability. Across the world, there is increased recognition that legal, social, and structural barriers to the response must be addressed. However, this recognition often does not translate into action by governments and other duty-bearers. As Jamie Enoch and Peter Piot (the former executive director of UNAIDS) note, there is no "guaranteed march to progress" on the human rights of people living with HIV and key populations, especially in a global climate of indifference, hostility, and contestation of human rights.

HIV-related stigma and discrimination remain pervasive. Nearly four decades into the epidemic, some 35 countries, territories, and areas still impose restrictions on entry, stay and residence for people living with HIV. Through an analysis of the legal and social situation in the Republic of Korea, Jessica Keralis shows that HIV-related travel restrictions perpetuate stigma, violate human rights, and threaten

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the HIV response.

From the beginning, the HIV epidemic has exposed the human cost of exclusion because of the increased burden of HIV on the most vulnerable segments of society. People who inject drugs have 36 times the risk of acquiring HIV than adults in the general population.[4] Men who have sex with men are 22 times and sex workers 10 times more likely to acquire HIV.[5] Transgender women are 49 times more likely to be living with HIV.[6] HIV prevalence among prisoners is five times higher than in the general population.[7] Gender inequality and the low socioeconomic status of women and girls in many parts of the world contribute to their vulnerability to the epidemic.

Carmen Logie et al describe the challenges faced by gay men, men who have sex with men, and transgender women in Jamaica, while Tingting Shen and Joanne Csete address the multifaceted human rights violations and barriers to health care services against sex workers in China. These two contributions involve qualitative research methods with key informant interviews, surveys, and focus group discussion, thus documenting the lived realities of the affected populations. Importantly, these contributions document the health and HIV impact of harassment, violence, and other human rights violations committed by police.The possession of condoms as evidence for arrest and prosecution of sex workers, described by Shen and Csete, is a vivid expression of punitive law enforcement that jeopardizes health and leads to human rights violations.

In addition to the negative consequences of ingrained discrimination against key populations, pervasive gender inequality and discrimination—often intersecting with other forms of discrimination—undermine progress in the HIV response. Luisa Orza et al and Terry McGovern et al highlight the increased vulnerability of women and girls, which remains of great concern. Young women and adolescent girls face heightened vulnerability to HIV infection, and 7,000 young women (aged 15–24) acquire HIV each week.[8] In some regions, women who have experienced physical or sexual intimate partner violence are 1.5 times more likely to acquire HIV.[9] Among women living with HIV, intimate partner violence can lead to lower antiretroviral therapy use and adherence to HIV treatment, and higher viral loads.[10] Michael L. Scanlon et al express serious concerns about the failure to prioritize access to HIV treatment for children, noting that it violates fundamental human rights principles. As several authors note in this special issue, these challenges occur in a context of contestation of human rights and decreasing funding for HIV and for human rights-based approaches to the epidemic. These are compounded by restrictions of political and legal space for civil society organizations.

Enduring stigma, discrimination, and emerging human rights challenges in spite of tremendous scientific and medical progress are proof that we will not treat our way out of the HIV epidemic. Increased efforts to address human rights challenges should be prioritized alongside engagements to expand prevention, treatment, and care services. This special issue describes some rights-based approaches that are desperately needed to advance protection and evidence-informed HIV and health services.

Several contributions point to the importance of access to justice for protecting human rights and ensuring accountability at national, regional, and global levels. R. Taylor Williamson et al describe the role of the Ghanaian Commission on Human Rights and Administrative Justice in addressing rights violations suffered by people living with HIV and key populations. This is a reminder of the potential role of such national institutions in advancing human rights, including in relation to HIV. Similarly, Keralis notes the important contribution of national and global human rights mechanisms in efforts to challenge HIV-related travel restrictions in the Republic of Korea.

Groundbreaking initiatives from funders, such as the Global Fund to scale up human rights programs described by UNAIDS and endorsed by UN members, as stressed by Ralf Jürgens et al, could provide strong impetus for accelerating interventions to address stigma and discrimination and increase access to justice.

Tomás A. Chang Pico et al offer an innovative framework for transparency, accountability, and participation that reaches beyond HIV and health

to address broader considerations of inclusive governance that are essential to advancing social justice. Furthermore, the language and tools of the right to benefit from scientific progress are explored by Scanlon et al as potential solutions to the challenges of access to treatment. The integration of human rights and community participation into the standards and process for the certification of the elimination of mother-to-child transmission, described by Kismodi et al, illustrates the strategic engagement of civil society in placing human rights at the center of global health practice. This provides critical lessons for other disease-related certification processes, at a time of emerging discourse on HIV epidemic control and transition.

Together, these innovations speak to the resilience and creativity of actors involved in the HIV response. AIDS activists have long recognized that HIV was broader than health, and that health was much more than pills. The transformative and integrated SDG framework, with its anchorage in the rule of law, equality, and commitment to leaving no one behind, holds promise for addressing the root causes of vulnerability to HIV and barriers to health services. But, as McGovern et al note, whether the SDG promises are met will depend on effective mechanisms for monitoring progress in rights-based, disaggregated, and inclusive data that demonstrate clear positive outcomes for all people.

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PERSPECTIVE

Human Rights in the Fourth Decade of the HIV/AIDS Response: An Inspiring Legacy and Urgent Imperative

JAMIE ENOCH AND PETER PIOT

Abstract

More than 35 years since the HIV/AIDS pandemic began, HIV continues to cause almost two million new infections each year, and the "end of AIDS" by 2030 remains elusive.[1] Violations of human rights continue to fuel high rates of new infections among key populations and a generalized epidemic in much of sub-Saharan Africa. Meanwhile, as political shifts worldwide threaten not only HIV funding but also progress toward the globalization of human rights, civil society mobilization and advocacy founded firmly on human rights principles have a more vital role to play than ever. Encouragingly, there are numerous examples of successful integration of human rights-based approaches into HIV prevention and treatment initiatives, and evidence increasingly demonstrates that norms enshrining the respect, protection, and fulfillment of human rights can translate into improved public health.[2] This essay will succinctly trace the historic emergence of human rights as an issue at the heart of the HIV/AIDS response; it will then provide examples of progress and setbacks in recent years and consider the potential for rights promotion to address the structural drivers of HIV. Finally, it will consider how the primacy of human rights in HIV/AIDS has affected other fields of global health and will highlight the continuing imperative to work with civil society to protect and promote human rights to reduce the burden of HIV/AIDS.

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Historical context of human rights in the HIV/AIDS response

The human rights discourse gained prominence in the early days of the epidemic in North America (and soon afterward in Brazil and Western Europe). In the face of authorities' neglect of the epidemic, many people living with HIV (PLHIV) became advocates for their right to health and, in the case of the LGBT+ community, their right to non-discrimination. The initial response by authorities in many countries was to stigmatize groups perceived to be high risk, such as men who have sex with men (MSM) and Haitian immigrants in the United States, and sex workers and truck drivers in India.[3] The marginal status and lack of political capital of many of those initially affected by HIV frequently allowed authorities to adopt a "law and order" response limiting individuals' rights—for example, restricting PLHIV from international travel and employment. This climate of fear, blaming, shaming, and isolation led groups most affected by the early HIV epidemic to mobilize against the interlocking stigma of living with HIV and being part of a minority group now associated with disease. Support and advocacy groups formed to demand that governments fund research, explore the potential of experimental treatments, and provide prevention and communication materials. The 1983 Denver Principles, for example, defined rights for "people with AIDS," who refused to be considered "passive" victims or patients.[4]

In the global policy arena, the more formal linkage of health with human rights emerged thanks largely to the efforts of Jonathan Mann, the first director of the World Health Organization's Global Programme on AIDS in the late 1980s.[5] Mann boldly framed AIDS as an issue of human rights and ethics, taking into account the broader social determinants and structural violence underlying the disease, in contrast to prevailing views of AIDS that focused on individuals' risky or deviant behavior. While legal frameworks and mechanisms had frequently been used to protect the "general public" from the disease, Mann worked innovatively to utilize the law to protect people with the disease from discrimination and exclusion. He articulated the epidemiological imperative for human rights, understanding that respecting the rights of PLHIV would improve their engagement with health programs, thereby enhancing HIV surveillance and control. Mann's advocacy work around the respect, protection, and fulfillment of rights for PLHIV helped drive major formal declarations and resolutions, such as the 1996 International Guidelines on HIV/AIDS and Human Rights.[6]

Once HIV infection became a treatable condition, access to antiretroviral therapy came to be framed as a human rights issue. This was amplified by legal disputes involving the governments of Brazil (where the United States had brought a World Trade Organization dispute settlement over TRIPS) and South Africa (where 39 pharmaceutical companies sued the government over changes to the law to expand access to generic drugs). The fight for access to HIV treatment represented a significant advance in the justiciability of the right to health and has provided salutary examples of how social, economic, and cultural rights under the International Covenant on Economic, Social and Cultural Rights can be progressively realized.[7] In Brazil, thanks in large part to rights-based mobilization and activism, the government passed a law in 1996 to provide free universal access to antiretrovirals, helping realize the government's obligation under the Brazilian Constitution to fulfill the right to health. In South Africa, the 2002 litigation of the Treatment Action Campaign and the AIDS Law Project, regarding the government's failure to provide pregnant women with nevirapine and thus prevent HIV transmission to their children, has become an exemplar of how civil society can hold governments accountable for their obligation to fulfill the right to health.[8] In countries across the world, PLHIV and human rights activists have used the law and the courts to challenge discriminatory laws and policies in areas such as employment, education, and social services.[9]

When UNAIDS was established, it took special care to listen to rights activists' concerns. Steps were taken to formally involve activists in UNAIDS decision-making processes, such as by including civil society representatives as (non-vot-

ing) members of its Programme Coordinating Board. Further, UNAIDS established the Reference Group on HIV and Human Rights in 2002 to advise the agency on human rights issues relevant to the response. Civil society representatives were also included as (voting) board members of the Global Fund to Fight AIDS, Tuberculosis and Malaria; and the Global Fund's board has since worked to better integrate human rights issues into country coordinating mechanisms and has made the promotion and protection of human rights one of the four major objectives of its 2017–2022 strategy.[10] Despite these positive and pioneering steps, ensuring the genuine, inclusive, and meaningful incorporation of activists, especially those representing key populations, into decision making at the United Nations level remains an urgent priority.[11] Addressing this challenge will require organizations leading the HIV/AIDS response to redouble engagement with activists at this pivotal juncture.

It is thanks to the efforts of activists of all stripes that we have, to some extent, seen the propagation of a global "norm cascade," with states increasingly promulgating laws to protect the rights of PLHIV (although the enforcement of such laws remains uneven). In 2014, 64% of countries reporting to UNAIDS had laws protecting PLHIV from discrimination based on HIV status.[12] There has also been a rapid reduction in the number of countries restricting the entry, stay, or residence of PLHIV, falling from 59 to 35 between 2008 and 2015, demonstrating the speed of improvements in legislation to enhance certain rights of PLHIV.[13]

Persisting and emerging human rights challenges

Nevertheless, many countries still have laws, regulations, and policies hindering effective HIV prevention, treatment, care, and support for key populations, including MSM, intravenous drug users, sex workers, and transgender people. Some 73 countries, nearly 40% of the global total, criminalize same-sex relations.[14] This is in spite of the evidence that criminalization and punitive laws negatively affect HIV transmission by compounding stigma and creating structural barriers to biomedical prevention, health education, and engagement with health services.[15] For example, in Caribbean countries where homosexuality is criminalized, 25% of MSM are reported to be infected with HIV, a significantly higher rate than in countries that do not criminalize homosexuality.[16] Similarly, HIV prevalence among sex workers is generally lower in European countries that have decriminalized aspects of sex work than those where it is criminalized.[17] Alongside evidence from these country-comparison studies, the TRUST cohort study has demonstrated that Nigeria's 2014 Same Sex Marriage Prohibition Act caused a decrease in engagement with HIV services among MSM.[18]

These examples serve to remind us that there is no guaranteed "march of progress" toward improved rights for PLHIV or key populations at risk, despite the continuous accumulation of evidence that respecting human rights enhances health. Laws protecting and promoting human rights exist in an unstable, precarious, and politicized equilibrium. For example, in India, home to the world's third-largest HIV epidemic, the high court struck down the Criminal Code provision criminalizing same-sex sexual relations in 2009 before it was reinstated by the Supreme Court in 2013. Today, in 2017, new waves of populist nationalism and a reinvigorated backlash against globalization may threaten hard-won rights gains. Human rights organizations have warned that the postwar international human rights system, founded on the Universal Declaration of Human Rights, is at risk from leaders who frame human rights as a hindrance to state sovereignty or traditional culture.[19] We have already seen President Trump reinstate and expand the Mexico City Policy, or Global Gag Rule, placing restrictions on several agencies (including the United States President's Emergency Plan for AIDS Relief) that may provide information on abortion. This policy is likely to infringe significantly on adolescent girls' and young women's access to contraception and HIV counselling services.[20]

Currently, HIV infection rates are rising rapidly in countries where there is a limited possibility of holding the government to account regarding its

human rights commitments. A prime example is Russia, where in 2015 in certain cities, one in three intravenous drug users was living with HIV.[21] Russia has a legal ban on opioid substitution therapy, despite its well-evidenced effectiveness for managing dependency and preventing HIV. Thus, the ban arguably contravenes article 12 (on the right to enjoy the highest standard of health) and article 15 (on the right to enjoy the benefits of scientific progress) of the International Covenant on Economic, Social and Cultural Rights, despite Russia being a party to the convention. Russia's policies have prompted concerns from the United Nations Human Rights Committee, but the onus falls on brave activists to attempt to redress violations through regional or international human rights mechanisms, such as the European Court of Human Rights.[22]

Despite these numerous challenges, it is important to highlight recent hard-won successes of HIV activists and human rights defenders who have advanced the rights of PLHIV through combinations of advocacy, activism, and litigation. For example, in England in March 2016, the National Health Service abandoned plans to roll out pre-exposure prophylaxis (PrEP), arguing that the health service was not responsible for preventative health. However, after a successful challenge from advocacy organizations such as the National AIDS Trust, England's Court of Appeal ruled in November 2016 that the National Health Service has the legal power to procure and provide PrEP.[23] A large, three-year implementation trial of PrEP is now set to begin in September 2017, providing PrEP to an estimated 10,000 people at high risk of HIV infection.[24] Moreover, in countries such as Ukraine, activists have been a driving force behind AIDS programs and continue to keep AIDS in the spotlight amid the civil conflict.[25] Finally, in Zimbabwe, where national policies seem to be moving against the tide of the expansion of human rights, grassroots activist Martha Tholanah has been waging a brave fight against HIV-related and LGBT+ stigma, despite recently facing court charges on the basis of running an "unregistered" organization.[26]

Perhaps the greatest concern for the future of the HIV/AIDS response is the largest-ever cohort of adolescents, particularly adolescent girls and young women, living with HIV in sub-Saharan Africa. Deeply entrenched social drivers and structural violence—especially inequality and poverty, symptoms of what Paul Farmer has termed "pathologies of power"—are fueling this epidemic. Vulnerability to HIV continues to be socially conditioned in a context of gender inequality, intimate partner violence, and limited economic and social rights (such as low education and low levels of socioeconomic independence) which undermine women's ability to exercise their sexual and reproductive rights. For example, phylogenetic data from recent research in KwaZulu-Natal, South Africa, shows that age-disparate sex (sex between women under 25 and men on average 8.7 years older), in a context of patriarchy and unequal gender power relations, is a significant driver of the epidemic.[27]

In countries such as South Africa, the promotion of equality and prevention of unfair discrimination are enshrined in the constitution; however, legal protections for civil and political rights mean little to those who are not in a sufficiently secure socioeconomic situation to exert those rights.[28] In such contexts, human rights approaches that reduce discrimination, stigma, and marginalization must also advance social and economic equality and justice, recognizing that poverty and inequality expose individuals to violations of their civil and political rights and thus negatively affect HIV transmission patterns.

The continuing imperative for integrating human rights into HIV/AIDS and global health efforts

Even if the future of the HIV/AIDS response is at risk in the current political climate, the centrality of human rights in HIV/AIDS provides a model for other areas of global health. For example, the fact that antiretroviral therapy was initially rolled out in the face of skepticism and pessimism but has today reached more than 19.5 million people, according to UNAIDS, has inspired advocates in other disease

areas to campaign for more affordable, equitable access to treatment.[29] The prominence of rights in the HIV/AIDS response will continue to provide lessons and precedents for our response to other epidemics and evolving health threats. For example, a lawsuit before Brazil's Supreme Court requesting access to information, health services, and safe abortion for victims of Zika builds on the model of litigating the right to health in the context of AIDS in Brazil and many other Latin American countries.[30] In addition, the 2013–2016 Ebola outbreak in West Africa brought human rights concerns to the fore, as quarantine and coercive measures were used during the outbreak in a climate of poor messaging, limited treatments, and social and political instability. Today, survivors face stigma, and learning from the HIV/AIDS pandemic may help ensure that they remain free from discrimination as they reintegrate into community life.[31]

Looking forward within the field of HIV and human rights, we increasingly find that legislation is in place but that individuals who might use the law to fulfill their rights do not have the resources, power, or sense of personal security and safety to do so. This is in the context of a "shrinking civil society space" that limits the ability of human rights organizations and defenders to operate, advance rights- and evidence-based responses, and advocate for political, economic, and social change. In a global climate that appears increasingly hostile—or at least indifferent—to human rights, and where competing priorities have a significant impact on AIDS funding, there are challenges ahead in terms of supporting rights-based advocacy and activism for HIV/AIDS.[32] In the context of HIV/AIDS, a bold defense of human rights can make the difference between life and death for entire groups of vulnerable people, as seen in the expansion of (and continuing gaps in access to) life-saving antiretroviral drugs. Limited resources and political instability across the world pose serious challenges, but we must do more to support rights-based approaches if we are to make good on our pledge to reduce new HIV infections and end AIDS without leaving anyone behind.

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At the Nexus: How HIV-Related Immigration Policies Affect Foreign Nationals and Citizens in South Korea

JESSICA M. KERALIS

Abstract

Effective HIV prevention requires the protection and empowerment of marginalized groups at high risk of infection. However, many policies persist that stigmatize these groups and hinder HIV prevention efforts, including HIV-related travel restrictions. In the Republic of Korea, which requires HIV tests for certain visa categories, these restrictions negatively affect the national HIV response and access to accurate information on effective HIV prevention. In addition, they violate migrants' human rights to confidentiality and informed consent to testing and the rights of persons living with HIV (PLHIV) to privacy, work, medical care, bodily integrity, and freedom from discrimination. Furthermore, the discrimination and misconceptions perpetuated by this policy may be driving South Korea's burgeoning infection rates.

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Introduction

The human immunodeficiency virus, or HIV, has been at the nexus of health and human rights since it first emerged as an epidemic in the early 1980s.[1] Because of its connection to male-to-male sexual contact, commercial sex work, and injection drug use—behaviors that are criminalized in many countries—its prevention and control quickly became the focus of significant controversy.[2] In the years following HIV's emergence, communities affected by the epidemic, human rights activists, and public health experts stressed that, contrary to traditional public health responses, the effective response to HIV required the protection of the human rights of those affected by and at risk of the epidemic. This approach, termed by Michael Kirby as the "HIV paradox," has since been confronted with substantial backlash from politicians and groups who view the criminalization of behaviors that spread the virus, and the further marginalization of those engaged in them, as acceptable means of controlling the epidemic.[3]

While substantial progress has been made in developing and strengthening the evidence base for effective HIV prevention strategies, these initiatives still face social and political hurdles. Social stigma persists, and laws and public health policy that harm efforts to control the spread of infection are common.[4] One such measure that is still frequently employed today—despite being consistently demonstrated as ineffective and roundly condemned by human rights and public health bodies around the world—is HIV-related travel and immigration restrictions. Immigration restrictions based on HIV status are enforced by the Republic of Korea (hereafter Korea) for specific visa categories, despite international treaty commitments and public statements to the contrary.[5] Many countries across the world still apply such restrictions, maintaining laws and policies that deny the entry, stay, and residence to people living with HIV on the basis of their HIV status.[6] These restrictions have been universally condemned as violating migrants' human rights to confidentiality and informed consent to testing, and the rights of PLHIV to privacy, dignity, bodily integrity, work, and medical care. In addition, Korea's policies also deprive its own citizens of the right to health and accurate information on effective HIV prevention.

HIV in Korea: Past and present

History of the epidemic and early policy responses

Korea's first case of HIV was identified in 1985.[7] The appearance of the virus coincided with the country's symbolic opening to the outside world with the hosting of the 1988 Summer Olympics in Seoul, and fears that the influx of tourists would result in the rapid spread of HIV were widespread among government officials and media commentators.[8]

There were strident calls for requiring "AIDS certificates" to certify that all who entered the country were not infected, and Korean government officials proposed the idea at the World Health Assembly in 1987.[9] The World Health Organization instead reaffirmed that "information and education on the modes of transmission ... are still the only measures available that can limit the further spread of AIDS."[10] Meanwhile, Korea passed the AIDS Prevention Act in November 1987, which in addition to requiring HIV diagnoses to be reported to the Korea National Institute of Health, implemented mass compulsory screenings for groups identified by the government as "high risk," including commercial sex workers, prison inmates, overseas sailors, and food industry sanitation workers.[11] This continued until 2000, when mandatory testing was abolished and funding priorities shifted from testing to medical care for PLHIV.[12] Korea's HIV travel ban remained in place until 2010.[13]

Exclusionary epidemiology: "Domestic" versus "foreign" infections

Epidemiological data on HIV in Korea are provided by the Korea National Institute of Health and the Korean Centers for Disease Control and Prevention. Although Korea has a comparatively low prevalence of HIV and is considered a low-burden country, the number of newly acquired HIV infections has increased nearly every year since the

first case was discovered, and new cases have risen substantially since 2000.[14]

In 1992, Korea's HIV epidemic shifted from the virus being brought in from overseas to it being transmitted through domestic sexual contacts.[15] However, the perception of HIV as a foreign contagion persists. Annual reports of the Korea National Institute of Health and Korean Centers for Disease Control and Prevention distinguish between "domestic" and "foreign" cases, and while detailed statistics on demographic information, modes of transmission, and CD4 counts at diagnosis are provided for Koreans, little to no data to this effect is given on foreign nationals diagnosed with HIV. The Korean HIV Cohort, which consists of patients aged 18 or older diagnosed with HIV who agreed to be enrolled in the study, is declared in scientific publications to be "representative" of the epidemic in the country. However, it was established in 2006, when the HIV travel ban was still in place and foreign nationals diagnosed with HIV were deported.[16] Peer-reviewed journal articles and publications on the topic of HIV in Korea appear to refer exclusively to HIV infections among native Koreans when describing the country's epidemic, as the figures provided match the number of infections among Korean nationals as reported by the Korean Centers for Disease Control and Prevention.[17] This apparent exclusion of migrants with HIV from Korea's body of HIV-focused epidemiological scholarship even after the removal of the travel ban precludes their consideration in the development of evidence-based prevention strategies. The absence of migrants from the discourse surrounding HIV in the Korean epidemiological research community deepens the public health marginalization they experience, which is, at least in part, driven by HIV-related immigration restrictions to which they are subjected.

Specific travel restrictions

The Department of Immigration continues to require HIV tests for certain visa categories, despite a declaration from a Ministry of Foreign Affairs official that the country had lifted all HIV-related travel restrictions.[18] These mandatory screenings are required for native English teachers, manual laborers under the Employment Permit System and industrial trainee programs, maritime workers, and entertainment workers. Those who test positive are usually denied work visas and forced to either leave the country or work illegally, in which case they cannot access treatment or medication.

Korea shifted from a labor-exporting country to a labor-importing one during its rapid development in the 1980s and began attracting migrant laborers soon after it hosted the 1988 Olympics.[19] The D3 visa was established in 1993 to process and employ these migrants under the existing Industrial Trainee System, providing a steady stream of cheap labor that had no right to benefits or medical care and no ability to form unions to lobby to improve their working conditions; the following year, compulsory HIV testing began.[20] Additionally, there have been reports of health officials visiting factories and asking managers to gather all migrant workers for compulsory HIV tests.[21] The Industrial Trainee System was replaced by the Employment Permit System (E9 visa) in 2004, which mandates HIV tests for all applicants either before departure or upon entry (or both), and annually thereafter.[22] These workers are often forced to pay out of pocket for these tests.[23] Migrants who are HIV positive or who wish to avoid testing are driven to enter the country illegally, cannot access regular medical care, and are forced to forgo treatment. Those who do test positive have their test results reported to their employers and immigration authorities, denying their right to privacy and confidentiality, and their visas are revoked.

Testing for sexually transmitted infections and other infectious diseases has been required of women working in bars and hostess clubs—formally employed as entertainers but who often engage in sex work—nationwide since 1977, and HIV was added to the testing scheme in 1986, shortly after it emerged on the peninsula.[24] Following the trend of manual laborers, the population of women working in the "pleasure industry" has shifted from being mostly Korean to consisting largely of migrants from the Philippines, Russia, the former Soviet Republics, Nepal, and Sri Lanka, and the government

has accommodated the influx of these migrant women (despite the fact that prostitution is officially illegal) by allowing them to enter and work under the E6 "entertainment visa."[25] Also similar to manual laborers, the women are deprived of their rights to accurate health information and medical confidentiality: they receive no counseling, their health checks are provided and processed in Korean (rather than their native language), and their test results are reported to their employers.

There are close to 16,000 native-speaking foreign language teachers in Korea, most of them English teachers from the United States, Canada, the United Kingdom, Ireland, South Africa, Australia, and New Zealand.[26] The advent of mandatory HIV tests for these native-speaking English teachers, who work in Korea under the E2 visa program, has been extensively documented by Benjamin Wagner and Matthew VanVolkenburg.[27] Until recently, the Korean government required E2 visa applicants to undergo annual HIV and drug testing as part of a policy that it had implemented in 2008 in response to a moral panic sparked by the Interpol arrest of Christopher Paul Neil, a Canadian national and child sex predator. Although Neil was arrested for activities that took place in Thailand, and there was no evidence that he had committed sex crimes in Korea nor that he was HIV positive, the revelation that he had been living and teaching English in South Korea generated nationwide outrage and fears of sexual exploitation and corruption of Korean women by "predatory" foreign men.[28] Several conservative nativist citizen groups seized on the opportunity to pressure the government to implement annual HIV and drug tests for foreign English teachers.[29] Notably, there was no such requirement for Korean citizens, and even noncitizens of Korean ethnicity who hold F4 visas (a multiple-entry visa designated for ethnically Korean foreign nationals) are not subject to the testing requirement.[30] Teachers were required to submit to the test when they arrived in country, and teachers who worked for public schools were retested annually when renewing their contracts.[31] Those who tested positive faced the possibility of being denied a visa and potentially being deported.[32] Their results were reported to immigration authorities and their employers, and no health information or counseling was offered in their native language. Many did not even realize that they were being tested when they went to the hospital for their required health check. Although the HIV testing requirement was lifted in July 2017, Korea's Ministry of Justice still requires that E2 applicants undergo mandatory testing for drugs and now syphilis, making it possible that they are still being tested for HIV without their knowledge or consent.[33]

Although there are no HIV-specific restrictions tied to the D2 visa required for university-level students, several scholarship programs operated by the Korean government list HIV/AIDS as a potentially disqualifying factor. For example, the Teach and Learn in Korea program, which recruits native English speakers with at least two years of undergraduate study to teach English in rural areas for six to twelve months, states in its contract that the participant's employer may terminate the contract if the participant is found to be HIV positive, and that the employer can request a "physical examination" (which presumably includes an HIV test) at any time.[34] Also, the Korean Government Scholarship Program, which provides funding and airfare for non-Koreans interested in pursuing a postgraduate degree at a Korean university, lists a medical examination as a stipulation for receiving the scholarship and specifies HIV as a cause for disqualification.[35]

HIV infection, medical care, and stigma in Korean society

New cases rising rapidly

While the Korean government assuages the public's fear of HIV by citing its HIV-related immigration restrictions, it is neglecting the country's own burgeoning infection rates. The number of new infections has risen steadily since the beginning of the epidemic, increasing by an average of 12% each year since 2000 among Korean nationals, even as the overall global trend declines.[36] One 2013 analysis modeling the number of future infections based on previous case counts predicted that new HIV in-

fections would increase rapidly if trends continued unchanged, and the number of new cases has either matched or surpassed the model's prediction in the three years since.[37] Multiple Korean public health experts have pointed out the potential for the epidemic to escalate quickly and the inadequacy of the government's current policies in slowing the rate of new infections.[38]

Homophobia and the gender disparity in infections

The ratio of HIV-positive Korean males to females rose from 6:1 in 2000 to 11:1 by 2011, and it is projected to rise to as high as 19:1 in 2017.[39] The growing gender disparity in infections indicates strongly that new infections are driven largely by male-male sexual contact.[40] However, official surveillance data and most surveys of men diagnosed with HIV have found that less than half (and often as low as a quarter) of respondents report that their infection resulted from sexual contact with other men.[41] This is most likely due to underreporting, as homosexuality is deeply stigmatized in Korean society, and many men who have sex with men may be reticent to disclose their sexual orientation.[42]

Stigma in society and medical care

Ignorance about HIV, how it is transmitted, and what measures can be taken to protect oneself from infection is widespread among Koreans. Discrimination against PLHIV is deeply entrenched in Korean society. Surveys of attitudes toward PLHIV have found high percentages of respondents who would feel uncomfortable living near someone with HIV, refuse to care for a family member living with HIV, and support the isolation of PLHIV.[43] Such attitudes toward PLHIV are common even among medical professionals who are educated about HIV and have a professional obligation to provide appropriate care to PLHIV. It is not uncommon for hospital personnel to refuse to treat or touch patients with HIV, or even to force them to leave the facility when they disclose their status. Tragically, this is found even in long-term care facilities *specifically designated for AIDS patients*, where patients are neglected by staff, not allowed to leave of their own free will or contact family members, and even charged additional fees not required of other patients.[44] Finally, it is worth nothing that rates of suicide and suicidal thoughts are much higher among PLHIV than the general population.[45]

At the nexus: HIV restrictions against migrants to protect citizens violate the rights of both

Travel restrictions as prevention: A failure for public health and human rights

Governments often couch HIV-related travel restrictions in terms of protecting public health. However, this rationale has been explicitly rejected by international health and human rights organizations, including the World Health Organization, UNAIDS, and multilateral human rights bodies (such as the International Organization for Migration, the International Labour Organization, and the Inter-American Commission on Human Rights).[46] HIV-related restrictions on travel, immigration, or residence violate the principles of nondiscrimination and equal treatment included in all international human rights laws, treaties, and agreements.[47] The International Covenant on Civil and Political Rights guarantees the right to equal protection under the law, without discrimination based on race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status, and the United Nations Commission on Human Rights has determined that this includes discrimination based on health status, including HIV infection.[48] According to the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights, while international human rights law allows governments to restrict rights in cases of emergency or serious public concern, the restrictions must, among other things, be the minimum necessary to effectively address the concern.[49]

HIV-related travel restrictions have been overwhelmingly deemed overly intrusive and ineffective. Numerous health and human rights organizations have made it clear that screening

travelers and migrants for HIV is ineffective in preventing the spread of HIV, as HIV is not transmitted by casual contact, and countries that do not have HIV-related travel restrictions have not reported any additional negative public health consequences compared to those that do.[50] Nonetheless, according to UNAIDS, 35 countries still have some form of official HIV-related travel restrictions, while others, including Korea, allow employers and individual government agencies to discriminate against PLHIV with impunity.[51]

HIV as "foreign contamination"

Public discussions of HIV in Korea cast the disease as a product of the contamination of Korean society by foreign elements, propagated by social deviancy (such as promiscuity and prostitution). This has been well documented by Sealing Cheng, who demonstrates "how the discourse of AIDS is embedded within larger nationalist fears of foreign contamination in a globalized world" in her coverage of a nationwide "Purity Campaign" led by a Korean nonprofit established for HIV prevention and supported by government funds and endorsed by the Korea National Institute of Health.[52] She documents how this discourse has been legitimized by opposition politicians and the Korean media (who have historically cited the government's failure to track and deport HIV-positive migrants in their criticism of the government) and embraced even by Korean public health officials (who attributed the spread of the virus to homosexuality and teenage prostitution at the time of the campaign). As Cheng notes, rather than providing accurate information about modes of transmission and effective prevention strategies, the campaign portrayed HIV infection as a consequence of promiscuous sexuality outside of marriage and sexual contact with foreigners (who represent deviancy and sexual corruption). This view of HIV as foreign contamination continues to be perpetuated by media reports and statements from government officials.[53]

Felicia Chang et al. point out that an overwhelming proportion (89%) of WHO member states with high percentages of foreign nationals have HIV-related travel restrictions and suggest that governments may employ them to exclude foreign workers from jobs, address citizens' concerns on foreign influences and cultural infringement, and appease voters.[54] Korea's immigration policies, much like its officially endorsed HIV-prevention messaging, support this view, marginalizing migrants from public life both by restricting their access to employment and health care and by portraying them as carriers of foreign disease and moral decay.

Violating migrants' rights to privacy, work, and medical care

The compulsory HIV testing of migrants and their exclusion on the basis of HIV infection is a blatant violation of numerous human rights. Forced testing violates the right to bodily integrity and dignity, and the accompanying deportation or loss of employment and residency status on the basis of infection violates the rights of PLHIV to privacy, work, appropriate medical care, and non-discrimination.[55] The International Labour Organization has stated that neither HIV tests nor private HIV-related personal information should be required of employees or job applicants.[56]

HIV-related restrictions against entry, stay, and residence, in addition to being an ineffective public health measure to protect health and prevent the spread of infection, regularly violate the rights of travelers, migrant workers, and asylum seekers. Furthermore, these policies also violate migrants' human rights to confidentiality and informed consent to testing and expose them to exploitation by their employers. A 2007 study on immigration policies in Asian countries that require HIV tests found that migrants entering Korea were routinely tested without their informed consent, not provided with test counseling, and deprived of the confidentiality of test results; further, those who tested positive were denied treatment and employment, and in some cases deported.[57] Subsequent investigations by Amnesty International have confirmed that this testing continues.[58]

Additionally, a 2015 decision by the United Nations Committee on the Elimination of Racial Discrimination established that such policies can

constitute racial discrimination. The decision, issued in response to a complaint filed by a New Zealand national who had lost her job for refusing to submit to Korea's HIV testing policy targeting E2 visa holders, found that the policy constituted racial discrimination and was not "justified on public health grounds or any other ground, and is a breach of the right to work without distinction to race, colour, [or] national or ethnic origin."[59]

Violating citizens' right to health

Rather than accomplishing their supposed goal of protecting a country's citizens from HIV infection, immigration policies banning or restricting entry or employment based on HIV status frequently have the opposite effect. Such policies legitimize and exacerbate the stigma surrounding HIV, further marginalize citizens living with HIV, and deprive citizens of accurate information on how to protect themselves from infection and their right to health. Regulations requiring HIV tests of immigrants can promote the idea that foreigners are dangerous to the national population and a public health risk, as well as create a false sense of security by reinforcing the notion that only migrants are at risk of infection.[60] Additionally, such attitudes can adversely affect the host country's HIV rates, as HIV-positive citizens who underestimate their own HIV risk and avoid testing due to stigmatization are more likely to transmit the virus to others, driving up infection rates.[61]

This chain of events appears to be playing out in Korea, contributing to the country's rapidly growing number of new HIV infections each year. The lack of robust evidence-based HIV-prevention programs marginalizes migrants and Korean PLHIV and perpetuates widespread ignorance and misinformation about how HIV is transmitted and how individuals can protect themselves from infection.[62] The stigma attached to HIV and the virus's association with foreigners and social deviants actively discourage Koreans from accessing HIV testing and treatment—two of the most effective public health strategies for reducing viral transmission and preventing new infections.[63] Bizarrely, the Korean government cites the general public's "terror" toward HIV and PLHIV as justification for maintaining its current policies—which perpetuate human rights abuses against both migrants and Korean citizens, contribute to diminished social participation and quality of life for PLHIV, and exacerbate the epidemic—rather than pursuing evidence-based HIV prevention strategies or enacting policies that actively protect human rights and empower HIV advocates.[64] These policies have fallen woefully short on both the health and human rights fronts, and their continuation will inevitably result in more human rights abuses against migrants and more new HIV infections in the country.

Conclusion

HIV-related immigration restrictions are framed as measures to protect public health by governments who employ them, including South Korea. However, this rationale has been explicitly rejected by international health and human rights experts and organizations. These policies have systematically deprived migrants to Korea of their rights to work, health, privacy, freedom from discrimination, and dignity, and they have been exposed as a public health failure and an ineffective means to control the spread of HIV. Furthermore, they are contributing to Korea's domestic HIV epidemic by failing to combat misinformation and ignorance about HIV prevention and transmission and by entrenching stigma and discriminatory attitudes, which leads to Koreans avoiding HIV testing and treatment.

The recent removal of the HIV testing requirement for E2 visas demonstrates the potential of international human rights frameworks to challenge these restrictions. In September 2016, the National Human Rights Commission of Korea issued a decision determining that the testing policy had no public health justification and constituted racial discrimination, and recommended its removal.[65] Additionally, the decision found that the policy violated Korea's obligations as a signatory to the International Convention on the Elimination of All Forms of Racial Discrimination and was a direct response to the Committee on the Elimination of Racial Discrimination's ruling the previous year.

In July 2017, the Korean Ministry of Justice

removed the HIV testing requirement, citing the recent commission ruling.[66] These decisions based on Korea's treaty obligations—which have the same weight as domestic law under the Korean Constitution—could, along with consistent pressure from international human rights and public health organizations, provide a mechanism to challenge HIV testing requirements for other visa categories.[67] However, this is only a partial solution, as local authorities and individual employers can still force workers to undergo testing either through coercion or by testing workers without their knowledge. It is worth noting that drug tests for E2 applicants remain in place, and a syphilis test is now required, leaving the potential for employers to request an HIV test from the health facility without informing their employees.[68] This surreptitious testing has already been documented for E6 and E9 visa workers, and even among Korean citizens.[69]

Laws forbidding discrimination against residents on the basis of HIV status are the surest way to protect the health and human rights of PLHIV and those at risk of infection. Without these explicit legal protections, HIV-related immigration restrictions have the potential to be revived even after being previously struck down. These types of restrictions are very popular among the Korean public, and similar measures have recently been discussed and even implemented in other nations.[70] Rather than using widespread horror toward HIV and cultural taboos about sexuality and risk behaviors as a shield for its current ineffective policies, the Korean government should abolish HIV-related travel restrictions for all visa categories, pass laws prohibiting the discrimination of PLHIV, and implement proven HIV prevention and education strategies on a nationwide scale.[71] In this way, Korea can bring its HIV epidemic under control and ensure the protection of human rights for citizens and migrants alike.

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HIV, Sex Work, and Law Enforcement in China

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Abstract

HIV prevalence in China is low in the general population but higher among certain key affected populations, including sex workers. Providing and purchasing sexual services are administrative offenses. Police engage in humiliating and repressive practices against sex workers. A study reported here based on the experience of over 500 sex workers highlights that the human rights abuses that sex workers face at the hands of the police directly undermine the country's HIV response toward sex workers. An important element of this phenomenon is the police's use of condoms as evidence of sex work, which impedes sex workers' possession and use of condoms. Whereas in some countries, sex worker collectives have helped empower sex workers to stand up to the police and safeguard their use of condoms, restrictions on civil society in China make such a strategy impossible. Removing sex work and related activities as offenses under the law in China, however politically difficult it might be, would ease this situation. Short of that, improving the coordination among and strategic harmony of public health and police roles and authorities would be useful.

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Introduction

China's HIV epidemic is characterized by low prevalence in the general population but higher prevalence among key affected populations, including people who inject drugs, sex workers, and men who have sex with men. According to government figures, sexual transmission accounts for most new HIV cases; in 2014, about 25% of new cases were estimated to be linked to sex between men.[1] There is no authoritative consensus on the number of female sex workers in China, but most estimates suggest there are several million.[2] There is limited information on the number of (cisgender) male and transgender sex workers. (Unless otherwise noted, in this paper "female sex workers" refers to cisgender women in sex work, and "male sex workers" refers to cisgender men. "Transgender women" refers to persons who have made a gender transition from male to female.) Sex work is prohibited under administrative law, and some activities associated with sex work are criminal offenses, as described in more detail below.

While Chinese authorities continue to crack down on sex work, the government has set up policies and programs to prevent the sexual transmission of HIV, including the extensive rollout of condom and HIV testing programs. Undermining the public health outcomes of condom programs, police often search for and confiscate condoms from sex workers and use condoms as evidence of sex work in order to detain or punish sex workers.[3] While this practice has been reported in many articles, there has been little investigation of its impact on sex workers' lives and human rights, as recounted by sex workers themselves. Mechanisms have been established from the central to local levels to coordinate and mobilize relevant departments, including police and security officials, in support of HIV prevention, but these mechanisms have failed to work. The government has also emphasized the importance of involving public security in the HIV response, including supporting the promotion of condoms in entertainment venues.[4] However, to date there is no definitive guiding document or plan on how exactly the police should carry out this order or who is responsible for ensuring whether and how they do so. This article explores that gap, highlighting sex workers' first-hand accounts of police practices and their impact on sex workers' ability to protect themselves from HIV. Other evidence related to the health impact of policing on sex workers with respect to HIV is also reviewed.

Methods

Asia Catalyst is a human rights organization that works with community-based organizations from marginalized communities in China and Southeast Asia that promote the right to health. In 2015, it worked with four sex worker organizations in China to conduct a survey among 517 female, male, and transgender sex workers to understand their interaction with law enforcement and the impact of that interaction on condom use and thus on China's HIV response as it relates to sex work. (For security reasons, the names of the four sex worker organizations are not included here.) These organizations were chosen because (1) they work with sex workers of different genders and have extensive knowledge and experiences with the sex worker community; and (2) they are located in three cities in northern, eastern, and southeast China, thus reflecting geographically diverse situations.

The survey combined quantitative and qualitative methods. The quantitative data collection instrument was a questionnaire, completed by 517 sex workers selected through convenience sampling during regular outreach work of the four organizations. For those survey respondents who reported experience with the police searching for or seizing condoms, the interviewer then invited them to give a further in-depth interview on the details of their experience. A total of 74 sex workers participated in this follow-up interview.

There was no formal ethics approval process, but Asia Catalyst's commitment to rights-based community assessment was well known to the four participating organizations. Written informed consent was obtained from all participants. Survey respondents and interview respondents received a small gift as appreciation of their time. Each participating organization numbered and entered its

survey questionnaire findings into a database without individual identifying information. SPSS 13.0 and Microsoft Excel were used to analyze the data and identify trends. All of the in-depth interviews were recorded using digital voice recorders. The recordings were then transcribed by the partner organizations.

HIV and sex work in China

Sex work is estimated to play an important part in the epidemiology of HIV in China. A 2014 survey by the Chinese National Center for AIDS/STD Control and Prevention estimated that as many as 59.3% of the HIV-positive men surveyed had contracted HIV through commercial sexual activity, though it was noted that sexual behaviors may be difficult to quantify.[5] In recent years, China has witnessed a rise in HIV prevalence among people aged 60 and over. Some 15% of the new cases in 2015 were recorded among people in this age group, a group that could include migrant workers who visited sex workers far from home and the wives they returned to after being on the road.[6]

According to government statistics, HIV prevalence among female sex workers has remained stable and low in recent years, estimated at 0.22% in 2014.[7] A 2012 meta-analysis based on various reports estimated HIV prevalence in this population to be 3.0%, much higher than the official figure, and also estimated that about half of women living with HIV in China are sex workers.[8] These figures were judged to be overestimates by government epidemiologists.[9] A 2016 study in Guangxi found that women sex workers who were paid less for their work (characterized as "low-tier" workers by the authors) were at higher HIV risk than other sex workers because customers were less inclined to use condoms with these sex workers than with "higher-tier" workers.[10]

China does not report HIV incidence or prevalence among male sex workers, but it does report on HIV among men who have sex with men (MSM), among whom there was an estimated HIV prevalence of 7.7% in 2014.[11] Of new infections, male-to-male transmission showed the most rapid increase, from 2.5% of new cases in 2006 to 25.8% in 2014.[12] A study conducted with 2,618 MSM in 2009 showed that the HIV prevalence among male sex workers (6.13%) was slightly lower than among non-sex worker MSM (7.59%).[13] The study also estimated syphilis prevalence to be 10.73% for male sex workers and 14.72% for MSM who were not sex workers.[14] A 2012 meta-analysis based on the results of 32 published articles estimated an HIV prevalence of 6.0% and a syphilis prevalence of 12.4% among MSM engaged in sex work.[15] In conclusion, plainly male sex workers are a population that faces high HIV risk.

There is limited data on transgender sex workers, but some evidence suggests that transgender women sex workers experience the highest vulnerability to HIV of all people in sex work, as they face deep-seated stigma and discrimination and are often socially, economically, and legally marginalized, which increases vulnerabilities that contribute to the risk of HIV.[16] A survey of 220 transgender female sex workers in Shenyang in 2014 found that 25.9% either self-reported or were tested and confirmed as HIV positive, though the authors note that these results may not be generalizable to the rest of the country.[17]

Sex work, law enforcement and HIV: Background

The Chinese government has taken a punitive approach toward sex work and sex workers. Under Chinese law, engaging in sex work and purchasing sexual services are subject to administrative penalties, while organizing or arranging for the selling of sex is a criminal offense. Possible administrative penalties include up to 15 days of detention and a fine of up to 5,000 yuan (about US$743).[18] Potential sentences for the criminal offense are much more severe: five to ten years' imprisonment, fines, and the confiscation of assets.[19] In addition, sex workers are subject to "custody and education" provisions, which authorize police to detain female sex workers and male clients for six months to two years without judicial oversight.[20] Furthermore, knowingly transmitting HIV is a criminal offense, with a penalty

of up to five years' imprisonment.[21] All reported prosecutions under this offense have been against sex workers only, not their clients. [22]

Since the 1980s, the government has regularly carried out "strike hard" campaigns and "anti-pornography crackdowns" against the sex industry. According to statistics published by China's police force, the Public Security Bureau, the police investigated and prosecuted 620,000 people for sex work-related offenses between 1984 and 1991; 250,000 between 1992 and 1993; and more than 2 million between 1993 and 2004.[23] Crackdowns in Beijing and Dong'guan in April 2010 and February 2014, respectively, spawned the harshest national anti-pornography campaign in more than a decade. The police forces deployed, the geographic area covered, the number of sex work venues shut down, and the number of people arrested were unprecedented.[24] In order to maintain a certain anti-prostitution momentum, many local governments assign specific quotas to the police with regard to the crackdown on sex work.[25] Law enforcement is thus an inevitable part of sex workers' lives. Harsh policing and the fear of harsh policing are part of these workers' daily environment, with consequences for their physical safety and health.

In 2004, China identified injecting drug users, sex workers, and MSM as "high risk" groups for HIV transmission.[26] The government adopted specific measures to reduce the HIV vulnerability of these key populations, which emphasized awareness raising and behavioral interventions.[27] As in other countries, the fact that a population affected by HIV (such as sex workers) is also a target of police activities poses a potential health and human rights challenge.

In an effort to control the transmission of sexually transmitted infections and HIV, condom programs have become an important element of China's HIV response. The government has devoted great efforts to promoting condom use. As of 2004, condoms were already identified as an HIV program priority not only by the Ministry of Health but also by authorities charged with overseeing such areas as mass media and family planning.[28] China's 2006 legislation addressing HIV/AIDS requires certain public venues—such as hotels, nightclubs and public baths—to provide condoms. Furthermore, it stipulates that "health, family planning, commercial, drug monitoring, quality monitoring, testing and quarantining, broadcast and film and other departments of the people's government at the county level and above shall organize and promote the use of condoms and establish and optimize networks to provide condoms."[29] In some provinces, such as Yunnan Province, some venues have received administrative penalties for "not displaying condoms or condom-vending equipment in their places of business in accordance with regulations."[30] The central government also allocates a specific amount of funds each year to purchase condoms, which are then widely distributed to key populations, including sex workers, by various levels of the Center for Disease Control and Prevention and community-based organizations across the country.

However, some policies and practices have not lived up to these goals of condom promotion or have undermined progress in this area. In particular, the police, while ostensibly part of an inter-sectorial response to HIV, are mandated to see condoms in another light. According to the Ministry of Public Security's guidelines, in sex work cases, condoms are "tools of an offense," and law enforcement officers should, "following seizure, take photographs of the condoms, and then destroy them following the conclusion of the case."[31] This view of condoms on the part of the police is easy to sustain given the image of condoms in the public mind. Although the Chinese government has issued various policies requiring the state media to promote condom use, in reality condoms are rarely mentioned in the mainstream media. Commercial advertisement for condoms was banned for 25 years by a document issued by the State Administration for Industry and Commerce in 1989, which was quietly scrapped in 2014.[32] This legal obstacle prevented condom manufacturers from advertising their products to the public on television or in public places such as the subway. When condoms appear in news reports, it is usually only in relation to anti-sex work and anti-pornography crackdowns.[33] These reports often show police officers raiding vice dens and sex

workers being arrested, along with descriptions of the discovery of large numbers of condoms. Such reports associate condoms with sex work and thus portray them as evidence of an illegal activity. In an environment in which sex work is considered dirty and harmful to public morals, condoms are likewise associated with such qualities.

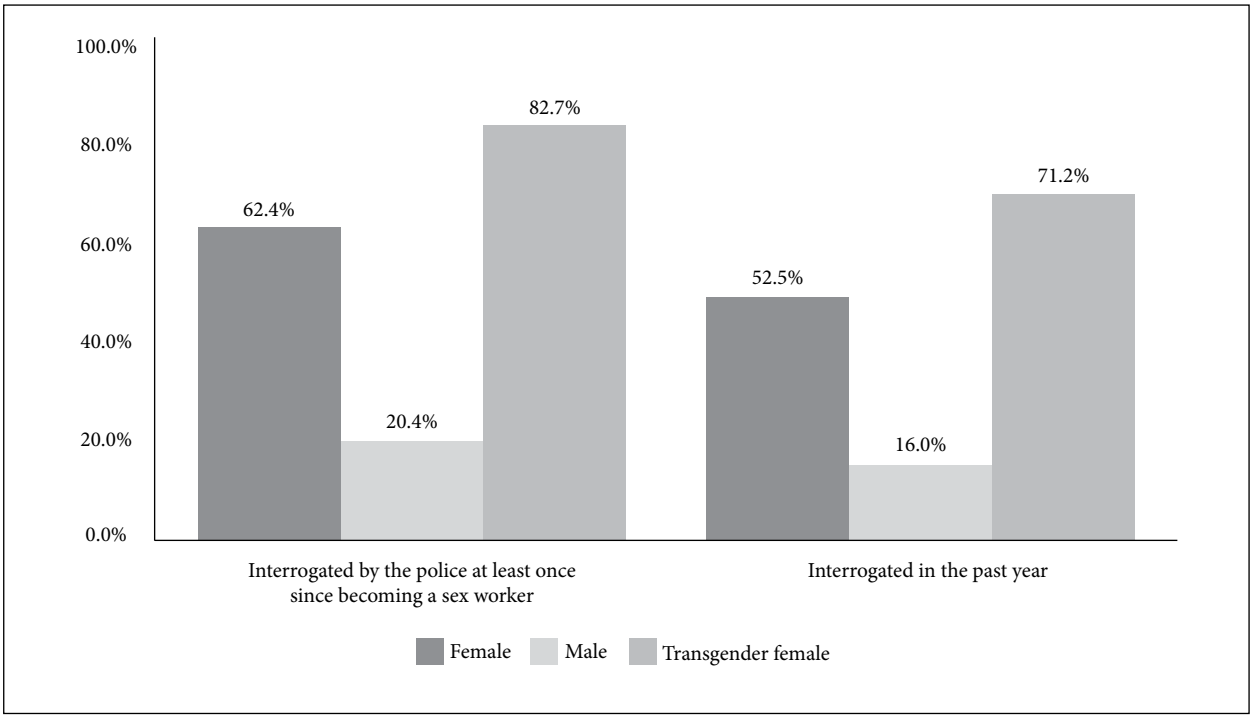
As early as 1998, when health departments were aware that the appearance of condoms in media reports on vice raids had an adverse effect on HIV prevention, the Ministry of Health joined with eight other ministries and commissions to issue an order requiring "spreading publicity on the use of condoms to prevent HIV/AIDS and STDs, while at the same time avoiding reports that treat condoms as evidence of prostitution."[34] But the document's lack of legal power has left the order unimplemented, and associations between condoms and illegal activity continue to be refreshed in the public mind.

In addition, while the government has been actively implementing its HIV strategy among sex workers, crackdowns on the sex industry have continued and have been actively encouraged in some major HIV prevention documents. For example, the 2004 and 2010 State Council notices to strengthen the HIV response and China's Thirteenth National AIDS Action Plan all have the stated objective of preventing HIV, but nevertheless require "public security departments to continue, as before, to crack down on prostitution, the assembling of licentious activity and other unlawful and criminal behavior."[35] Crackdowns take the form of regular raids on sex work venues, often leading to the arrest and detention of sex workers and sometimes the cessation of commercial sex activities at that venue.

Results

The 517 survey sample was 59% female, 31% male, and 10% transgender, with an average respondent age of 32.6. The survey found that a high percentage of sex workers had been interrogated by the police, both during their time as sex workers and in the past year (see Figure 1). More than half (51.3%) of sex workers reported that they had been interrogated

FIGURE 1. Percentage of sex workers interrogated by the police at least once since becoming a sex worker and in the past year



by the police at least once since beginning sex work, and 42.9% said that they had been interrogated in the past year. Among respondents who had been interrogated in the past year, 64.9% had been interrogated once, and 35.1% had been interrogated twice or more. Among those who had been interrogated twice or more, the overwhelming majority (78.2%) were women.

Among survey respondents who were interrogated during their time in sex work, most had negative experiences as part of those interrogations: 78% had experienced verbal humiliation, 64.5% had experienced entrapment, and 50.9% had experienced physical violence (see Figure 2).

FIGURE 2. Negative experiences encountered by sex workers during police interrogations

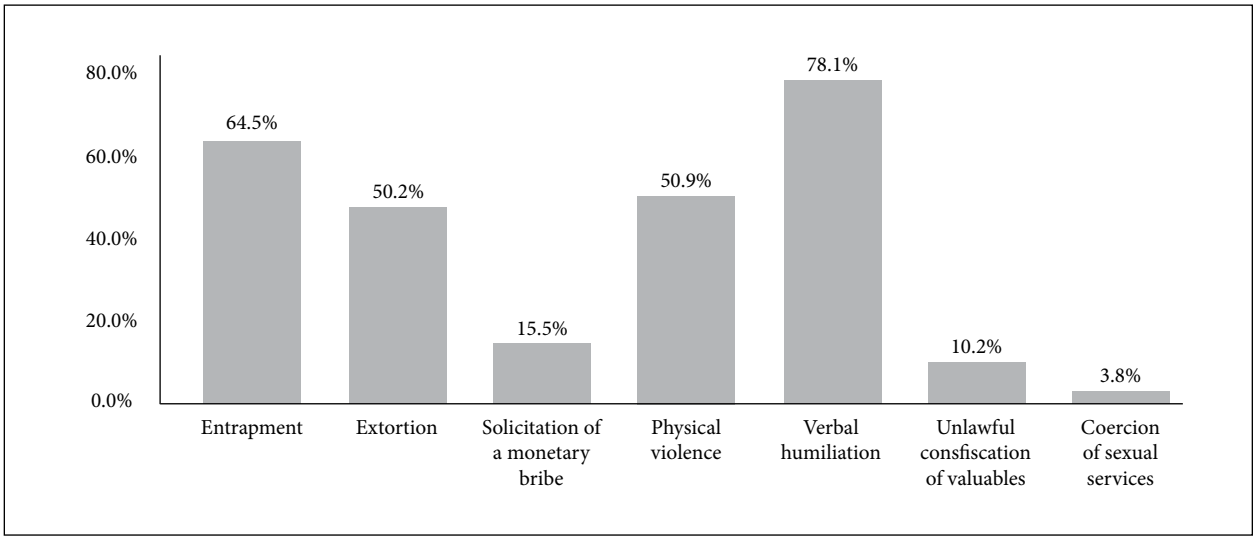
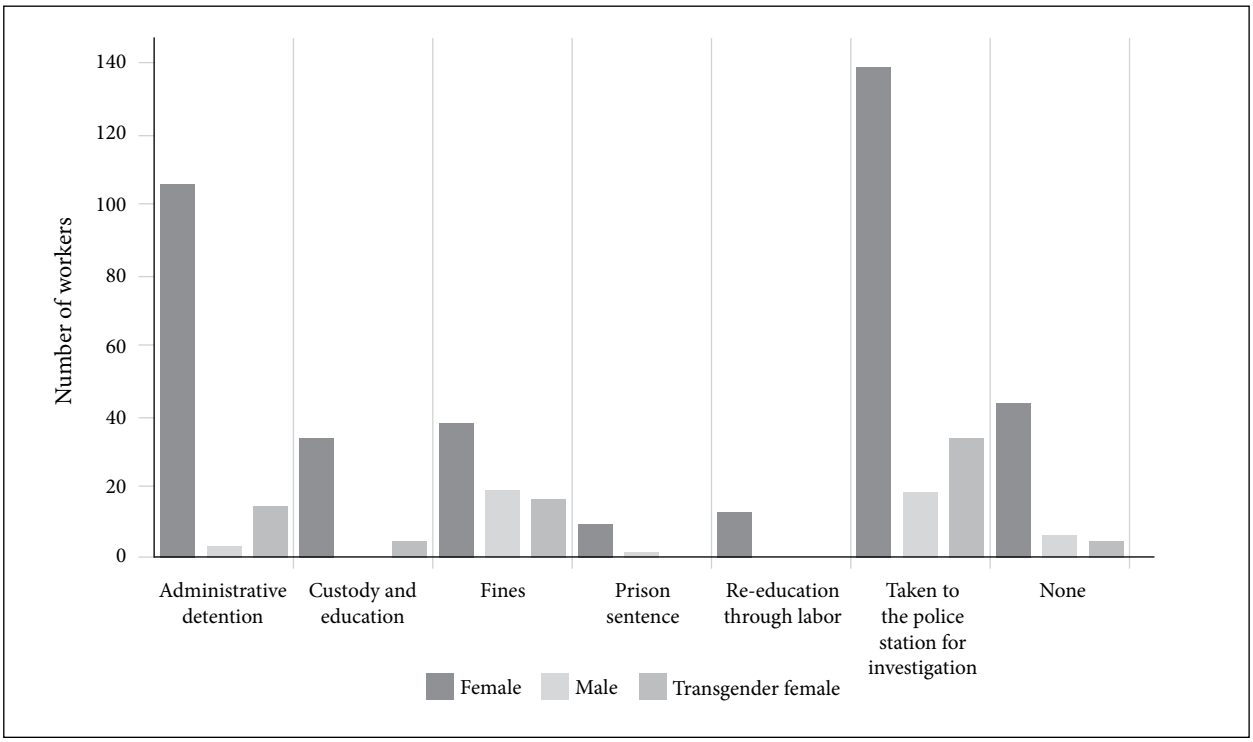


FIGURE 3. Penalties received by sex workers who had been interrogated by the police



Among the survey respondents who had been interrogated by the police as sex workers, 70.9% were taken to the police station for questioning. According to Chinese law, police officers can detain suspects for questioning, usually for no more than 24 hours. Though the questioning itself is not a form of administrative or criminal penalty, it triggers a formal investigation process, and a penalty can be imposed as result of the investigation.[36] Having been taken to the police station was frequently reported across genders, with 72.5% of women sex workers, 60.6% of male sex workers, and 72.1% of transgender sex workers experiencing this. Just over 47% of those interrogated by the police were subjected to administrative detention, and 26.8% were required to pay fines. Women respondents (56.1%) were more likely to be subject to administrative detention than men (9.1%) and transgender respondents (37.2%). Male and transgender respondents (57.6% and 39.5%, respectively) were more likely to be subjected to fines.

Over one-third (35.4%) of respondents said that the police had searched them for condoms at least once during their time as sex workers. Police officers' principal actions toward condoms included confiscating unused condoms (36%), collecting used condoms (38.2%), and asking sex workers about condoms (72%). Qualitative interviews from this study indicated that police used two main methods for handling sex work cases: (1) attempting to catch sex workers "in the act" and (2) conducting inspections of sex work venues. Condoms were the main focus of police action in both operations. Among the 74 qualitative interview respondents, more than half (47) reported that they had experienced one or more police raids while in the process of engaging in or attempting to engage in a commercial sexual transaction, or while soliciting clients. Twenty-nine experienced "stop and search" operations by the police on the street, in parks, in rented rooms, or in entertainment venues.

The experiences of sex workers in this study indicated that the aforementioned instructions to police about condoms are effective—that is, there is a common belief among police officers that merely possessing condoms is hard evidence of selling sex. Respondents' experiences showed that the police treat finding condoms as the determinative factor in whether to take a sex worker back to the police station for further inquiries or penalties. Among the 29 interview respondents who experienced police searches in sex work venues when they were not involved in a sexual transaction and condoms were found, 69% were taken to the police station and received an administrative penalty, 14% were taken to the police station for further inquiries but did not receive any penalties, and 17% had no further action taken against them.

Law enforcement actions and the use of condoms as evidence against sex workers have a direct impact on condom use and availability among sex workers. In this sample, the condom use rate (during the previous month) among sex workers who had been interrogated by police in the past year was 47.7%, compared to 67.8% among those who had no such experience. There were similar findings with regard to possession of condoms: 47.7% of sex workers who had been interrogated by the police always carried condoms in the previous month, compared to 75.9% of those who had not been interrogated.

Respondents reported that, to the extent possible, they promptly disposed of condoms before encountering the police. For example, sex workers working in a room would throw their condoms out the window or flush them down the toilet before the

Streetwalking keeps you on pins and needles; as soon as I see [the police] I run away, and if it's too late, I just throw away my money and condoms to spare myself trouble. I don't know how many condoms I've thrown away.

—Xiaoyan, a female sex worker

After I came out [from a detention center], I lost my nerve for a long time, and when I started working again I asked clients if it could be quick, and they usually demanded not to use a condom. I also hoped to finish quickly, and this way even if the police came, if they didn't see a condom they would have no evidence.

—Xiaoxue, a female sex worker

police entered, and street-based sex workers would throw away their condoms as soon as they saw a police officer in the vicinity. The fear of arrest drove sex workers to shorten their service time with clients as much as possible, making them more likely to agree to a client's demand not to use a condom. Sex workers were also reluctant to carry a sufficient quantity of condoms, preferring to carry just a few to avoid police suspicion and making efforts to hide condoms in various places. Reducing the number of condoms carried or not carrying them at all creates a direct health risk for sex workers and their clients.

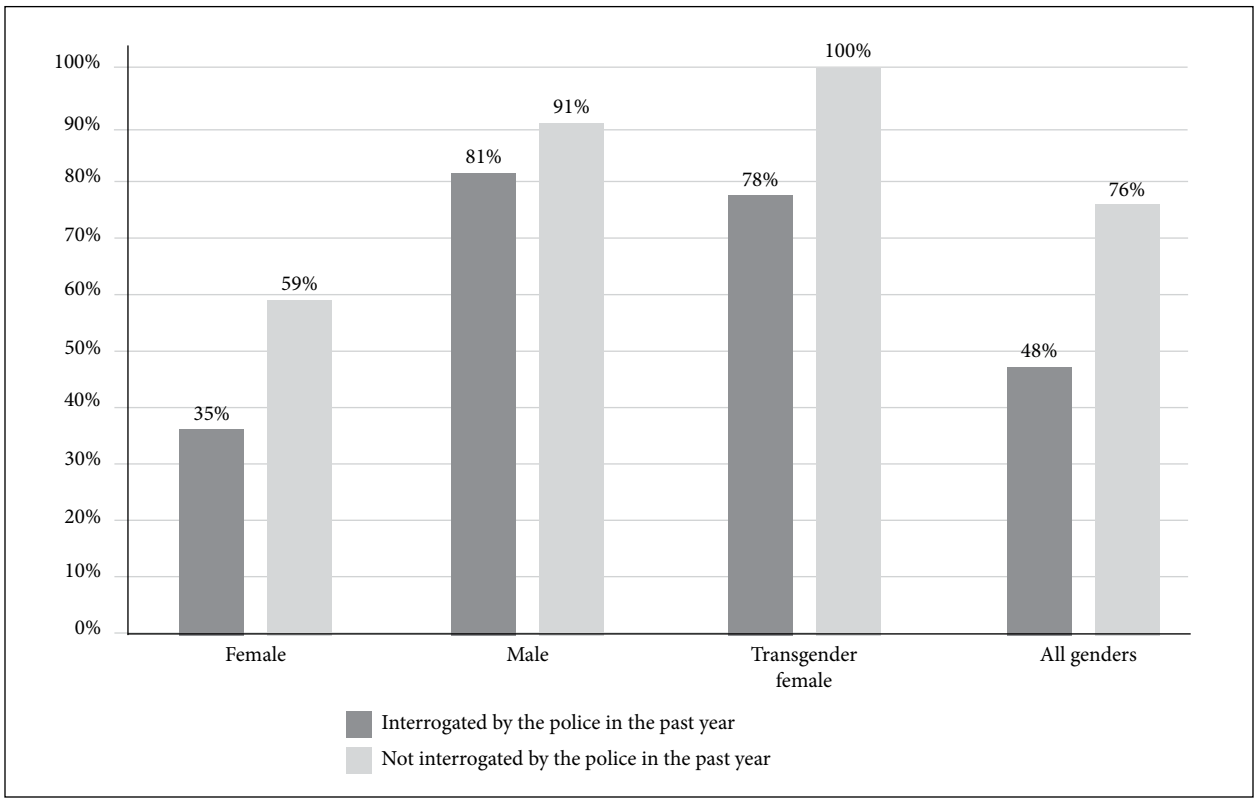
Respondents' experiences also highlighted other ways in which public health policy and police practice are in conflict. Because of law enforcement practices, some managers of sex work venues did not want to display condoms publicly, as required by public health policy, resulting at times in a reduction in the overall availability of condoms in sex work venues. In other words, while condom displays are required at entertainment venues by the health department, if condoms are actually displayed the police will consider the venue to be a "place of prostitution." Many venues react by putting condoms out when the health authorities come, and putting them away when police officers come, according to respondents.

> *The boss doesn't dare to put condoms out in the open and hides them all away. It's a real hassle for us to find them. Every three to five days he distributes them to us a few at a time.*
>
> —A-Hong, a male sex worker

Discussion

This study, conducted in three major Chinese cities, found that coming into contact with the police is a common occurrence for male, female, and transgender sex workers and that these sex workers struggle to protect their safety and health as a result. Condoms, a tool that can protect sex workers from HIV and other sexually transmitted infections, are categorized and targeted as a "tool of offense" in police actions against sex workers.

FIGURE 4. Percentage of sex workers reporting possession of condoms in the previous month



The police search for and confiscate condoms, and possession of condoms is used as leverage to pressure individuals into a confession. This practice has a significant impact on sex workers. Sex workers are more likely to agree to client demands not to use condoms, reduce the numbers of condoms they carry, not carry condoms at all, or try various methods to hide condoms. Entertainment venues are also deterred from publicly displaying condoms in their establishments, despite central government policies advising them to do so. This problem is compounded by the limited communication and coordination between health and police authorities. There is no formal mechanism for police and public health departments to work together on interventions for sex workers. With the government's launch of large-scale crackdowns on sex work in recent years, the police have taken an even harsher approach toward sex workers, decreasing opportunities for the police force's participation in HIV prevention efforts aimed at sex workers.

The crackdowns and other police practices documented in this study constitute violations of sex workers' human rights and have direct negative health impacts. Law enforcement authorities' practice of treating condoms as evidence of sex work has also been documented in other countries, including Kenya, Namibia, Russia, South Africa, the United States, and Zimbabwe.[37] Based on a thorough review of the evidence, the World Health Organization has stated that "the police practice of using possession of condoms as evidence of sex work and grounds for arrest should be eliminated."[38]

A survey conducted by UNFPA focusing on HIV and sexual and reproductive health programs for lower-paid female sex workers in four counties in China from 2011 to 2015 found that the involvement of other government departments (beyond health departments) in efforts to prevent HIV among sex workers has been decreasing.[39] Some 75.8% of health officers reported that they "often worked with other departments" at the beginning of these programs in 2012, but this collaboration dropped to 51.4% by the end of the programs in 2015.[40] The major drop in collaborative work was with the police department, at a time when the police were more focused on cracking down on sex work than on supporting HIV prevention goals, which are meant to be a priority for all departments. UNFPA concluded that this change was one important reason behind the significant decline in the number of sex workers receiving HIV-related health services during this period.[41]

The human rights abuses experienced by sex workers in our study could possibly be addressed if sex workers had functioning organizations of their own. In many parts of the world, collectives and other organizations of sex workers have been crucial for enabling sex workers to collaborate to ensure condom use among all clients in a given location, to stand up to the police, and to have a political voice.[42] In China, nongovernmental organizations (NGOs) operate in a very restrictive environment, although the NGO sector has been growing rapidly in the past decade. For a long time, it was very difficult to officially register as an NGO, so many organizations remain registered as private businesses or unregistered altogether. In recent years, registration requirements have been eased for organizations focusing on service delivery, and the Chinese government has provided increasing financial support to NGOs.[43] Nevertheless, receiving government support usually requires recognition from or close ties with local authorities.

The formation of sex worker organizations, however, has not been encouraged. In its work to address the sexual transmission of HIV, the government has acknowledged the importance of community-based organizations in reaching out to and conducting interventions among sex workers, though most of those interventions are led by health-related organizations rather than sex worker organizations.[44] The number of organizations serving sex workers is minimal in light of the size of China's population, and they are largely not organizations of sex workers themselves. Among 1,309 NGOs documented in the 2015 China HIV NGO Directory, which is published by the China HIV/AIDS Information Network, only 6.2% work with female sex workers, whereas, for example, 22.6% work with MSM and 23% work with people living with HIV.[45]

This greater focus on MSM compared to sex

workers may be partly due to the relatively low and stable HIV prevalence among female sex workers. As noted above, there has been a rapid rise in HIV incidence among MSM in recent years. The resources available for prevention among MSM sex workers, in addition to other MSM, are considerably greater than for other sex workers. In addition, while consenting same-sex behavior is legal, sex work is illegal, and it is potentially riskier for NGOs to work with illegal groups. The illegality of sex work also makes it more difficult for sex workers to organize. By contrast, MSM groups are quite well established, and channels have been created for them to be consulted and involved in the work of health departments. But for sex workers and drug users, such consultation and partnership opportunities have not materialized.[46]

In 2009, with support from UNAIDS China, the China Sex Worker Organization Network Forum was established with the aim to support the development of member groups, improve occupational health for sex workers, and promote sex workers' human rights. The network consisted of 17 organizations, including two in Hong Kong and Taiwan.[47] During its time in operation, the network undertook important work to advocate for the rights of sex workers. For example, in 2011, it conducted qualitative and quantitative research to assess the impact of a massive crackdown on sex work in 2010. But China's restrictive policy environment constrained the network's operation. During a major domestic AIDS conference in 2012, the network was supposed to share the findings of its 2011 research, but its presentation was removed from the agenda because of the sensitiveness of the issue. Due to a lack of funding and human resources, the network suspended operations in 2014, leaving sex workers again without an organizational platform.

With China's rapid economic growth, many international donors that previously funded China's HIV response have withdrawn their support. Those funders, including the Global Fund to Fight AIDS, Tuberculosis and Malaria, previously supported prevention efforts directed at key populations, including sex workers, drug users, and MSM. The withdrawal of this funding has led to the closure of many small community-based organizations. The Chinese government promised to compensate for this gap in funding, and now 98% of the HIV response in China is shouldered by the government.[48] But the funding provided by the Chinese government is generally restricted to service delivery, such as HIV testing, counseling, and treatment, with little support for programs addressing discrimination, human rights violations, and other legal and policy barriers facing by marginalized populations.[49]

In spite of the official focus on service delivery, there is an increasing awareness among the few organizations working with sex workers about the importance of enabling sex workers to understand their rights under the law. Some organizations have started working with lawyers to provide legal training to local sex workers. The United Nations Development Programme has also initiated a program to provide legal support for people living with HIV and at-risk populations.[50] Still, this work is taking place on a very small scale, with few lawyers available to provide legal support and scarce funding to support the programs. And the government's repression of human rights lawyers and activists makes it even more difficult to find lawyers willing to work with a population whose activities are forbidden by law.[51]

China has also increased its control over the operations of international NGOs working in the country. In 2016, the government passed the Law on Management of Domestic Activities of Overseas Non-Governmental Organizations.[52] This law, which took effect in January 2017, requires that any international organization wishing to fund or conduct activities in China first register with or get approval from the Public Security Bureau and also requires the organization to work under the direction of a government agency that acts as its "professional supervisory unit." The new law has led to greater police oversight and stricter financial scrutiny of international NGOs.[53] It is believed that the law's ultimate goal is to restrict Chinese NGOs by cutting off their connections with foreign groups

and funding.[54] This will further constrain the development of sex worker organizations, networks, and coalitions.

Sex workers, together with other "illegal groups," are seen as immoral by many in Chinese society. Their behavior is considered harmful to themselves and society. There is thus some tolerance for police repression of sex workers. However, police actions have sometimes been so extreme as to raise concerns in society for the well-being of sex workers. Besides the massive crackdown on entertainment venues, police have threatened and humiliated sex workers in many other ways. For example, in 2006, in the southern city of Shenzhen, the police sponsored a public "shame parade" of 100 sex workers. The sex workers who were arrested by local police were handcuffed and paraded along the city's main avenue.[55] And in 2010, police in Hangzhou sent letters to the families of women who were detained for engaging in sex work, informing them of the infractions of their family member.[56] Finally, in January 2017, the police in a city in Guizhou Province set up an "exposure board" on the street that publicized photos and information on 10 people who had been detained for engaging in the sale and purchase of sexual services, gambling, and drug use.[57]

Some of these actions caused an outcry among the public, and people even called for respecting the dignity of sex workers. In 2010, the Ministry of Public Security issued a statement calling on the police to respect women, stressing that police officers should not humiliate or discriminate against sex workers during law enforcement actions. It also suggested that sex workers be referred to as "women who lost their way" (失足妇女) instead of "prostitutes."[58] Now the term "prostitute" is seldom used in state media; however, the phrase "women who lost their way" portrays sex workers as persons without agency and without capacity for rational decision making. These sporadic calls for respecting sex workers and this ill-conceived attempt to find more respectful terms ring hollow when police abuse and social marginalization persist.

Waves of crackdowns and other forms of repression and humiliation of illegal groups, including sex workers, have been shown to cause great harm to these populations' human rights and to undermine China's HIV prevention and treatment efforts. China should stop using the repression of sex workers to express a moral judgment of the state. This misuse of state power has a high cost: sex workers fear using testing and treatment services, and police actions prevent the condoms distributed by the government and community-based organizations from being accepted and used. China's experience in dealing with sex workers shows that sex work can never be eliminated, but those who practice it can be driven underground and away from health services, which in turn fuels their risk of contracting HIV and other sexually transmitted infections.

Conclusion and recommendations

The experience of sex workers in this study illustrates that a useful public health policy can be undermined by police action against a socially marginalized group, especially where public health authorities cannot or will not stop harmful police practices. An accountability mechanism for harmful police action is needed. Intersectoral collaboration may be the answer, but it is not easy.

China's HIV response toward sex workers is hampered by the absence of human rights protections, conflicting policies, and a lack of coordination among the various government departments, including the police, that should be doing their part. China should immediately cease the use of possession of condoms as evidence to arrest, question, or detain persons suspected of sex work. Any directives to the police to view condoms in this way should be rescinded. Moreover, HIV strategies at various levels must take note of the effect that law enforcement actions are having on the spread of HIV so that their response does not directly undermine parallel efforts by health departments. With the government's recent launch of large-scale crackdowns on sex work, the police have taken an even harsher approach and attitude toward sex workers, undermining enforcement

authorities' participation in HIV prevention efforts for sex workers and exposing sex workers to HIV risk and human rights abuses.

The Chinese government should also encourage and support partnerships between local governments and NGOs and establish mechanisms for NGOs to be involved in policies and programs targeting sex workers. Resources should also be allocated to support and build sex worker networks that are led and managed by sex workers themselves and that would enable sex workers to participate meaningfully in developing and implementing projects that affect them.

None of this is likely to be possible without decriminalizing sex work-related offenses and removing sex work itself as an infraction under administrative law. A number of other Asian countries have decriminalized at least some aspects of sex work without witnessing the unraveling of social mores.[59] The United Nations Special Rapporteur on the right to health has noted that "[t]he failure of legal recognition of the sex-work sector results in infringements of the right to health, through the failure to provide safe working conditions, and a lack of recourse to legal remedies for occupational health issues."[60] The fact that some of the police's more humiliating and heinous abuses of sex workers have elicited criticism from at least some in Chinese society may be a positive sign for liberalization of the law on sex work in the years to come. In the near term, however, improving coordination between public health and law enforcement authorities in the pursuit of the government's multisectoral HIV strategy—and the pursuit of some level of health-related accountability of police practice—is essential. UNAIDS, the World Health Organization, and other international actors represented in the country should advocate for modifying police practices in order to remove repressive policing as a barrier to sex workers' access to and utilization of HIV services.

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PERSPECTIVE

Associations between Police Harassment and HIV Vulnerabilities among Men Who Have Sex with Men and Transgender Women in Jamaica

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Background

The criminalization of same-sex practices constrains HIV prevention for gay, bisexual, and other men who have sex with men (MSM) and, in part due to the conflation of gender and sexuality, transgender women.[1] Criminalization is a structural driver of HIV that indirectly influences HIV vulnerability through multiple pathways: decreased funding for HIV prevention, treatment, and care programs tailored for MSM and transgender women; increased fear of seeking health care; denial of services due to stigma; social and familial exclusion that may contribute to elevated rates of homelessness; employment and housing discrimination that elevate economic insecurity and increase survival sex work; and a lack of human rights protection that increases exposure to violence from community members and the police.[2] Criminalization may result in enacted stigma, such as overt forms of social exclusion and violence, and perceived stigma, whereby people experience fear and concerns of rejection and negative treatment by others because of actual or perceived sexual or gender minority identity.[3]

There is scant evidence directly linking human rights violations of MSM and transgender women to HIV vulnerabilities in middle-income contexts where same-sex practices are criminalized. MSM in Jamaica have the highest HIV rates in the Caribbean, estimated between 14% and 31%.[4] A recent study of transgender women in Jamaica reported an HIV prevalence of 25% among this group and reported that HIV infection

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was associated with violence.[5] Qualitative studies have highlighted that violence targeting sexually and gender diverse people in Jamaica compromises their human rights and well-being.[6]

The criminalization of same-sex practices in Jamaica dates back to 1864, during British colonial rule, with article 76 of the Offences Against the Person Act, which states that "buggery" (anal intercourse) is punishable by up to 10 years of imprisonment with possible hard labor.[7] Under this provision, MSM and transgender women who are mislabeled as male, a concept known as misgendering, can also receive up to two years of imprisonment with possible hard labor if convicted of "being a male person who is party to the commission of any act of gross indecency with another male person."[8] Advocates suggest that arrest and prosecution are rare; instead, the law is used to justify other human rights violations, such as discrimination in employment, health, and housing, as well as violence.[9] Human rights violations are not easily challenged given that sexual orientation and gender identity are not protected under Jamaica's Charter of Fundamental Rights and Freedoms. A 2014 study by Human Rights Watch interviewed LGBT community members in Jamaica (n=71) and found that more than half had been victims of homophobic or transphobic violence. Over one-third had reported crimes to the police, who took formal statements in eight cases, resulting in only four arrests.[10]

Some studies have begun to describe the impact of the criminalization of same-sex practices and homosexuality and, to a lesser extent, police harassment on HIV vulnerability among MSM and transgender women.[11] A quantitative study conducted by Sonya Arreola et al. among MSM (n=3,340) from 115 countries found that lower levels of access to HIV prevention, testing, and treatment were associated with criminalization based on sexual orientation and gender identity and expression.[12] In Nigeria, Sheree Schwartz et al. found that fear of seeking and avoidance of health care were higher for MSM after the country's implementation of the Same Sex Marriage Prohibition Act.[13] In Jamaica, current or previous incarceration due to being transgender was associated with substantially reduced odds of HIV testing among transgender women.[14] Similarly, ever having been in jail was associated with increased odds of HIV infection among MSM in Jamaica.[15] And in India, transgender women sex workers report experiencing such relentless police harassment that they are often forced to relocate and work in unfamiliar settings, decreasing their choice of clients and safety, which in turn increases their HIV vulnerability.[16]

Utilizing Jamaica as a case study, this essay examines factors associated with police harassment targeting MSM and transgender women. We aim to demonstrate how police harassment in contexts where consensual same-sex sexual relations are criminalized shapes HIV vulnerabilities and operates as a social driver of HIV for MSM and transgender women.

Methodology

We conducted a cross-sectional study with gay, bisexual, and other MSM, as well as transgender women, in Kingston, Ocho Rios, and Montego Bay in 2015 to examine social drivers and protective factors influencing HIV and STI vulnerability among sexual and gender minorities in Jamaica. Participants were recruited using a chain referral sampling method by peer research assistants and hired and trained staff who self-identified as gay, bisexual, or other sexual or gender minorities. All participants completed a tablet-based survey with some overlapping and some unique questions tailored to their experience as MSM or transgender women. Written informed consent was sought at the time of the interview. The Research Ethics Board at the University of Toronto in Canada and the University of the West Indies, Mona Campus, in Kingston, Jamaica, provided approval for the study (Protocol #: 30130-UT; ECP 27, 13/14 UWI). Detailed descriptions of the methods and measures are documented elsewhere.[17]

For this analysis, the main outcome "ever experiencing police harassment" was measured by asking, "How often have you been harassed by police for being gay or bisexual (for gay, bisexual and MSM) or for being trans (for transgender women),"

dichotomized as "never" and "ever" (for those who reported sometimes, many times, or always).

Individual- and historical-level factors measured included age (continuous, years), education (less than high school versus high school or higher), monthly income (continuous, USD), HIV status (positive versus negative), and depression (continuous, measured using the Patient Health Questionnaire-2).[18]

Interpersonal level factors measured included social support (continuous, measured using a brief social support sub-scale to assess unmet social support needs), consistent condom use (dichotomous, yes versus no; participants were coded as practicing "consistent condom use" if there was parity in the number of times participants reported having sex and using condoms), relationship status (categorical: in relationships/casual dating, no partner, concurrent partners), safer sex self-efficacy (continuous, using a scale for negotiating safer sex), and physical violence (dichotomous, ever versus never).

Structural and environmental factors measured included any sex work in the past 12 months, food insecurity (dichotomous, yes versus no; participants were coded as "food insecure" if they reported at least one occurrence of going to bed hungry in a week), unstable housing (dichotomous, yes versus no; participants were coded as having unstable housing if they usually slept outside, in a shelter, or at a friend's or relative's house), personal experiences of perceived sexual stigma (continuous, five-item scale measuring awareness of negative social and community norms about MSM; for example, "How often have you heard that gay or bisexual men are not normal?"; Cronbach's alpha = 0.73; range 7–35), personal experiences of enacted sexual stigma (continuous, seven-item scale measuring acts of discrimination, violence, and mistreatment based on sexual orientation; for example, "How often have you been hit or beaten up for being gay or bisexual?"; Cronbach's alpha = 0.88; range 7–49); personal experiences of perceived transgender stigma (continuous, five-item scale measuring awareness of negative social and community norms about transgender persons; for example, "How often have you heard that transgender people are not normal?"; Cronbach's alpha = 0.77; range 7–28), and personal experiences of enacted transgender stigma (continuous, seven-item scale measuring acts of discrimination, violence, and mistreatment based on transgender identity, for example, "How often have you been hit or beaten up for being transgender?"; Cronbach's alpha = 0.61; range 5–20). We also assessed whether participants had experienced any barriers to health care access (dichotomous, yes versus no) and had regular access to a health care provider (dichotomous, yes versus no), and we measured participants' empowerment scores (continuous, measured using the Growth and Empowerment Measure).[19]

We used quantitative analysis methods—specifically logistic regression—to estimate the unadjusted and adjusted odds ratios (ORs) and 95% confidence intervals (CIs) for the odds of ever experiencing police harassment among (1) MSM and (2) transgender women. Variables that were statistically significant, indicated with a p-value of <0.05, or theoretically important in determining HIV vulnerability were considered for inclusion in the full multivariable model. A manual backward stepwise approach was used, whereby variables with lower strength of association were systematically removed from the model so that the final model included only those variables most significantly associated with ever experiencing police harassment. Tables 2 and 3 show two-sided p-values and unadjusted and adjusted odds ratios with 95% confidence intervals for those factors significantly associated with the outcome for MSM and transgender women, respectively. All statistical analyses were conducted using SAS software version 9.3 (SAS Institute, Cary, NC, USA) or SPSS version 24 (SPSS, Chicago, USA).

Study results

Participant characteristics (Table 1)

This sample of young MSM (n=556; median age 24, IQR: 22–28) and transgender women (n=137; median age 24, IQR: 15–44) was characterized by extreme economic insecurity, poor health, and high rates of police harassment. Specifically, almost half of MSM and over half of transgender women reported food insecurity, and one-third and one-

TABLE 1. Participant characteristics

Characteristic	MSM		Transgender women	
	n=556	Missing	n=137	Missing
Age, years (median, IQR)	24 (22–28)	14	24 (15–44)	7
Has at least a high school diploma (n, %)	478 (86.0)		109 (80.7)	2
Monthly income in USD (median, IQR)	144 (10–280)	20	123.45 (0–2469)	23
Is HIV positive (n, %)	67 (13.5)	58	26 (25.24)	34
Relationship status (n, %)		2		1
Is in a relationship or casually dating	383 (69.1)		79 (58.1)	
Does not have a partner	133 (24.9)		31 (22.8)	
Is in concurrent partnerships	33 (6.0)		26 (19.1)	
Has experienced physical violence (n, %)	338 (61.3)	5	62 (45.93)	1
Has undertaken sex work in past 12 months (n, %)	182 (32.7)		71 (51.82)	
Is food insecure (n, %)	266 (47.9)	1	82 (59.9)	
Has unstable housing conditions (n, %)	175 (32.8)	23	71 (51.8)	3
Does not have access to a regular health care provider (n, %)	235 (42.3)		95 (69.34)	
Has experienced police harassment due to sexual orientation or gender identity (n, %)	124 (22.3)		60 (43.8)	
Has been incarcerated seemingly as a result of transgender identity (n, %)				10
1 to 3 times	-	-	15 (11.8)	
4 to 6 times	-	-	6 (4.4)	

TABLE 2. Bivariable and multivariable analyses of factors associated with police harassment among men who have sex with men in Jamaica (n=556)

Characteristic	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Individual-level factors		
Education, less than high school	2.73 (1.64, 4.53)**	
Monthly income	0.89 (0.80, 0.99)^+*	
HIV positive	1.96 (1.12, 3.44)*	1.85 (1.01, 3.38)*
Sex work in the last 12 months	4.05 (2.67, 6.15)***	2.47 (1.54, 3.96)**
Interpersonal-level factors		
Relationship status		
Concurrent partnerships (versus in a relationship)	5.68 (2.68, 12.04)***	
Social support score^	1.06 (1.03, 1.09)^**	
Consistent condom use	1.74 (1.06, 2.87)*	
Safer sex self-efficacy score^	0.90 (0.83, 0.97)^**	
Structural- and environmental-level factors		
Food insecurity	3.47 (2.25, 5.35)***	2.44 (1.51, 3.94)**
Unstable housing	2.23 (1.46, 3.40)**	
Currently unemployed	1.85 (1.21, 2.85)**	
Perceived sexual stigma score^	1.33 (1.24, 1.44)^***	
Enacted sexual stigma score^	1.54 (1.42, 1.66)^***	
Empowerment score^	0.95 (0.93, 0.98)^**	
Experienced 1 or more barriers to health care access	1.76 (1.17, 2.64)**	
Does not have a regular health care provider	1.99 (1.30, 3.05)**	1.66 (1.02, 2.71)*

^ per 1-unit increase
+ per 100 USD increase
*p<0.05; **p<0.001; ***p<0.0001

half of MSM and transgender women reported unstable housing, respectively. While 13.5% of MSM were HIV positive, over one-quarter of transgender women were HIV positive. One-fifth (n=124, 22.3%) of MSM reported having experienced police harassment due to their sexual orientation, and 60 (43.8%) transgender women reported having experienced police harassment due to their gender identity. Among transgender women, 11.8% reported being incarcerated one to three times, and 4.4% reported being incarcerated four to six times, due to being transgender.

Factors associated with police harassment among men who have sex with men in Jamaica (Table 2)

In unadjusted bivariable analyses with MSM, having less than a high school education, being HIV positive, reporting any sex work in the past 12 months, being in a concurrent partnership versus in a relationship, having a higher need for social support, having consistent condom use, experiencing food insecurity, having unstable housing, being currently unemployed, experiencing perceived and enacted sexual stigma, experiencing one or more barriers to health care access, and not having a regular health care provider were all associated with increased odds of experiencing police harassment due to one's sexual orientation. A higher monthly income, higher safer sex self-efficacy, and higher empowerment were associated with lower odds of experiencing police harassment. In the final multivariable model, the adjusted odds of experiencing police harassment were higher for those who were HIV positive (adjusted OR: 1.85, 95% CI: 1.01, 3.38), who reported undertaking sex work in the past 12 months (adjusted OR: 2.47, 95% CI: 1.54, 3.96), who were food insecure (adjusted OR: 2.44, 95% CI: 1.51, 3.94), and who did not have a regular health care provider (adjusted OR: 1.66, 95% CI: 1.02, 2.71).

Factors associated with police harassment among transgender women in Jamaica (Table 3)

In unadjusted bivariable analyses with transgender participants, the factors of depression, HIV-positive serostatus, any sex work in the last 12 months, a higher need for social support, ever experiencing physical abuse, food insecurity, unstable housing, and perceived or enacted transgender stigma were all associated with increased odds of experiencing police harassment due to one's transgender identity. In the final multivariable model, the adjusted odds of experiencing police harassment were higher for those who were HIV positive (adjusted OR: 3.11, 95%

TABLE 3. Bivariable and multivariable analyses of factors associated with police harassment among transgender women in Jamaica (n=137)

Characteristic	Unadjusted OR (95% CI)	Adjusted OR (95% CI)a
Individual-level factors		
Depression	1.23 (1.01, 1.50)*	
HIV positive	2.44 (1.01, 5.86)*	3.11 (1.06, 9.12)*
Sex work in the last 12 months	2.61 (1.30, 5.25)**	
Interpersonal-level factors		
Social support score^	1.09 (1.03, 1.15)**	
Physical abuse	2.24 (1.12, 4.48)*	
Structural- and environmental-level factors		
Food insecurity	2.47 (1.20, 5.05)*	
Unstable housing	2.30 (1.14, 4.64)*	
Perceived transgender stigma score^	1.19 (1.06, 1.33)**	
Enacted transgender stigma score^	1.46 (1.28, 1.66)***	1.32 (1.15, 1.52)***

^ per 1-unit increase
*p<0.05; **p<0.001; ***p<0.0001
[a] Controlling for education and income

CI: 1.06, 9.12) and reported higher levels of enacted transgender stigma (adjusted OR: 1.68, 95% CI: 1.26, 2.07, per one unit increase in enacted transgender stigma score).

Implications

Our study highlights widespread police harassment among MSM (22%) and transgender women (43%), an indicator of human rights violations. In contexts where consensual same-sex sexual relationships and practices are criminalized, it is likely that MSM and transgender women have little to no recourse to justice when police are perpetrating violence. In multivariable analyses, we found clear linkages between police harassment and HIV vulnerabilities: HIV-positive MSM and transgender women were more likely to report police harassment than HIV-negative peers. While this comparison has not been documented elsewhere, among MSM HIV-prevention outreach workers in India, 85% reported harassment by the police, suggesting the potential targeting of MSM due to their association with HIV or HIV-related work.[20]

Among MSM participants, those who were engaged in sex work, were food insecure, and lacked a health care provider were more likely to report police harassment; and among transgender women, police harassment was associated with enacted transgender stigma. This evidence points to the need for an intersectional approach to understanding the impacts of police harassment among MSM and transgender women who experience marginalization on the basis of multiple, intersecting identities and experiences: sex work, poverty, and transgender stigma.[21] Studies on sex workers globally have highlighted the negative impacts of sex work criminalization on their human rights, well-being, and access to HIV prevention tools.[22] According to Kate Shannon et al., the decriminalization of sex work would avert 33% to 46% of HIV infections in the next decade and would increase access to health care and respect for human rights.[23] Similarly, it is suggested that behavioral interventions to mitigate HIV vulnerability for transgender women sex workers be coupled with structural changes (for example, economic and community empowerment, the provision of culturally competent health services, and a protective legal and social environment that upholds their human rights).[24]

Our study's limitations include a cross-sectional design that precludes understanding of causality, self-reporting measures that are subject to recall and social desirability bias, and the use of only one measure of police harassment. Our study would have been further strengthened by asking MSM about their incarceration history. Despite these limitations, our analyses provide quantitative evidence for HIV vulnerabilities associated with police harassment in Jamaica among key populations: MSM and transgender women. The negative effects of criminalization and subsequent police violence compromise efforts to reduce HIV transmission among key populations and reduce the likelihood of reaching goals of engaging people living with HIV in Jamaica in the HIV care cascade. Future studies could use a longitudinal design to better understand the directionality of the relationships between police violence and HIV infection, to identify potential mediators, and to answer key questions. For instance, does police harassment contribute to reduced access to health care and HIV prevention services, and in turn increase vulnerability to HIV acquisition among MSM and transgender women in Jamaica? Are HIV infection and police violence both associated with a third variable (such as community-level stigma or poverty)? Future research could further explore the complexity of the relationships between police harassment and HIV vulnerabilities among these key populations in Jamaica and elsewhere.

Police harassment among HIV-positive MSM and transgender women in Jamaica has clear implications for the protection of human rights in order to ensure access to the HIV care cascade. There has been a call to action to increase research on effective strategies for collaboratively engaging the police in addressing discrimination, stigma, and HIV risk.[25] These programs may involve components such as trainings that integrate information on the importance of police engagement in HIV prevention efforts and police collaboration with affected com-

munities on human rights and harm reduction; peer advocacy and education; and, strategies that bring the police together with communities in non-conflict settings.[26] However, as Andrew Scheibe et al. suggest in their study describing attempts to implement interventions to improve the relationship between the police and key populations in South Africa, without buy-in from the police or society more broadly, such interventions remain small in scale or unimplemented altogether.[27] Future interventions in Jamaica may include joint discussions between the police and communities and the development of shared language that seeks to shift negative interactions between the police and key populations.[28] Interventions that address stigmatizing social attitudes, legal protections to increase access to health and social services, and strategies to strengthen relationships between the police and MSM and transgender women may help reduce HIV vulnerabilities and promote human rights for MSM and transgender women in Jamaica.

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In Women's Eyes: Key Barriers to Women's Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being

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Abstract

There is rightly a huge global effort to enable women living with HIV to have long productive lives, through treatment access. However, many women living with HIV experience violence against women (VAW), in both domestic and health care settings. The ways in which VAW might prevent treatment access and adherence for women has not to date been reviewed coherently at the global level, from

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women's own perspectives. Meanwhile, funding for global health care, including HIV treatment, is shrinking. To optimize women's health and know how best to optimize facilitators and minimize barriers to access and adherence, especially in this shrinking funding context, we need to understand more about these issues from women's own perspectives. In response, we conducted a three-phase review: (1) a literature review (phase one); (2) focus group discussions and interviews with nearly 200 women living with HIV from 17 countries (phase two); and (3) three country case studies (phase three). The results presented here are based predominantly on women's own experiences and are coherent across all three phases. Recommendations are proposed regarding laws, policies, and programs which are rights-based, gendered, and embrace diversity, to maximize women's voluntary, informed, confidential, and safe access to and adherence to medication, and optimize their long-term sexual and reproductive health.

Introductory overview

Since 2016, the World Health Organization (WHO) has recommended life-long anti-retroviral therapy (ART) for all people with HIV, from their diagnosis date, regardless of CD4 count or clinical stage.[1] Efforts are needed for ensuring that all people living with HIV have access to life-saving medication that can turn HIV into a manageable chronic condition. ART is central to the Sustainable Development Goal (SDG) of ending AIDS by 2030 and to UNAIDS' "90-90-90" targets aimed at ensuring that, by 2020, 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV will access treatment; and 90% of all people receiving ART will achieve viral suppression.[2]

Meanwhile, women living with HIV continue to face widespread violence, both at home and in health care settings after their diagnosis.[3] Policy makers are increasingly aware that this violence may act as a barrier to treatment access and adherence.[4] To date, however, there has been scant formal evidence, from women's own perspectives, regarding if and how this violence affects women's ability to start and continue with treatment.[5]

Further, funding for HIV, and global health, is shrinking.[6] While there is continued focus on strategic investments in biomedical approaches, psychosocial programs and complementary community initiatives remain under-resourced.[7]

Thus, to maximize women's health in this highly constrained funding context, it would be beneficial for policy and program makers to understand more about facilitators and barriers to treatment access and adherence, for women living with HIV, *from women's own perspectives*. Indeed, as this review reveals, the very manner in which women are tested for HIV and start ART can be a barrier, if based on compulsion, instead of informed *choice* as a fundamental principle of human rights.[8]

We describe a global review of HIV treatment access which has explored facilitators and barriers, through the normative framework of the human right to health, as established by relevant United Nations treaties and commitments relating to women, the Committee on the Elimination of Discrimination Against Women (CEDAW Committee), the Global Commission on HIV and the Law, and the recent WHO woman-centered guideline on the sexual and reproductive health and human rights (SRHR) of women living with HIV.[9] ATHENA, AVAC, and Salamander Trust—three civil society organizations—undertook this review effort in three phases: a qualitative and quantitative literature review (phase one); focus group discussions and one to one interviews (phase two); and three country case studies (phase three). The review was commissioned and funded by UN Women.

This is the first peer-led global study to date that looks at HIV care and treatment access for women living with HIV.

Method

The review methodology was led and governed by women living with HIV, based on a relationship of trust between the review organizers and those women living with HIV who agreed to take part in the review.[10] Our approach recognizes that women living with HIV are best positioned to frame and prioritize the topics that need interrogation, to best understand facilitators and barriers to treatment access. Few HIV treatment access analyses exist where women living with HIV are central to design and implementation. A Global Reference Group (GRG) of 14 women living with HIV—representing 11 countries and a range of diverse identities and experiences—guided the project throughout all phases.

Phase one, the literature review, is an extensive and exhaustive review of all the qualitative evidence regarding facilitators and barriers in relation to ART access and adherence. A quantitative review then addressed women's access to HIV treatment, with an unprecedented analysis of all available sex-disaggregated data from PEPFAR (United States President's Emergency Plan for AIDS Relief), the Global Fund for AIDS, Tuberculosis and Malaria, UNAIDS, and other sources.[11] In phase two, community dialogues via focus group discussions (FGDs) were conducted with 175 women in Bolivia, Cameroon, Nepal, and Tunisia; together with consultations with all 14 GRG members; nine one-on-one interviews; and an online listserv discussion. In total, 197 individual women were consulted in this phase. In phase three, country case studies were undertaken in Kenya, Uganda, and Zimbabwe, and included in-depth focus groups, one-to-one interviews, country-level policy analyses, and an additional literature review to provide a fuller picture of women's access in specific contexts. Younger and older women were purposively sampled.

The whole process was guided by the Ethical Guidelines of the International Community of Women Living with HIV (ICW) for conducting research with women living with HIV, and WHO guidelines on research with women who have experienced violence.[12]

The participants described a wide range of barriers, including many, such as transport costs, child care issues, travel permissions and limited time, which are common to most women seeking health care. However, some of these key barriers were exacerbated by HIV and other barriers, specific to women living with HIV were also described. This paper addresses these barriers—and facilitators—that are specific to women living with HIV.

The dialogues, although relatively small in scope, explicitly report the perspectives of women living with HIV. The review's primary limitation was that it was designed as a snapshot with a modest budget: the findings could thus be limited in their generalizability. Nonetheless, there was marked similarity in the respondents' experiences across phases two and three. These also resonated with the studies led by women living with HIV, which were included in the literature review. This 'convergence of evidence' across continents and between the varied formats indicates widespread uniformity in the reported findings.[13]

In this paper, we analyze the phase two findings employing Gender at Work's change matrix, also used in the new ALIV[H]E Framework document (Figure 1).[14] This change matrix amplifies the normative framework offered by the socio-ecologic model, by providing a second analytical axis representing informal through formal life spheres.[15]

Findings

All three review phases reflected clear similarities in findings with uneven progress in women's HIV treatment access and adherence. There have been improvements in women's access to ART and treatment program scale-up, but women face complex experiences in both accessing and continuing to take treatment. In particular, violence from family, community members, and health care professionals act as barriers to accessing ART.

Findings from the treatment access literature

Our qualitative and quantitative literature review shows that HIV treatment is being scaled up as a global policy; that women's treatment access worldwide is higher than that of men, partially due to ARV provisions for pregnant women; and that women increasingly access treatment over much longer timeframes.[17] Formal research has primarily focused on the number of people receiving treatment rather than on the quality of their care or retention, and on treatment initiation alone, rather than on adherence.

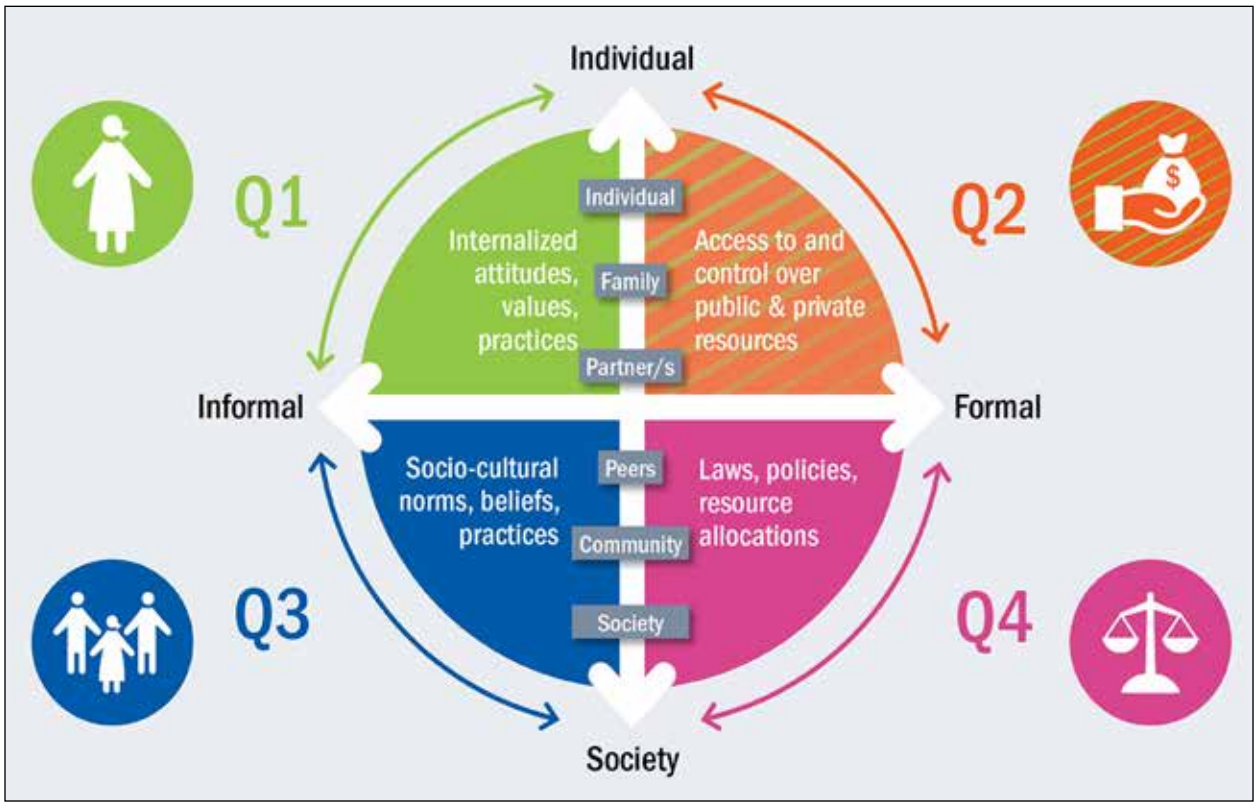
The precursor of the 2016 universal 'test and treat' guidelines was Option B+, which involved pregnant women living with HIV starting on treatment for life straight after diagnosis. Literature regarding Option B+ rollout in several countries is useful in ascertaining likely universal 'test and treat' treatment access patterns for women. While high numbers of women *initiating* Option B+ are reported, there have been high levels of 'loss to follow up' (retention in care), resulting in lower adherence rates.

Beyond pregnant women, treatment access and adherence research has limited sex-disaggregated data.

There is further confirmation that women from key populations continue to face particular barriers in accessing and benefiting from treatment. Meanwhile, the formal treatment literature lacks a focus on women living with HIV who are also members of key populations or at higher risk of acquiring HIV, such as women who inject drugs, women partners of men who have sex with men (MSM), displaced and migrant women, and girls and young women. Scant data exist from fragile and conflict-affected states.

Finally, formal quantitative evidence has, to date, placed limited focus on human rights violations, gender inequality, and discrimination in care: issues which may be acting as access barriers. Such major data gaps hamper current policy makers' awareness and understanding of, and ability to respond to, women's treatment access barriers.

FIGURE 1. Gender at Work's change matrix[16]



By contrast, some formal qualitative research and much grey literature strongly indicate that gender inequality, related to cultural, economic, and human rights issues, poses considerable barriers to women's choices regarding access and adherence to HIV care and treatment services. Women's decision-making on disclosure is shown to be significantly influenced by gender-based violence, including the fear of negative reactions, abandonment, and abuse. This can, in turn, limit their ability to access care and to both start and adhere to treatment. Many women may have lower retention rates over the long term than men.

The grey literature especially indicates that challenges to women of overcoming barriers at the household, family, and community levels are exacerbated by the discriminatory attitudes of health care staff and weak health systems, including poor treatment supplies, a lack of counseling, and long wait times. Negative health impacts such as side effects and having to take ART with food challenge women with HIV and inhibit the decision to access care and maintain treatment. Crucially, policy makers still lack understanding regarding women's own perspectives on what would help their sustained healthy prognosis.

Findings from community dialogues, consultations, and interviews with women

Barriers. Using the change matrix, we analyzed the phase two findings as follows, on the basis of four quadrants. Quadrant 1 is related to the individual and informal spheres; quadrant 2 refers to the individual and formal spheres; quadrant 3 addresses social-cultural norms, beliefs, and practices; and quadrant 4 relates to the formal, societal spheres.

Quadrant 1. This quadrant relates to the individual and informal spheres. It concerns individual women's values, attitudes, and practices. Women described experiencing internalized stigma due to their HIV status, resulting in depression, low self-esteem, and other mental health problems. These issues can also have an impact on their health-seeking behaviors, including HIV treatment access and adherence.[18]

Fear and experiences of violence led to HIV status non-disclosure, which respondents linked to higher anxiety rates, missing services, and lower adherence. Lack of privacy was also cited, with no safe space at home or work to take medications.

> *In this case, the woman goes to hospital secretly, if not she will miss the appointment if she can't justify the reason to go out the day that she is supposed to collect medicine.* (FGD, Cameroon)

HIV treatment side effects were also consistently cited as a barrier to long-term adherence. Side effects take various forms.[19] Some, especially body shape changes, had psychological repercussions, particularly around gendered norms regarding women's perceptions of their bodies and sexuality. One participant described how she no longer feels sexually attractive to her husband due to the ART side effects:

> *What affected me most is that I do not feel attractive to my husband. He does not say anything, but that is how I feel and that is why I get depressed.* (FGD, Bolivia)

Quadrant 2. This quadrant relates to the individual and formal spheres. It concerns access and control over public and private resources. Respondents referred to many financial and structural challenges in private and at institutional levels. First, we look at basic resource needs.

All FGD participants struggled to meet their basic needs due to poverty, including food security, nutrition, housing, school fees, and transport. While these are problems for many women, each served as a treatment access and adherence barrier for the respondents when coupled with their HIV status.

Regarding food security and nutrition, women reported prioritizing feeding children over themselves, making it difficult for women to access the healthy diets they need to take treatment effectively.

Some women lost their housing, post-diagnosis:

> *After the death of my husband started my journey with the suffering when his family repudiated me and my children, and they attacked and beat us then we were fired from the house. We are now living in*

> *the street homeless, depending on the righteousness and charity of some people and sometimes we lodge in the open without food or clothing.* (FGD, Tunisia)

Women's unequal power relationship is also reflected in lack of authority, affecting access to and control of resources, that would allow them to move freely. Participants also raised challenges in getting to the clinic due to high transport costs and distances. While ART is normally free, the associated services such as blood tests or transport are often not. This was another barrier, both to initial access and to continued adherence for many women, particularly those living in rural areas.

Once at the clinic, violence in health care settings, coupled with fear of violence, were also frequently cited as barriers for treatment access and adherence. We describe the institutional level violence here as "structural violence."[20] General human rights abuses, including violations of rights to privacy, confidentiality, and bodily integrity, were frequently cited, especially by Tunisian and Bolivian participants. These included health care providers disclosing female clients' HIV status to family members, other staff, and other clients; and refusing them and their children treatment. Additionally, violations of the rights to health and to protection from gender-based discrimination were experienced during and after labor and delivery, as well as through forced and coerced sterilization.

> *When I was pregnant, I went from hospital to hospital for fear of talking about my diagnosis. When my waters broke in the Dutch Hospital, I wet everything, I was 21 years old (cries), the nurse scolded me, they did not want to clean it up, they told me to clean it up, how could I clean it if I was sick? I was trembling with cold. They did not take care of my son. "You have to clean it," they said. I was in pain, but they didn't even give me a bed.* (FGD, Bolivia)

> *I feel bad for the pregnant women, they are young but already they have had their tubes tied, the doctors insist on tubal ligation sterilization when they do their caesareans, really they tell you "do not have children." It shouldn't be like that. Their duty is serving us.* (FGD, Bolivia)

Women also reported poor health care communications. This included limited time with, or effort by, health care providers to address women's concerns, or to deliver full information. They cited lack of or insufficient information regarding benefits and complications of treatment, what to take and when, or any information about drug interactions. These were reported as frequently ignored or dismissed by health care staff. Women cited lack of counseling, being unable to ask questions, side effects not being discussed, and being pressured to make quick decisions without adequate information. One woman living with HIV stated about her health care providers:

> *They ignore counseling about treatment.* (FGD, Nepal)

Women from marginalized groups especially (including women engaged in sex work, transgender women, women who inject drugs) or women partners of men who are at increased HIV risk, reported high levels of stigma and discrimination in health care settings and the community, that violated their rights to health and to protection from gender-based discrimination, and impeded their treatment access.

Lastly, workplace-based structural violence was also discussed. Participants frequently raised work termination, or being refused employment because of their HIV status, as a key barrier to treatment access and adherence. There are two distinct but closely connected issues here. Firstly, respondents described labor rights abuses (termination due to HIV status, being refused employment due to HIV status); secondly, because women are frequently employed in informal or unregulated sectors, including sex work, they lack employment rights and protections, including health insurance, often linked to employment.

Seeking treatment can also result in workplace colleagues finding out about one's status, and being

sacked, which can damage economic security and the capacity to care for one's health.

More, this can lead to women experiencing discrimination and harassment (also described as "psychological violence") in the workplace without recourse, reflected by this Uganda sex worker experience: "When a client comes, they will shout out 'she is HIV positive! Don't take her, take me.'"[21] Such experiences create a barrier for sex workers who prefer not to risk being seen accessing HIV services, or carrying ART, for fear of raising suspicion among their colleagues regarding their HIV status.

Quadrant 3. This quadrant relates to the societal and informal spheres. It concerns socio-cultural norms, beliefs, and practices. Respondents throughout repeatedly described their experiences with violence. This included physical, sexual, and psychological/emotional violence at the intimate partner, family/community, and institutional levels.[22] Violence, both in the home and at work, coupled with fear of violence, were the most commonly cited barrier for women. While some violence was no doubt already present for women before their HIV diagnosis, it is clear from here as well as from other research that intimate partner violence (IPV) can both start and worsen upon diagnosis.[23]

> *I am living with HIV AIDS since 2005 and I have knew (sic) about my infection when I gave birth to my daughter and from that date began my journey with agony, pain, and oppression of my husband, who started threatening me to reveal the story of my infection to the neighbors.*

> *I am living with HIV/AIDS since 2004 and I was infected by my husband, he made my life with him a living hell every day I live in a state of terror and fear because of beatings and various kinds of insults and verbal abuse.* (FGD, Tunisia)

Women living with HIV from key affected populations reported additional marginalization and violence in the community.

> *Stigma is on 2 levels in the family. Often we do not take care of you for what you are, sex workers. Worse yet, you are HIV positive…* (FGD, Cameroon)

A US-based transgender woman described how fear of violence acts as a strong and immediate disincentive to accessing care and treatment:

> *If just simply leaving the house increases the chance of being assaulted or being killed vs. not taking medication and starting later, which one do you think they would choose?*

Through HIV-related violence at home or in the community, it is either physically or psychologically difficult for women to care for themselves by accessing treatment.

Conventional gender roles and responsibilities and resultant power inequalities also include women having to ask partners/husbands' or other relatives permission to do many things. Fear of rousing suspicion or disclosure of HIV status is also a related treatment access barrier and a manifestation of violence. Women reported how fear of home-based violence can lead to missing appointments or treatment:

> *I have to ask permission from my mother in law... She always used to say that I am going to die because of my status so no need to go. So most of time it was really hard to go [to the] hospital.* (FGD, Nepal)

Respondents cited gender-based caregiving responsibilities as another treatment barrier.

Quadrant 4. This quadrant relates to the formal, societal spheres. It concerns laws, policies, and resource allocations. Participants also raised many issues relating to this quadrant.

> *The legal environment in Uganda has created lots of fears. Already, people who were strong and accessing medication, they are now hiding away because of the fear of being seen and known to be HIV positive now that you can be criminalized for HIV transmission.* (Interview, Uganda)

Punitive laws, including criminalization of HIV non-disclosure, of exposure, or of transmission,

exacerbate structural and community violence against women living with HIV and/or from key affected populations.[24] This then acts as a barrier to accessing or staying on treatment, as described in Uganda.

Legal status can also be a barrier to access and adherence for women who are migrant workers, seeking asylum, or who have moved to a country for other reasons, since migrants may be charged for services or incarcerated.[25]

Concerns were also raised about patient rights in the context of the implementation of national treatment policies. For example, Option B+ was not in fact offering an informed choice to women. Instead it was designed for health ministries to choose between Options A, B, or B+. There have also been concerns from physicians about the ethics of the Option B+ policy and, more recently, ART policy for pregnant women.[26]

> *I was really in favour of early treatment and to have this Option B+. But now my worry is: are we being given this as an option or is this being pushed on us with no option?* (Interview, Zimbabwe)

Resilience, agency, and positive strategies

Despite the treatment barriers, women also shared positive strategies, highlighting areas of resilience and agency.

Quadrant 1. Some women described three factors that provided strength, value and motivation to maintain their health post-diagnosis. These were: the ability to plan for or have children (especially in a supportive environment); their positions within families as mothers, partners and caregivers; and their roles as leaders within their communities.

Quadrant 2. Women named building trusting relationships with health care providers as important to treatment adherence.

Relating to quadrants one, two and three above, women in all discussions perceived that treatment access has improved over the last decade, for themselves and others around them, including access for women in marginalized contexts. They identified tailored women-specific treatment literacy as key to: becoming an informed advocate for one's own health; overcoming power dynamics and gender roles between patients and providers; and mobilizing communities for expanded treatment access.

Quadrant 3. Key among these was the reported importance of contact with other women living with HIV, through peer-led treatment literacy and support groups, networks, or other peer support services. Women described how their involvement in these groups was directly linked to accessing and remaining on ART over time. Supportive friends and family were also cited as important facilitators.

Quadrant 4. Participants did not identify any facilitators specifically related to this quadrant (laws, policies and resource allocations.) This perhaps unsurprising observation echoes a systematic review which observed: "the language of rights is used most often to describe their apparent neglect or violation rather than their promotion or inclusion in programming or services".[27]

Discussion of key findings

Given the existing literature on why patients in general decide whether or not to adhere to medication, and the importance of provider/client interactions to successful adherence, there is surprisingly little formal research exploring women's own perspectives of their voluntary choices around medical therapy initiation, continuation and adherence/retention, and the related barriers they face.[28]

By contrast, the women's discussions presented here dispel the dominant premise in the biomedical HIV treatment literature that women's treatment access is a straightforward process. This assumption describes women who do not access treatment immediately, and adhere to it, as 'lost to follow-up,' itself a loaded phrase. At best, there are calls for renewed efforts at community linkages to get women onto treatment, with no discussion about women's voluntary choices around if, why, or how women might be avoiding treatment.[29] At worst, women are subject to veiled or more open

criticism for 'failing' to take up or adhere to treatment, with no exploration of why this may be so.

Thus, there is an unspoken—and often unrecognized—dissonance between what most of the formal HIV literature is assuming, with global promotion of '90-90-90' and 'fast-track,' and what barriers women actually face. This is of particular concern, not only regarding women's rights but also in light of increasing concern about potential development of drug-resistant HIV strains, through limited adherence.[30] If violence is affecting treatment, which in turn increases drug resistance, it is additionally critical to address women's experiences of violence.

It is thus vital to interrogate rigorously the socio-cultural and economic barriers to all women—both pregnant and non-pregnant—and especially to marginalized women. Then we may develop global policies that enable long-term, positive physical, psychological, and sexual health outcomes.

Treatment access barriers facing women in fragile and conflict situations are also severely under-researched. Ending AIDS involves listening to all women's experiences and translating this knowledge into solutions that leave no woman behind.

The nature of what constitutes the 'evidence base' also needs to change. Updating measures for treatment access and adherence to fill the data gaps are one key part of assessing effectiveness in reaching women with services and the impact of service provision at an individual and population level.[31] Recent research on evaluations of violence against women also confirms the importance of community-based participatory research to understand community perspectives, to build strong sustainable, rights-based policies and programs.[32] The new ALIV[H]E Framework (see Figure 1), also describes how the evidence base can be expanded, through holistic approaches to formal and participatory, quantitative, and qualitative research. This will ensure rights-based, peer-reviewed literature focused on women's expertise through their lived experiences. Harnessing the power and leadership of peer-led and -governed analyses of treatment access, such as this review, as part of a participatory research, implementation, and evaluation framework, can reveal invaluable new insights into what works for women.

The review further shows that while the 2016 Guidelines mean that women should increasingly take treatment over much longer timeframes, treatment access literature to date has focused on the numbers of people with HIV initiating treatment rather than on the quality of their care or length of retention in care.

We have seen how funding is shrinking, and yet HIV acquisition continues in many settings to outpace treatment availability or retention. To make best use of available funds, we need to maximize understanding of how to support women living with HIV, in all their diversities, in their voluntary choices regarding whether or not to initiate, continue, and adhere to treatment. This review has moved beyond the current bio-medical paradigm, to address this challenge through women's eyes.

This review maintains that the foundation of an enabling environment and the pursuit of solutions are found in women's insights and resilience. Women living with HIV know what has helped to improve or maintain their physical and/or mental health and wellbeing. The review has identified both gaps and sources of resilience, depth of knowledge, concrete, actionable recommendations, and a clear vision of what a rights-based, women-centered approach to the offer of ART provision must look like, moving forward.

Below are some key recommendations to donors, policy makers, and health care providers, for a human-rights-based treatment paradigm for long-term access for women living with HIV to care and treatment. These are offered as wayfinders for a wholescale revision of current policy and practice, to remove the structural, community-level, and intimate partner violence barriers that current policies have overlooked. This will lead to more effective treatment outcomes for women, and thus their dependents.

Human rights, gender equality, respect for diversity, multi-sectoral approaches, and relevant holistic research form the key concepts behind these recommendations. Once states, service providers (and employers) ensure that these key

concepts are promoted, implemented, upheld, and that they can be held accountable to observing these—through laws, policies and programs—then there is more likelihood that women living with HIV will benefit. A process based on these concepts will enable treatment access—and adherence—to flourish, based on informed choice, safety, and a wider enabling environment.

Conclusions and recommendations

This extensive review reflects the lived realities and rights of women living with HIV globally. It confirms, through in-depth, qualitative analysis, what epidemiological figures and treatment program data suggest: that the AIDS response has improved over the past two decades but that much more needs to be done. Finally, evidence from this review demonstrates that while there has been immense, and often poorly conceived, focus on treatment access for pregnant women, there remains scant attention to, and significant treatment access barriers facing, women from key populations. Here, we offer recommendations for each quadrant in turn.

Quadrant 4 (laws, policies, resource allocations)

At this level, punitive laws which violate the rights of women living with HIV should be reformed and replaced with laws which are gender transformative, and which recognize and respect the rights of women living with HIV in all their diversities. Key normative frameworks, such as the UN conventions highlighted above, have been adopted in most countries. What is missing is how to hold states to account on these. Ensuring that all WHO and other global guidelines observe these international human rights protocols would be invaluable. Whilst further discussion of this is beyond the scope of this paper, there is urgent need for this. How laws and policies can most benefit women living with HIV appeared least well known to respondents. Literacy and advocacy initiatives around international laws, policies and guidelines and support for other accountability initiatives could help here.

Quadrant 2 (access to resources)

At this level, action is critical since this is where most women first learn of their HIV status and how this happens can determine their long-term prognosis.[33] Funders, policy makers, and practitioners should define, implement, and evaluate women's access to health services in a rights-based framework that encompasses availability, accessibility (including affordability), acceptability, and quality of care, to address gender-related social and structural barriers. This must include voluntary and informed choice, with real options for women in all their diversity, whether pregnant or not, so they can exercise their right to voluntary choices around medical therapy initiation, continuation and adherence/retention, which is primarily for their own intrinsic health. The use of treatment as prevention, while this can be an additional benefit, should not be considered the primary driver for women's treatment.[34]

How women living with HIV are treated by health care providers also has consequences for how they are treated by intimate partners, family members, in the community, and at work.[35] If health care providers do not treat women living with HIV with respect and violate women's rights to privacy, information about their HIV can quickly spread, with negative consequences for the women's overall health, safety, and psychosocial well-being.

Furthermore, many health staff seeing patients are women who are themselves living with HIV or are caring for family members with HIV. They fear that sharing this information would negatively affect their own employment. They too can often experience workplace-based treatment access barriers.[36]

Generally, negative attitudes and practices toward other people are usually based on lack of information and fear of the unknown.[37] It is therefore strategic to consider sector-wide HIV and gender-awareness training. This could ensure workplace care, treatment, and support for all health care staff affected by these issues, and could promote similar care and support by health workers for those seeking their services. This training, such as WHO's new Innov8 approach, should be

career-long and health sector-wide, including for ancillary staff, embedded in continuing professional development.[38]

Further, health care providers should:

- implement a minimum package of services, with "know your rights" and treatment literacy programs available to all women on treatment in the community, and in health and other related settings (for example, with employers, police, and prison staff);[39]
- implement health center-based VAW prevention and reduction programs as core to all services;
- ensure that IPV mitigation programs are in place, such as the WHO clinical guidance for counselling and referral
- train service providers to deliver safe services for women, to:
- ensure the right to confidential, voluntary services at all times (to remove forced disclosure, which can lead to violence and/or clinic avoidance);
- understand gender and diversity issues and rights of all people in their care;
- improve providers' ability to address and minimize gender-specific HIV-related vulnerabilities in health care settings;
- ensure that providers are trained and resourced to offer ART non-judgmentally, supporting women's decision-making while providing adequate information and support on treatment uptake, adherence, and side-effects management;
- ensure that safe mechanisms exist for women to provide feedback on the quality and effectiveness of services, including on confidentiality, treatment literacy, respect, and safety;
- provide quality life-long, life-stage appropriate sexual and reproductive health care for all women living with HIV, including informed choice in the context of pregnancy and fertility desires; and
- provide clinic spaces, hours, and structures that are accessible to women in all their diversities (women with childcare and other family responsibilities during the day, those engaged in sex work, school age girls, etc.); and
- provide peer-support/counseling and mentoring schemes within health services.

Workplace policies related to Quadrant 2 that take place outside health care settings and promote care, respect, and support for women living with HIV, and ensure labor rights irrespective of HIV status, are also key. However, respondents discussed these issues less. This suggests the need for greater awareness around gender, HIV, and livelihood rights, across both formal and informal labor sectors.

L2 Quadrant 3 (community)

At this level, a rights-based gendered and diversity-based analysis should be incorporated into expansion of support for community-based service delivery, which is a core component of UNAIDS' Fast-Track goals. Community-level programs that transform gender norms, including gendered power inequalities, are also needed. These can reduce violence against women, promote grassroots understanding of HIV treatment access challenges and facilitators, and thereby create a respectful, supportive environment for people with HIV to look after themselves safely. Such support should:

- promote respect, support for, and inclusion of women in all their diversities in community-level responses through community-based programs;
- define gender-specific elements of community-based service delivery, while ensuring that, where possible, existing peer groups and individuals with relevant lived experience design, implement, and evaluate them;
- track all resources allocated to community-based groups to ensure that funding includes women-led organizations at grassroots level; and
- increase funding for networks of women living with HIV and peer support groups to provide

supportive services along the treatment and care continuum.

Quadrant 1 (internalized)

So much of women's experiences at this level depends on what happens in the other three quadrants. If women are surrounded by an enabling environment at home, in the community, the workplace, at health centers, and have their legal rights upheld, then they are likely to feel respected, cared for, safe and valued, able to deal with their HIV diagnosis, and supported to take their medication. This is essentially what is needed to uphold women's sexual and reproductive health and human rights. If women's own SRHR are upheld, which is their intrinsic right, they are then also far better placed to support their dependents.[40] Further, research reform is needed. Two practical steps are recommended in this regard to improve quantitative data collection rapidly. First, we recommend a rapid scan of types of data that are and are not routinely reported by treatment programs intended for women, such as 'test and treat' and sero-different couples' programs. Then we propose a coordinated plan to fill gaps in information, with attention to issues of choice, coercion, supportive services, and clinical and psychosocial outcomes for women. Second, we recommend a system for improved data collection at the national level that addresses the above issues, developed and implemented with coordination and cooperation from PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, UNAIDS, and other relevant entities. This system must ensure age- and sex-disaggregation of treatment data relating to women living with HIV in all their diversity, including information on access for pregnant and non-pregnant women.

It is our hope that this extensive review will catalyze change and dialogue at the international and national levels in board rooms, clinics, and communities in the context of expanded access to ART. Women's voices are clear, consistent, and urgent in their articulation of what must be done to create a women-centered, rights-based approach to maximize their holistic health and well-being, especially in the constrained funding climate. It is also our hope that the methodology described in this study will be adapted and expanded as a basis for continuing to monitor progress and map gaps in the global AIDS response.

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Neglected Population, Neglected Right: Children Living with HIV and the Right to Science

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Abstract

The laws, language, and tools of human rights have been instrumental in expanding access to lifesaving treatment for people living with HIV. Children, however, remain a neglected population, as evidenced by inadequate child-specific and child-friendly HIV treatment options. In this article, we explore the right to science, a potentially powerful but underdeveloped right in international law, and its application to research and development for pediatric HIV treatment. Drawing on reports of human rights bodies and scholars and applying the human rights typology of state obligations to respect, protect, and fulfill, we argue that states have five core obligations related to research and development for child-specific and child-friendly treatment: (1) adopting a public goods approach to science and science policy; (2) including and protecting children in research activities; (3) adopting legal and policy frameworks to support research and development through public funding and private sector incentives; (4) promoting international cooperation and assistance; and (5) ensuring the participation of marginalized communities in decision-making processes. In concluding, we make a number of recommendations for states, human rights bodies, international organizations, civil society, and private industry to further develop and implement the right to science.

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Introduction

An estimated 1.8 million children under the age of 15 are living with HIV—over 90% of whom reside in sub-Saharan Africa—and 150,000 are newly infected each year.[1] Strikingly, HIV is the second leading cause of death globally among older children (10 to 19 years of age) and the leading cause of death in sub-Saharan Africa.[2] While AIDS-related deaths fell in all other age groups between 2005 and 2013, they increased by 50% among older children.[3] Treatment for children living with HIV, particularly for those under the age of five, lags behind treatment for adults; there are fewer child-specific and child-friendly treatment options, fewer data on the safety and efficacy of existing medicines to inform treatment guidelines, and insufficient drug pipelines for new treatments.[4] This has prompted some experts to refer to pediatric HIV as a "neglected disease," defined as a disease that predominately affects populations in the developing world and that is typically overlooked by drug developers.[5]

The laws, language, and tools of human rights have been instrumental in responses to the HIV epidemic, particularly in supporting access to expensive lifesaving treatment for millions of people in the developing world.[6] Human rights approaches, however, are underutilized in terms of promoting the need for new and better HIV treatment options for children. The right to enjoy the benefits of scientific progress and its applications (hereinafter abbreviated as "the right to science") is a little known but potentially powerful human right that is explicitly recognized in both the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights (ICESCR).[7] While the specific obligations of states under the right to science remain underdeveloped, there is an emerging consensus among human rights bodies and scholars that the right to science obliges states to take specific actions, both domestically and internationally, to ensure that scientific research, funding, and policy address the rights and unmet health needs of all, particularly marginalized populations.

In this article, we develop a framework to identify state obligations under the right to science, specifically obligations related to research and development (R&D) in areas such as pediatric HIV treatment. Using this framework, we show that many of the obligations laid out under the right to science address (either directly or indirectly) key shortcomings in the current R&D environment that ignore the needs of vulnerable populations around the world. Thus, we provide a novel rights-based perspective on why and how states and other actors should adopt a more just and equitable approach to biomedical R&D and scientific progress as a whole.

Following this introduction, we review the current state of pediatric HIV treatment to show that children living with HIV, particularly those in low-income countries, have had and continue to have fewer treatment options compared to adults. The next section of the article locates the right to science in human rights law and presents a framework on the normative content of the right to science and state obligations. Then, we apply this framework to analyze the obligations of states to respect, protect, and fulfill the right to science, focusing specifically on those obligations related to R&D on pediatric HIV treatment. The final section makes five recommendations to support the development of the right to science and its implementation.

Children living with HIV: A neglected population

Since the beginning of the HIV epidemic, children have had fewer treatment options and faced worse outcomes than adults, due in large part to insufficient pediatric-specific R&D.[8] In 2015, the World Health Organization (WHO) recommended for the first time that everyone diagnosed with HIV, including children, should immediately initiate lifelong treatment regardless of symptoms or clinical stage. Today, however, only 49% of children living with HIV are on treatment.[9] In the absence of treatment, children born with HIV experience significantly faster progression to AIDS-defining illness and death compared to adults; more than half of children born with HIV will die within two years without treatment.[10] Moreover, even children on treatment have lower rates of viral suppression

(a clinical indicator of successful HIV treatment) compared to adults, which puts children at higher risk for drug resistance and HIV-related morbidity and mortality.[11]

Poorer viral suppression among children is at least partly attributable to a lack of child-specific and child-friendly treatment options, which leads to suboptimal efficacy, side effects, non-adherence to treatment, and dropping out of care.[12] Many children require that their HIV drugs in pill form be cut in half or quarters to achieve proper dosing (in other words, these drugs are not child-specific), while other children are forced to ingest unpalatable alcohol-based syrups that sometimes require refrigeration (in other words, they are not child-friendly). Fixed-dose combinations in which multiple drugs are combined into a single pill to reduce pill burden are less likely to be available to children compared to adults.[13] Younger children have even fewer treatment options, and only one drug (zidovudine) is currently approved for use in preterm infants and available for intravenous delivery.[14] Second- and third-line regimens, which are increasingly needed for children, are expensive.[15] The relative lack of pharmacokinetic data (data on the absorption, distribution, metabolism, and excretion of HIV drugs) for children results in less evidence-based treatment guidelines for specific dosing of different drugs, their potential side effects, and drug-drug interactions.[16] An estimated 40% of children on treatment are not on optimal regimens.[17] Children urgently need additional child-specific and child-friendly HIV treatment options, and this requires increased levels of pediatric-specific R&D.[18]

The human right to science: A neglected right

The right to science is recognized as a component of cultural rights in both article 27 of the Universal Declaration of Human Rights and article 15 of the ICESCR. Similar provisions on the right to science are also in the Revised Arab Charter on Human Rights and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights.[19] Addressing health specifically, the Convention on Human Rights and Biomedicine of the Council of Europe identifies "the need for international cooperation so that all humanity may enjoy the benefits of biology and medicine."[20] Additionally, a general comment from the African Commission on Human and Peoples' Rights references article 15(1)(b) of the ICESCR in stating that women's lack of access to safe abortion services is a violation of the right of access to scientific progress and its applications.[21] Despite all these provisions, the right to science is still an "emergent right," as its recognition in international human rights law is relatively recent; however, its standing and legitimacy is growing, and its interpretation and related obligations are gradually developing.[22]

In this article, we focus on article 15(1)(b) of the ICESCR, which is the most widely applicable international legal provision on the right to science, as it applies in all 165 countries that have ratified the ICESCR.[23] Article 15(1)(b) guarantees the right of everyone "to enjoy the benefits of scientific progress and its applications."[24] Former United Nations (UN) Special Rapporteur in the field of cultural rights Farida Shaheed has identified three elements of this right: (1) the right of everyone to access the benefits of science without discrimination; (2) the right of everyone to have opportunities to contribute to the advancement of science, and the right to the freedom necessary to do this research; and (3) the right of individuals, communities, and peoples to participate in science-related decision making.[25] Importantly, non-discriminatory access to the benefits of science refers broadly to access to scientific knowledge, information, and processes (such as R&D)—in other words, access to "science as a whole, not only to specific scientific outcomes or applications."[26]

Following subsection (1)(b) of article 15 of the ICESCR, which recognizes the right to science, subsection (2) sets forth the corresponding obligations of the parties. Subsection (2) mandates that states take steps "necessary for the conservation, the development, and the diffusion of science and culture."[27] While "conservation" involves safeguarding scientific knowledge and "diffusion"

means disseminating that knowledge, including through publishing, "development"

> *demands an explicit commitment to the development of science and technology for human benefit by, for example, developing national plans of action. Usually, this implies the adoption of programmes to support and strengthen publicly funded research, to develop partnerships with private enterprises and other actors, … and to promote freedom of scientific research.*[28]

Finally, subsection (4) of article 15 obliges states to "recognize the benefits to be derived from the encouragement and development of international contacts and cooperation in the scientific and cultural fields." Thus, the right to science also includes an international dimension that goes beyond the general requirement for "international assistance and cooperation" in article 2(1) of the ICESCR, which applies to all economic, social, and cultural rights. The UN Committee on Economic, Social and Cultural Rights, which is responsible for monitoring states' implementation of the ICESCR, in its 2014 concluding observations to El Salvador, stated:

> *The Committee urges the State party to work with neighboring countries, international bodies … and increase scientific resources needed to carry out independent research into [chronic kidney failure] and its causes and then to use that knowledge to prevent and cure it, thereby enabling those affected to enjoy the benefits of scientific progress.*[29]

The committee recognizes R&D as a vital element of the right to science and, therefore, obliges states to provide resources for research to understand the causes and develop treatments for diseases; to do independent research to address health issues in national contexts; and to collaborate with international bodies and other countries on this research.

To date, the Committee on Economic, Social and Cultural Rights has not released a general comment on article 15(1)(b) to elaborate more fully on the normative content and related obligations of states under the right to science. Preliminary work to inform a general comment through multi-stakeholder discussions was undertaken by the United Nations Educational, Scientific and Cultural Organization (culminating in the 2009 Venice Statement) and the Office of the United Nations High Commissioner for Human Rights (summarized in a report by the office in 2014).[30] Further, the American Association for the Advancement of Science (AAAS) actively supports the development of the right to science, including surveying the views of scientists, engineers, and health professionals on the right to science; collecting and analyzing state reporting on the right to science in states' periodic reports to the Committee on Economic, Social and Cultural Rights; and organizing briefings for the committee to inform a general comment.[31] Finally, several academics, most notably Audrey Chapman and Lea Shaver, have published pioneering articles to assist in unpacking the content of the right to science.[32]

Drawing on these sources, we investigate state obligations under the right to science to ensure that adequate and appropriate R&D is conducted in the area of pediatric HIV treatment. To do so, we employ the Committee on Economic, Social and Cultural Rights' typology of state obligations to respect, protect, and fulfill the entitlement relating to R&D as a component of the right to science.[33] The obligation to respect means that states must ensure that their actions, through laws and policies, are consistent (and do not interfere) with an enabling environment for R&D, while the obligation to protect means that states must prevent third parties from engaging in R&D to the detriment of human rights and protect the human rights of people participating in research activities essential to drug development. The obligation to fulfill requires states to take proactive measures, including adopting and implementing laws, policies, and programs to promote R&D in neglected areas.[34] This tripartite typology provides a useful starting point to analyze state obligations related to R&D as a component of the right to science.

State obligations related to R&D on pediatric HIV treatment

Obligation to respect

The obligation to respect requires first that state

laws and policies do not interfere with or create barriers to R&D on pediatric HIV treatments. At the time that the General Assembly adopted article 27 of the Universal Declaration of Human Rights (1948) and article 15 of the ICESCR (1966), science was broadly understood to be a public good from which everyone should benefit.[35] Since then, there have been two important changes in state governance of R&D, which have negatively affected the right to science: national laws have privatized the products of publicly funded research, and international agreements have forced this model of R&D on low- and middle-income countries.[36]

First, starting in the 1970s, many states moved away from the public goods approach to an increasingly commercialized and profit-driven approach to R&D.[37] In the United States, for example, the 1980 Bayh-Dole Act allowed, for the first time, scientists in universities and the private sector to patent discoveries from publicly funded research. The subsequent proliferation of patents created a "tragedy of the anticommons" by impeding the cooperation needed for innovation, particularly in biomedical R&D.[38] In the case of HIV medicines for children, the current system introduces both "horizontal" patent gridlock in developing new fixed-dose combinations, as each pill contains multiple drugs often patented by different companies, and "vertical" patent gridlock in which upstream patents limit their use in downstream drug development.[39] As noted by the Pediatric HIV Treatment Initiative, a multi-stakeholder initiative to increase R&D for pediatric treatments, "the development of new adapted pediatric formulations requires collaboration of each patent holder to pool [intellectual property], data, and know-how."[40] Under their obligation to respect, states have a duty to revisit these laws to ensure that they are consistent with an enabling environment for R&D and to avoid adopting laws that create barriers to R&D for pediatric HIV medicines.

Second, states must ensure that their agreements with other states, international organizations, and multinational corporations do not create barriers to R&D, particularly in areas affecting neglected populations.[41] The laws governing science and technology are increasingly globalized, introducing important concerns about their impact on international cooperation. High-income countries often push strict intellectual property and patent protections on developing countries through international agreements and organizations. For example, the World Trade Organization's 1995 Agreement on Trade-Related Aspects of Intellectual Property Rights and "TRIPS-Plus" provisions in bilateral and regional free trade agreements define global standards for a more commercialized approach to science.[42] The right of states to adopt flexibilities in intellectual property to protect public health is enshrined in the 2001 Doha Declaration, but these flexibilities often do not address the more upstream limitations of privatized, for-profit R&D. As Shaver pointedly argues, "[b]y overwhelmingly promoting the privatization of knowledge, we rob individuals of opportunities to take part in cultural life and enjoy the fruits of scientific progress."[43]

Obligation to protect

States have an obligation to protect the rights of individuals, particularly vulnerable populations, who participate in clinical trials and other research activities conducted by third parties.[44] Protection is often ensured through accredited institutional review boards, which may be well developed in high-incomes countries but are less robust in resource-limited settings, where much research into neglected areas takes place. Moreover, there is actually little evidence that institutional review boards are doing their job effectively—that is, protecting human subjects—given the lack of accountability systems.[45] A 2008 report by the Center for Research on Multinational Corporations investigated numerous undisclosed harms to research participants in clinical trials conducted by US and European pharmaceutical companies, mostly in the developing world.[46] Under the obligation to protect, states need to revisit their oversight policies of third parties, particularly private industry, and work collaboratively with other states to develop complementary research protection policies that do not allow third parties to skirt their responsibilities. Children living with HIV may be especially

vulnerable in clinical research because researchers are often not from the host community.[47] To address these issues, states, alongside those in the research community (universities, nonprofits, and private industry), should promote community participation in the development of research protocols, including defining risks and benefits for children in research that meets both international and local ethical standards.[48] The obligation to protect further means that states should take effective measures to prevent and redress infringements to the enjoyment of the right to science, including the benefit of R&D.

Obligation to fulfill

The obligation to fulfill requires that states enact and implement laws and policies to support R&D.[49] According to the Venice Statement, the obligation to fulfill requires states, among other things, to

1. adopt a legal and policy framework and to establish institutions to promote the development and diffusion of science and technology in a manner consistent with fundamental human rights;
2. promote access to the benefits of science and its applications on a nondiscriminatory basis, including measures necessary to address the needs of disadvantaged and marginalized groups;
3. take measures to encourage and strengthen international cooperation and assistance in science and technology to the benefit of all people and to comply in this regard with the States' obligations under international law;
4. provide opportunities for public engagement in decision-making about science and technology and their development.[50]

First, states must adopt a legal and policy framework, as well as a national plan of action, that promotes the development and diffusion of science in a manner that respects human rights. The national plan of action should include benchmarks and indicators to measure progress over time, and the state must provide the funding and other resources necessary to implement and monitor the national R&D plan. Transparent reporting on progress is also required so people may hold their government accountable.

Second, states must ensure that their national plans are non-discriminatory and address the needs of disadvantaged and marginalized groups, particularly in areas neglected by the private sector. For neglected areas such as pediatric HIV, states must step in through both "push" (direct public funding) and "pull" (incentives to third parties to invest in key areas) mechanisms.[51]

Publicly funded research remains essential for drug discovery, particularly for infectious diseases.[52] While public and philanthropic donors in high-income countries are responsible for about 40% of all health R&D funding, they are responsible for more than 80% of funding for neglected diseases.[53] Data on R&D expenditures in low- and middle-income countries are less accessible but suggest that R&D spending is more likely to be public, particularly in sub-Saharan Africa, where up to 70% of health R&D is funded by the public sector.[54] Since many states lack the capacity to conduct R&D or have ceded responsibility for R&D to the private sector, public funding is often directed through domestic and global product development partnerships between the public sector, academia, and private industry to target the development of technologies in specific areas.[55] For example, the Pediatric HIV Treatment Initiative was launched in 2014 as a joint initiative between Unitaid, the Drugs for Neglected Diseases Initiative, and the Medicines Patent Pool, in coordination with WHO and pharmaceutical companies. The initiative's goal is to "catalyze development of, and accelerate access to new, better-adapted pediatric [drugs] and formulations to improve treatment for all children living with HIV."[56] Unfortunately, an analysis of government funding for R&D on neglected diseases from 2007 to 2012 shows decreasing support for product development in favor of basic research, which will lead to further delays for pipeline drugs awaiting evaluation in clinical trials.[57]

States can (and *should*) use a variety of pull mechanisms to incentivize third party actors to invest in R&D in areas affecting vulnerable pop-

ulations. Pediatric patent extensions (awarded to firms that conduct pediatric studies on certain new or existing drugs) and priority review vouchers (awarded to firms that conduct R&D in high-priority areas, entitling them to speedy reviews of other pipeline products) are employed in a number of countries; however, these programs are inefficient (because the incentive is not directly tied to the innovation) and short-sighted (because they do not lead to sustained private sector R&D).[58] Moreover, generic firms that are essential to producing new fixed-dose combinations for children are often excluded from these incentive mechanisms. Laws such as the US Best Pharmaceutical for Children Act of 2002 and the Pediatric Research Equity Act of 2003 actually require drug companies (under certain circumstances) to study their products in children. These acts have led to increases in pediatric clinical trials, but loopholes allow companies to delay conducting these studies, and their drugs are often not targeting neglected groups of children, such as those living with HIV.[59] Patent pools are another potential tool to encourage R&D in neglected areas, and states should consider policies to incentivize companies to join them.[60] The Medicines Patent Pool, a UN-backed multi-stakeholder initiative funded by Unitaid, works in part by partnering with pharmaceutical companies to license patented drugs for generic production and promote R&D on new child-specific HIV formulations. Finally, various prize-based approaches have been proposed whereby companies receive awards from the state, monetary or otherwise, on par with a desirable outcome that their innovation achieves (for example, lives saved).[61] States need to decide which of these policies (among others) are most appropriate for them, but the right to science mandates that states adopt a legal and policy framework that both pushes public funds and pulls private industry to ensure that R&D is conducted on a non-discriminatory basis and addresses the needs of vulnerable populations.

Third, states are required to encourage and strengthen international cooperation and assistance as an essential component of the right to science. This includes providing direct bilateral and multilateral aid, supporting international organizations, and promoting technology transfers. Despite unprecedented international assistance, funding for HIV will remain far below the estimated US$36 billion needed annually to achieve Target 3.3 of the Sustainable Development Goals, which seeks to end the AIDS epidemic by 2030.[62] Moreover, international assistance is often ad hoc and does not necessarily address developing countries' needs nor support the development of domestic R&D capacity.[63] In 2012, WHO's Consultative Expert Working Group on Research and Development highlighted the ongoing needs of developing countries both for new medicines, vaccines, and diagnostics, and for new and innovative sources of international aid. The group's principal recommendation was that all states should commit to spend at least 0.01% of their GDPs on government-funded R&D to meet the health needs of developing countries.[64] These commitments could be pursued through a global binding instrument (such as an international convention on cooperation for R&D) or mandatory minimum financial contributions.[65] The right to science contributes to the human rights grounds for such a treaty and should inform its content.

Innovative global public financing mechanisms offer potential alternatives to traditional bilateral and multilateral aid.[66] For example, Unitaid, established in 2006, is an initiative by Brazil, Chile, France, Norway, and the United Kingdom to fund underserved health product markets, including pediatric HIV treatment, through a levy on airline tickets. Between 2007 and 2014, Unitaid raised US$2.4 billion, which assists in funding pediatric HIV R&D through patent pools, direct negotiations, and product development with partner organizations and pharmaceutical companies.[67] States' support for initiatives such as Unitaid has been cited by the UN Special Rapporteur as consistent with the obligations under the right to science requiring international cooperation that targets the needs of disadvantaged groups, such as children living with HIV.[68]

In addition to financial assistance, the obligation to strengthen international cooperation requires that states enhance collaboration on R&D

activities, particularly in neglected areas. Cooperation through transfers of scientific knowledge, processes, and applications (often referred to broadly as "technology transfer") from high-income countries to low-income ones is consistent with this obligation and reflects a commitment by states made in the Sustainable Development Goals.[69] Many low-income countries have some R&D capacity both in the public and private sectors, including for pediatric HIV medicines, but these sectors are underdeveloped and face stiff competition from high-income and some middle-income countries.[70] The case of South Africa illustrates how a rights-based commitment to universal HIV treatment can inform regulatory and investment policies to develop domestic pharmaceutical capacity through tax relief, investment credits, and technology transfers with international partners.[71] As international commitments for technology transfer develop, greater consideration of the human rights dimensions of these policies and their impact on R&D for diseases affecting vulnerable populations is needed.

Finally, states are required to support the participation of everyone, particularly vulnerable communities, in science-related decision making to ensure that R&D addresses their priority needs. Shaheed explains, "major decisions regarding funding and research priorities, science policies, emerging areas of research, and new technological applications should entail a participatory process."[72] In other words, participation goes beyond enrollment in clinical trials and should be an empowering process for communities.[73] States must create public forums and proactively ensure the participation of disadvantaged groups when discussing and deciding on R&D priority setting and public funding. Further attention must be paid to children's participation in these processes, as their rights to seek and impart information and to freely express their views in all matters affecting them is guaranteed under the Convention on the Rights of the Child.[74] Under the obligation to fulfill, states should ensure that children, their families, and affected communities have a voice in this research, as well as in access to its benefits.[75]

Recommendations

Under the right to science, states have obligations to respect, protect, and fulfill. In the context of R&D on pediatric HIV and other neglected areas, these obligations include shifting the pendulum back toward a public goods approach to R&D both domestically and in agreements with other states to ensure that R&D addresses the priority health needs of the population, including marginalized groups; protecting the human rights of individuals involved in research; adopting a legal and policy framework to support R&D through push and pull mechanisms; strengthening international cooperation and assistance for R&D; and ensuring the participation of marginalized communities in decision-making processes. To further develop the right to science so that more specific obligations are developed to support R&D in neglected areas, we have five key recommendations.

First, the Committee on Economic, Social and Cultural Rights should urgently elaborate the normative content of the right to science and states' minimum core obligations in a general comment.[76] To assist the committee, the Human Rights Council should request that the Office of the United Nations High Commissioner for Human Rights convene another seminar (the first was held in 2013) so that states, the Special Rapporteur, and other relevant stakeholders can reach a consensus on its normative content and the obligations of states, providing a basis for the general comment.[77] Additionally, authoritative bodies in the public health arena should voice their support for developing and subsequently implementing the specific obligations under the right to science. For example, key international organizations working on HIV, health, and access to medicines—such as UNAIDS and the United Nations Development Programme—should play a stronger role in forums and debates on the right to science. WHO has been involved in these forums but thus far has not incorporated the right to science in recent reports on global health R&D. For example, WHO's 2012 report *Research and Development to Meet Health Needs in Developing Countries* frequently references the right to health to bolster its arguments but does not mention the

right to science.[78] However, a 2016 report of the UN High-Level Panel on Access to Medicines refers several times to the right to science, suggesting that this right might be gaining greater awareness in public health circles.[79]

Second, authoritative bodies and scholars should clarify the overlap of the right to science with other human rights.[80] Former UN Special Rapporteur on the right to health Paul Hunt has cited the right to science as both potentially overlapping and complementary to the right to health in protecting the rights of people living with neglected diseases.[81] In a recent article exploring the rights to science and health in the context of multidrug-resistant tuberculosis, Leslie London and colleagues argue that while the right to health requires access to essential drugs, the right to science "can potentially take this further and suggest that essential drugs need to be 'created' through scientific research and development in addition to being made accessible."[82] Still, as Yvonne Donders points out, the normative content and obligations of states under the right to science in relation to health-related R&D are vague, which undermines its potential to be employed alongside the right to health.[83] Additionally, while children have special status in human rights law, the Convention on the Rights of the Child does not specifically mention a child's right to science; however, a general comment of the Committee on the Rights of the Child cites children's right to "drugs [that] are scientifically approved … [and] child-specific (when necessary)" and encourages states to allow children to participate and express their views, according to age and maturity, on matters regarding health, including research.[84]

Third, states must monitor their implementation of the right to science and report to the Committee on Economic, Social and Cultural Rights and other human rights mechanisms on their progress and achievements. Standard reporting efforts are critical for developing implementation and monitoring frameworks that include indicators on the right to science.[85] These reports should specifically refer to a right-to-science "national plan of action with a timetable and goals to rectify existing inadequacies and a monitoring strategy to evaluate the extent to which these milestones are being realized."[86] Amrei Müller argues that "the reporting process before the [Committee on Economic, Social and Cultural Rights] could become a catalyst through which, first, the obligations set out in the Venice Statement can be tested and clarified; and second, the priorities for their implementation in different countries and contexts can be identified."[87] Indeed, the committee has repeatedly requested that states include more information on the implementation of the right to science in their periodic reports.[88]

Fourth, members of civil society—including adults and young people living with HIV, human rights activists, professional associations of scientists, and medical researchers—should ramp up efforts to educate government officials and the public on the spirit of the right to science and on commitments made in recognizing this right. As noted earlier, the AAAS has been a leader in this area through its Science and Human Rights Coalition, which organized a two-day meeting on the right to science in July 2017 involving human rights scholars, public health experts, and representatives from the Committee on Economic, Social and Cultural Rights.[89] AAAS' Article 15 Project has compiled a database of state reports on implementing article 15 of the ICESCR and exemplar cases to illustrate different aspects of the right to science in practice.[90] Civil society efforts to monitor states' investment in R&D can also help, particularly in supporting accountability mechanisms. For example, the Global Funding of Innovation for Neglected Diseases tracks global R&D funding and investments for 35 neglected diseases from public, private, and philanthropic sources.[91] These data now support the recently launched Global Observatory on Health R&D housed at WHO, whose goal is to monitor, benchmark, and create standardized indicators for global health R&D.[92]

Fifth, states and international organizations should further engage with non-state actors, particularly private industry, to develop cooperative approaches to meeting obligations under the right to science for more equitable R&D. Hunt's pioneering work *Human Rights Guidelines for Pharmaceuti-*

cal Companies argues that these companies have human rights-based responsibilities to "in-house research and development for neglected diseases, or support [of] external research and development for neglected diseases, or both."[93] As we have shown, there are several examples of multi-stakeholder models, including those involving pharmaceutical companies and other non-state actors, that are consistent with human rights principles; however, these efforts are underfunded and insufficient to meet the needs of the vast majority of poorer and marginalized populations throughout the world.

Finally, important shifts have also occurred in how scientific research is disseminated and who has access to it. Scientific publishing houses often require expensive subscription fees that create barriers to the flow of scientific information, and these thus deserve human rights scrutiny.[94] The "open access movement" driven by a loose coalition of civil society organizations and initiatives, with the support of some states, has recently made positive steps in pushing states to adopt open access policies consistent with the right to the benefits of science while respecting authors' rights to protect their material and moral interests.[95]

Conclusion

The right to science obliges states to adopt legal and policy frameworks that enable and promote R&D in a manner consistent with fundamental human rights. This makes the right to science a potentially powerful tool for human rights practitioners and activists working to protect the rights of children living with HIV and for people all over the world suffering from neglected diseases. The fact that we are in the fourth decade of the HIV epidemic yet lack sufficient treatments for children powerfully illustrates the profound inadequacies of the current approach to advancing medical science. It also raises the core equity question of *cui bono*?, or who benefits from science? Increased and sustained engagement by the human rights community is necessary to address these inadequacies—inadequacies which can, in part, be rectified through the development and implementation of the right to science.

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Human Rights and the Global Fund to Fight AIDS, Tuberculosis and Malaria: How Does a Large Funder of Basic Health Services Meet the Challenge of Rights-Based Programs?

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Abstract

The Global Fund to Fight AIDS, Tuberculosis and Malaria was created to greatly expand access to basic services to address the three diseases in its name. From its beginnings, its governance embodied some human rights principles: civil society is represented on its board, and the country coordination mechanisms that oversee funding requests to the Global Fund include representatives of people affected by the diseases. The Global Fund's core strategies recognize that the health services it supports would not be effective or cost-effective without efforts to reduce human rights-related barriers to access and utilization of health services, particularly those faced by socially marginalized and criminalized persons. Basic human rights elements were written into Global Fund grant agreements, and various technical support measures encouraged the inclusion in funding requests of programs to reduce human rights-related barriers. A five-year initiative to provide intensive technical and financial support for the scaling up of programs to reduce these barriers in 20 countries is ongoing.

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Introduction

The Global Fund to Fight AIDS, Tuberculosis and Malaria (hereinafter the Global Fund), which began its operations in 2002, emerged during a period in which the nexus between health and human rights had established itself as a distinct area of public health practice and an intellectual discipline. By 2002, the United Nations (UN) entities brought together to form the Joint United Nations Programme on HIV/AIDS (UNAIDS) had a strong commitment to rights-centered approaches to HIV, as seen, for instance, in UNAIDS's inclusion of nongovernmental organizations (NGOs) in its governance body and its work on discrimination and other human rights abuses related to HIV. As explained below, the Global Fund was born out of the idea that a different kind of institution might be needed to expand financing to HIV programs. As a financial institution without field staff, the Global Fund would operate very differently from a direct service provider or UN agency. But it would operate in accordance with agreed-on norms contained in HIV programs and policies, including the meaningful participation of people living with HIV, the prohibition of discrimination based on HIV status, and the inclusion of often criminalized persons—such as sex workers, people who use drugs, and LGBT persons—in HIV programs. It was also challenged to bring lessons from HIV efforts to bear on programs to address tuberculosis (TB) and malaria.

This article describes the strategies and initiatives undertaken by the Global Fund in its effort to support human rights-based programs to address HIV, TB, and malaria. It suggests that within institutional constraints specific to its foundational values and processes, the Global Fund has found progressively more active ways to assist grantees in designing, implementing, and evaluating rights-centered health programs.

Human rights and basic operation of the Global Fund

The Global Fund was created partly as a response to the reluctance of many traditional providers of development assistance in health to finance antiretroviral treatment, which had been available since 1996 but was seen by some donors to be unsustainable in low-income countries.[1] Donor-supported HIV interventions in the period before the United States President's Emergency Plan for AIDS Relief initiative and the "3 by 5" initiatives of the World Health Organization and UNAIDS (both dating from 2003) were largely focused on awareness-raising campaigns and health worker training.[2] For some years, the French government had called for a "solidarity" fund for antiretroviral treatment.[3] The International AIDS Conference in Durban in 2000 brought global attention to a growing North-South movement to challenge the prices and patents of antiretroviral medicines, as well as the indifference of donor nations to the plight of Africans living with HIV.

The 2001 UN General Assembly Special Session on HIV/AIDS committed member states to providing support for "a global HIV/AIDS and health fund to finance an urgent and expanded response to the epidemic based on an integrated approach to prevention, care, support and treatment."[4] This resolution gave the Global Fund official UN member state backing that earlier large-scale public-private health initiatives such as the Vaccine Alliance (GAVI) did not have. There was great hope in many quarters that the Global Fund's existence would not only scale up antiretroviral treatment dramatically but, in so doing, also drive down the prices of HIV medicines.[5]

The board of the Global Fund, which institutes funding strategies and policies and approves budgeting and funding decisions, was constituted to include representatives of governments, civil society from the Global North and South, foundations, and people affected by the three diseases; this last constituency sets it apart from GAVI and other similar entities and signals a commitment to the meaningful involvement of people affected by the diseases in all decisions about the Global Fund and its activities. The Global Fund also incorporated another distinctive element with human rights importance—a commitment to "country-driven" grant-making. The foundation document of the Global Fund said that it would "base its work on

programs that reflect national ownership and respect country-led formulation and implementation processes."[6] Country coordination mechanisms (CCMs)—meant to include representatives of government, NGOs, other private-sector entities, UN agencies in the country (often called "technical partners"), and people living with or affected by the diseases—were created to develop proposals. CCMs were entrusted to submit proposals requesting a realistic level of funding for health programs that could be absorbed and programmed readily. The Global Fund's foundation document also pledged to "give due priority to the most affected countries and communities, and to those countries most at risk" and to "aim to eliminate stigmatization of and discrimination against those infected and affected by HIV/AIDS, especially … women, children and vulnerable groups."[7]

As of February 2017, the Global Fund estimated that with total disbursements of more than US$30 billion since 2002, it has supported antiretroviral treatment for about 10 million people, TB testing and treatment for about 16.6 million people, and the distribution of over 700 million bed nets for malaria prevention.[8] From a human rights perspective, it is important to note that the Global Fund has also supported an unprecedented scale-up of HIV prevention activities for certain marginalized populations, including people who inject drugs. In its first nine rounds of funding, for example, approximately US$180 million enabled the expansion of drug-related harm reduction services in 42 countries, many of which had never been able to scale up services of this kind.[9]

"Country ownership" and country-driven processes may not have worked out ideally in every case, but they represented an attempt to do business in a new way. Both the formal independent evaluation commissioned by the Global Fund after five years and the conclusions of other observers of the Global Fund's work echoed the long-held concern of some donors that although the Global Fund had indeed put program design and implementation more squarely in the hands of recipient countries than ever before, some of those programs floundered for lack of outside technical assistance.[10] The Global Fund defended its approach, asserting that it was high time that programs for infectious diseases not be designed in Geneva or Washington.[11] Key actors in the field appreciated this sentiment. Médecins Sans Frontières, for example, said that entrusting countries with the responsibility to estimate resources that could be absorbed and realistic rates of scale-up of programs resulted in unprecedented progress both in the programs themselves and in strengthening health systems.[12]

As of 2004, the Global Fund had already stepped a bit over the "country ownership" line and required that CCMs include a person living with HIV among their members. And in 2008, it issued guidance "strongly encouraging" CCMs to include key populations affected by the three diseases among their members—beyond just people living with HIV—and to ensure their participation in decision making.[13] Though the inclusion and meaningful participation of key populations—especially persons affected by the criminalization of drug use, sex work, and aspects of sexual preference and gender identity—remains a challenge in many places, in some countries CCMs became the first platform in which key population groups could sit with policy makers and program managers and participate in decision making on programs affecting them.[14]

While "country ownership," with its ring of empowerment, was appealing from a human rights perspective, human rights advocates over the years noted the other side of the coin—that "ownership" of programs by countries with poor human rights records or little culture of human rights might mean that these countries would steer programs in rights-unfriendly directions and have little incentive to do otherwise.[15] Some observers concluded that the Global Fund's commitment to rights-based programs was too passive. At a Global Fund "partnership" meeting in 2006, civil society organizations presented an appeal signed by over 250 health and human rights NGOs, calling on the Global Fund to

> *increase funding for programs to eliminate human rights abuses against people living with and at high risk of HIV/AIDS—including sexual and gender-based violence; discrimination; and violations of*

> *the right to complete and accurate information about HIV/AIDS prevention, treatment and care.*[16]

Dr. Michel Kazatchkine, director of the Global Fund from 2007 to 2012, noted that the country ownership principle did indeed pose human rights concerns but that the Global Fund had processes to ensure that it would not fund programs that contributed to human rights violations or that did not reflect sound evidence-based approaches.[17] With respect to human rights questions, the Technical Review Panel, the independent expert body that reviews Global Fund proposals and makes recommendations for funding, is asked to consider whether proposals address

> *issues of human rights and gender equity and use human-rights based approaches to address the three diseases, including by contributing to the elimination of stigmatization of and discrimination against those infected and affected by tuberculosis and HIV/AIDS, especially populations that are marginalized or criminalized, such as injection drug users, men who have sex with men, transgender communities, sex workers and other key affected populations.*[18]

Indeed, efforts to ensure that marginalized and criminalized populations are reached by Global Fund-supported programs, particularly for HIV and TB, have been challenging throughout the Global Fund's history. The 2011 Political Declaration on HIV/AIDS called on countries to implement specific programs to ensure that national HIV responses were inclusive, effective, and rights based. UNAIDS identified these key programs as consisting of the following: (1) the reduction of stigma and discrimination; (2) access to HIV-related legal services; (3) the monitoring and reform of policies, regulations, and laws that undermine HIV programs; (4) legal literacy, or "know your rights," efforts; (5) the sensitization of lawmakers and law enforcement agents; (6) the training of health care providers on rights and ethics related to HIV; and (7) the reduction of discrimination against women and gender-based violence.[19]

The UN Development Programme led an investigation of whether these types of programs figured in two Global Fund funding rounds (6 and 7).[20] The study found that successful HIV funding proposals generally included at least a few programs to address human rights barriers, but that about a quarter of these programs were dropped before they made it into work plans.[21] In addition, it was noted that stigma and discrimination reduction was the most common of the seven programs to be included and that countries with generalized epidemics were unlikely to identify program needs for key populations. The Global Fund had developed information notes and technical briefs on human rights, gender, sexual orientation, and gender identity meant to help CCMs include, in their funding proposals, measures that would ensure access to services for marginalized persons and would promote gender equality, but clearly more needed to be done.[22]

Recognizing the continuing challenge of getting funding proposals to embody human rights norms and universal access, the Global Fund, in its tenth round of funding, established a special reserve allocation for programs for "most at risk populations," which were defined as (1) men who have sex with men, transgender people, and their sexual partners; (2) female, male, and transgender sex workers and their sexual partners; and (3) people who inject drugs and their sexual partners.[23] About one-third of applicants in this round requested support from this special reserve, for a total of about US$100 million in programs over two years; about half that amount was finally approved.[24] Two countries, Malaysia and Uruguay, received Global Fund support for the first time through this special reserve.[25]

The Global Fund's support for what it calls "community systems strengthening" was also an important step in encouraging rights-based programming for the three diseases. The community systems strengthening framework, developed by the Global Fund in 2010 (and revised in 2014) in consultation with many civil society organizations, encourages funding applicants to see the "mobilization of key affected populations and community networks" as an essential element of effective programs.[26] It urges applicants to include

in their analyses and funding requests an emphasis on "strengthening community-based and community-led systems for prevention, treatment, care and support; advocacy; and the development of an enabling and responsive environment."[27]

Formalizing and addressing strategic objectives for human rights and gender

As the time came to prepare an institutional strategy for 2012–2016, the Global Fund heard from civil society organizations and technical partners on the continued need for attention to human rights issues. A consultation convened by the UN Development Programme and the Open Society Foundations in 2011, which included wide civil society representation, stressed the need for the Global Fund to have a formal commitment to human rights goals. In a paper prepared for that meeting, Daniel Wolfe of Open Society Foundations and Robert Carr of the Caribbean Vulnerable Communities Coalition urged the Global Fund to address situations in which it might unwittingly undermine rights-based approaches, including the following:

- when health programs to benefit criminalized people who use drugs, prisoners, sex workers, and LGBTI persons expose these populations to arrest, arbitrary detention, and other abuses, without adequate protections of their human rights;
- when programs are carried out in closed settings—such as prisons, remand centers, and drug detention centers—where abusive practices are prevalent and health programs may be part of the abuse; and
- in countries with poor human rights records and weak protection of marginalized persons, where health programs are carried out in ways that undermine rights, deny meaningful participation to key populations, and do not embody evidence-based health practices.[28]

These points partly reflected concerns about the particular case of compulsory detention of people who use drugs, ostensibly to treat their dependence on drugs. Human Rights Watch, among others, had for some time investigated compulsory drug "treatment" centers in East and Southeast Asia, finding that these facilities provided virtually no scientifically sound health care but rather were scenes of forced labor and physical and psychological abuse of "patients."[29] In 2012, a joint statement by 12 UN bodies called for the closure of these centers.[30] Dr. Kazatchkine, as the Global Fund's executive director, also called for the centers to be shut down but noted that while they operate, the Global Fund should seek out ways to provide basic care, including HIV treatment, for detainees "in an ethical manner and respectful of their rights and dignity."[31] The Global Fund would eventually adopt a policy of generally not funding "treatment" programs where there is detention without due process, where "treatment" is not scientifically sound, and where there is torture or cruel, inhuman, or degrading practices.[32] This case is another example of the challenge of remaining true to country ownership while also seeking to ensure maximum impact of health services through rights-based programming.[33]

With many explicit and implicit efforts to address these and other human rights concerns in place but not formalized, the Global Fund's board made the decision to adopt strategic objectives on human rights and gender equality as part of the entity's 2012–2016 strategy. That strategy, unlike its predecessor, included the strategic objective of "promot[ing] and protect[ing] human rights."[34] With this strategic objective came three "strategic actions": (1) ensure that the Global Fund does not support programs that infringe human rights; (2) increase investments in programs that address human rights-related barriers to access; and (3) integrate human rights considerations throughout the grant cycle.[35]

The strategy noted that these objectives and actions reflected a "broad consensus" that the Global Fund could do more to address "poor and inequitable targeting of interventions, discriminatory social and legal environments, unsupportive policy settings, and sometimes severe and persistent human rights violations" that undermine

programs in many countries.[36] It also recognized that the Technical Review Panel, in its review of round 10 funding proposals, expressed its concern about "the limited inclusion in proposals of existing human rights instruments and measures to address stigma and discrimination" and other barriers to services for HIV and TB. At the same time, the strategy made it clear that the Global Fund as an institution needed to balance many factors in choosing strategic priorities and actions, including "additionality, sustainability, country ownership, multi-sectoral engagement, partnership, pursuing a balanced and integrated approach in dealing with the three diseases, human rights, performance-based funding, value for money, transparency and accountability."[37]

Meeting implementation challenges

Shortly after the new strategy was approved, the Global Fund unveiled what it called a "new funding model" in which, among other things, ceiling amounts of Global Fund grants would be determined by the Global Fund secretariat based on policies adopted by the board rather than by applicants, an important change in one of the pillars of "country ownership." In addition, the new model featured a commitment to focus "on those countries with the highest needs and least ability to pay, while remaining global, and supporting the highest-impact interventions."[38] According to the Global Fund, the new funding model is a means "to re-balance and give strategic direction to the organization's portfolio of investments" and to ensure greater predictability of funding for grantees.[39] The model's country-level process includes a "country dialogue" envisioned not as a single event but as a continuing process by which key affected populations and others "involved in the response to the diseases," including persons not well represented in the CCM, can take part in identifying needs, developing strategies, and identifying program priorities.[40]

A number of civil society organizations raised concerns about the new funding model. Médecins Sans Frontières, for example, charged that in the name of funding predictability, the model would disempower countries and deflate the constructive capacity and ambitions that had resulted in scaled-up programs and unprecedented progress on infectious disease responses.[41] Some NGOs expressed the concern that upper middle-income countries with concentrated epidemics, which were likely to be phased out or receive much less funding under the model, were home to millions of people who use drugs and other key populations and that the programs for these politically unpopular persons were unlikely to be funded by governments if the Global Fund withdrew.[42] The NGO Eurasian Harm Reduction Network has documented resurgent HIV epidemics among people who inject drugs in Romania, Bosnia and Herzegovina, and other Balkan countries, criticizing both the governments in question and the Global Fund for having inadequate transition plans to prevent the collapse of services.[43]

In time, the Global Fund developed a policy on "sustainability, transition and co-financing" that allocated resources to support transition planning and allow for several years of funding after the period of a country's formal eligibility.[44] Under this policy, upper middle-income countries in particular can apply for transitional funding for programs for key populations. In practice, it will remain very challenging for the Global Fund (and other donors) to ensure that much-needed programs to reduce human rights-related barriers to services and programs for key populations will continue once countries are no longer eligible to receive funding or other donors withdraw.

As the new funding model was put into place, the Global Fund began implementation of the human rights objectives and actions in the 2012–2016 strategy. In 2013, the entity established a Community, Rights and Gender Department, whose staff included a senior human rights advisor (later expanded to include another human rights expert) and advisors on gender, key populations, and community systems strengthening.[45] This department organized training sessions on human rights and gender equality for grants management and legal staff at the secretariat, as well as the Office of the

Inspector General (an independent office) and the Technical Review Panel. A Community, Rights and Gender Advisory Group of external—mostly NGO—experts helped steer the work and comment on priorities, as did a Human Rights Reference Group and a Harm Reduction Working Group established at about the same time.

In addition, a number of key human rights provisions were added to the language of Global Fund grant contracts. These points were meant to articulate some fundamental elements of rights-based programs that would be relevant to the three diseases in all countries. The provisions were that Global Fund-supported programs would provide non-discriminatory services to all, including people in state custody; would be based on scientifically sound and approved medicines or medical practices; would not employ methods that constitute torture or that are cruel, inhuman, or degrading; are expected to respect and protect informed consent, confidentiality, and the right to privacy concerning medical testing, treatment, or health services rendered; and would avoid the use of medical detention and involuntary isolation, except as measures of last resort.[46] These provisions were reviewed extensively by the Global Fund secretariat, the Human Rights Reference Group, and human rights experts.[47] In 2014, the Global Fund also joined UNAIDS and its cosponsor agencies in publishing guidelines for responding to HIV-related human rights crises.[48]

In 2015, the Global Fund announced the establishment of a mechanism for reporting human rights concerns linked to Global Fund-supported programs. A telephone hotline and email address were allocated to receive complaints, which could be anonymous and could come from anyone who experienced or witnessed a human rights violation linked to a Global Fund-supported program.[49] Information disseminated about this procedure explained what kinds of violations might be reported, especially with respect to the five points in the grant contracts noted above. The Office of the Inspector General was charged with responding to complaints. This office was founded in 2005 as an entity independent of the Global Fund secretariat and staff, and it reports directly to the Global Fund's board of directors. It was pledged that the Office of the Inspector General would respond to all complaints within 48 hours and would determine promptly whether to conduct a full investigation.[50] As of early 2017, nearly two years into the mechanism's operation, only a few complaints considered eligible for resolution by the Office of the Inspector General had been received, and an independent assessment was underway to determine why there has been such low uptake of the mechanism.[51]

Another initiative was a US$15 million allocation to offer technical assistance to NGOs aimed at improving their participation in Global Fund processes in their countries and supporting their longer-term capacity to develop and provide leadership in human rights programs.[52] By early 2016, there were over 100 requests for technical assistance through this initiative and 34 expert providers of assistance responding to them.[53] The initiative also supported six regional "platforms" for communication with and the coordination of civil society organizations. The regional platforms are meant to improve awareness of and participation in Global Fund processes and related national decision-making opportunities and to help organizations receive technical support for human rights programs. Alliances with Roll Back Malaria and the Stop TB Partnership were also formalized to provide assistance for the development of programs and situation analyses that would reflect human rights and gender equality concerns.[54]

After the first few years of the new funding model, civil society organizations reported experiences of inclusion in the model's processes but also continued challenges. A 2015 survey conducted by the regional NGO African Men for Sexual Health and Rights, for example, found that representatives of key populations largely understood the new funding model and participated in many aspects of the country dialogue.[55] But many respondents said that they faced serious barriers to participating, especially in later stages of the process, including the selection of principal respondents; these barriers included the criminalization of some key populations, the fact that some key population

organizations were not officially registered or did not have good technical capacity to deal with CCM processes, and discrimination.[56]

The new funding model included a revision of the instructions for funding applications, which would be submitted in the form of concept notes that were designed to be simpler than the previous application forms.[57] The concept note guidance suggested that they be organized according to topical "modules." Reflecting the place of human rights in the new strategy, a module entitled "removing legal barriers" was added to the concept note templates. As part of this module, applicants could include actions in the areas of assessment of the legal environment; "know your rights" awareness raising; human rights training for law enforcement officers or health care providers; community-based monitoring of human rights issues; and policy advocacy.[58] These areas of activity overlap significantly with UNAIDS's seven program areas noted above for reducing human rights barriers to HIV services. (The "removing legal barriers" module was later revised to correspond more exactly to UNAIDS's seven categories for HIV; see below.)

One goal of the 2012–2016 strategy was for the Global Fund to reflect on its work in "challenging operating environments"—meaning countries experiencing acute emergencies and those in chronic crisis with chronically weak state institutions. In these situations, the normal succession of Global Fund processes—country dialogues, regular CCM meetings, and reliance on the health sector for a certain standard of functioning and care—may be compromised. The rule of law and justice systems may also be undermined. An initial consultation with representatives of humanitarian assistance organizations led to the identification of a number of human rights and gender-related issues, which were followed up in more detail at a second consultation. These consultations led to the development of general guidelines for "challenging operating environments," as well as guidance for human rights-based and gender-responsive programming in such environments.[59] The latter emphasized that the seven categories of programs to address HIV-related human rights barriers and the analogous actions for TB and malaria are essential for the uptake, effectiveness, and sustainability of health programs, whether in "challenging operating environments" or not. The guidance recognizes, however, that special efforts may be needed to reach marginalized people when the work of community-based groups and traditional means of access to justice are disrupted.

In 2015 and early 2016, the Community, Rights and Gender Department conducted an in-depth analysis of challenges that had arisen in the Global Fund's human rights work, as well as opportunities moving forward. The department concluded that while much progress had been made in realizing two of the strategic actions under the human rights objective (ensuring that the Global Fund does not support programs that infringe human rights and integrating human rights considerations throughout the grant cycle), investments in programs that address human rights-related barriers to access had not increased sufficiently.

The department's analysis of the "removing legal barriers" programs in the new funding model concluded that there was strong recognition in many countries that addressing human rights barriers was important for successful health service outcomes, and that NGOs were leading many small-scale programs to remove human rights barriers but that scaled-up versions of these programs remained scarce as budgeted items in Global Fund grants. According to the department's analysis, in the five "windows" of the new funding model (in 2014–2015), about US$33 million was allocated to interventions to remove legal barriers in country grants, and about US$15 million was allocated to regional advocacy efforts to address harmful policies, which represents a tiny fraction of the total allocations.[60] In Latin America, about 2.2% of Global Fund support went to "removing legal barriers" programs, but the percentages were considerably lower in other regions. Of the 119 concept notes received in the first five "windows," 72% identified human rights barriers to programs, especially HIV services, but only 10% sought funding specifically for removing legal barriers.[61] The special initiative to provide technical assistance for including the

reduction of human rights barriers in funding applications was still getting under way during this period and perhaps could not be expected to yield results so quickly. While that initiative continued to grow, there was a determination to find additional means—including more direct means—for scaling up the removal of human rights barriers.

Post-2016: Efforts to scale up programs to remove human rights barriers

In addition to a much greater, explicit focus on gender equality and programs to support women and girls, the Global Fund strategy for 2017–2022, as well as policies and funding allocation decisions adopted to support the new strategy, includes a greater commitment to scaling up programs that remove human rights barriers to accessing HIV, TB, and malaria services. Under a core objective to "promote and protect human rights and gender equality," the 2017–2022 strategy includes a commitment to the following "operational objectives":

1. Scale up programs to support women and girls, including programs to advance sexual and reproductive health and rights.
2. Invest to reduce health inequities, including gender- and age-related disparities.
3. Introduce and scale up programs that remove human rights barriers to accessing HIV, TB, and malaria services.
4. Integrate human rights considerations throughout the grant cycle and in policies and policymaking processes.
5. Support the meaningful engagement of key and vulnerable populations and networks in Global Fund-related processes.[62]

Along with these ambitious objectives, the Global Fund's board approved a revised sustainability, transition, and co-financing policy that requires all funding proposals to include an "appropriate focus on interventions that respond to key and vulnerable populations, human rights and gender-related barriers and vulnerabilities in all countries, regardless of income level."[63] Importantly, the objective is also supported by key performance indicators that will measure, among other things, "the extent to which programs to remove human rights barriers to services are implemented in 15-20 countries that will be selected for an intensive effort"; and the percentage of the country allocation invested in programs to reduce human rights-related barriers and programs targeting key populations, with a target to increase this percentage more than fourfold.

Finally, the Global Fund launched an intensive five-year effort to scale up programs that address human rights barriers in selected countries, accompanied by US$40 million in dedicated funds that countries can access only if they match the funding provided by the Global Fund. In brief, the 20-country effort consists of the following elements:

- A review of evidence from peer-reviewed publications and other credible evaluations of the effectiveness and cost-effectiveness of programs to reduce human rights barriers to services for the three diseases across the world.
- Extensive consultation with civil society, health and human rights experts, and Global Fund staff on strategic options for building more and bigger programs to address human rights barriers as part of Global Fund-supported activities. An extensive consultation also informed the selection of the countries in this initiative.
- At the time of writing, teams of independent researchers are in the process of conducting baseline assessments of human rights barriers to HIV, TB, and malaria services in a first set of the selected countries and are rapidly assessing existing programs to address these barriers, including an analysis of why small-scale programs have remained that way.
- Informed by these baseline assessments, CCM members and other key actors at the country level, supported by Global Fund staff, will make national five-year plans to scale up programs to reduce human rights barriers (including removing policy and legal impediments). The cost of some of these new or improved programs will

be covered as part of Global Fund grants, both from within the country allocation and from supplemental "matching funds" that have been made available to countries under the condition that they use them to scale up such programs. However, it will be important to ensure that countries themselves and other donors join in this effort and work together toward the goal of having comprehensive programs to reduce human rights-related barriers to services.

- The programs introduced and scaled up to address human rights barriers and the state of the barriers themselves will be assessed twice by researchers in each country, at about 2.5 and 4.5 years after the national plan is agreed on. Detailed assessments will be made of the effectiveness, cost, and cost-effectiveness of the measures, with particular attention to how key affected populations experience the impact of these programs.
- The evidence from these assessments and lessons learned from the experiences in these selected countries will be disseminated and added to the existing evidence base on the importance of programs to reduce human rights barriers. In addition, the detailed information on scaled-up programs will be the basis for mathematical modeling and other means of estimating the impact of reducing human rights barriers on HIV, TB, and malaria services and their outcomes.[64]

This is an enormously challenging initiative, but it is also much needed, for three reasons. First, there is an urgent need to achieve impact in the form of increasing access to services for people living with and experiencing enhanced risk and vulnerability to HIV, TB, and malaria. Second, intensive efforts appear necessary to overcome the long-standing impasse on insufficient inclusion and scale-up of the programs. Finally, there will be much to learn from intensive efforts undertaken in a number of countries in different regions, resulting in knowledge and experience that can inform ongoing and future efforts in other countries and settings.

The 20 selected countries include some where CCMs have already identified and, to some degree, tried to address human rights barriers to health programs and where community-based organizations are present to ensure that key affected populations participate meaningfully in program design, implementation, and evaluation. But the potential obstacles are many and will require sustained efforts to address them. Legal and policy environments, as well as political unpopularity, may undermine the scale-up of efforts to include criminalized populations, for example. There may be a lack of technical capacity to build and sustain programs to reduce human rights barriers and disagreements on priorities and strategies. More broadly, even if evidence is generated to show that investing in the reduction of human rights barriers through scaled-up programs has direct benefits—including overall medium-term cost reductions linked to prevention and control of infectious disease—that evidence may still not be convincing to some policy makers. But an effort such as this has not been tried on this scale and is needed to move from rhetoric to real action on removing human rights barriers to services.

Another important element of implementing the Global Fund's human rights objectives is improved collaboration with UN agencies and other technical partners in efforts to remove human rights barriers. With respect to HIV, in 2016 the Global Fund realigned the elements of its "removing legal barriers" module to correspond to the seven human rights program categories identified by UNAIDS and noted above. This realignment enables more effective Global Fund-UNAIDS coordination in promoting and monitoring these programs. Similarly, with respect to TB, the Global Fund has formalized collaboration with the Stop TB Partnership, including joint efforts to reduce human rights barriers in Global Fund-supported TB programs. Guided in part by the Stop TB Partnership's publications on key populations affected by TB, a TB working group convened by the Global Fund developed a technical brief on TB, gender, and human rights that is meant to guide CCMs and others seeking to design rights-based TB programs.[65] The TB technical brief is more detailed

and program oriented than previous information notes on the subject. In addition to concerns about key populations—including migrant workers, prisoners, and people who use drugs—it discusses the need for a legal framework and standard practices that reflect the World Health Organization's recommendation that involuntary isolation for the purpose of TB treatment must be used only as a measure of last resort.[66] A group of experts also helped develop a technical brief on malaria and human rights, an area that had not previously been well developed.[67]

Conclusion

The Global Fund's commitment to human rights-centered health programs is a testament to the international understanding established before its founding that HIV cannot be effectively addressed without reducing rights-related barriers to health services, including for the most marginalized people affected by HIV. The continuing challenge of encouraging CCMs to prioritize addressing human rights barriers as part of health programs is evidence of the depth of political and social disfavor of those affected by HIV (and to some degree TB and malaria). It may also be the result of the virtual absence of large-scale (as opposed to small, piecemeal) human rights programs that should be a pillar of the evidence base for rights-centered health services.

Some human rights advocates have criticized UNAIDS's focus on "investment frameworks," arguing that this focus encourages a perspective whereby removing human rights barriers is important because they impede a good return on investment in HIV programs rather than because it is the right thing to do.[68] From the Global Fund's perspective, building programs to reduce human rights barriers on a scale not previously achieved is both a way to demonstrate the disease impact—and cost-effectiveness—of these programs and a tangible commitment to the human rights of affected populations. It is a way to address the persistent and deep underfunding of human rights-based efforts in HIV responses. In addition, the inclusion of TB and malaria in the Global Fund's efforts to reduce human rights barriers to services is pioneering and can help concretize the impact of rights-centered approaches in health more broadly.

The Global Fund's initiative to build, scale up, sustain, and evaluate programs addressing human rights barriers represents a shift to an active programmatic approach to this challenge—beyond public espousal of the principles of rights-based approaches. Devoting considerable resources explicitly to removing human rights barriers, based on a rigorous analysis of where and why these barriers occur, may not succeed everywhere, but it has the potential to be a major step forward in the scaling up of efforts to ensure rights-based HIV services, which have been too small and weak in too many countries. As the principal international funder for TB and malaria programs and one of the largest HIV funders, the Global Fund is uniquely placed to be an example of how to make rights-based health programs a reality.

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No More Broken Promises: Challenges and Opportunities for Key Populations in Demanding More Transparency, Accountability, and Participation in the Global Response Against the HIV and AIDS Epidemic

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Abstract

The global fight against HIV/AIDS continues to pose challenges: infection rates are on the rise in many settings, stigma and discrimination remain rampant, and the global response is under increasing financial pressure. There is a high risk of losing what has been achieved so far in the fight against HIV and AIDS, but also the momentum to meet the so-called Fast Track targets for 2030. In light of these trends, it is fundamental to focus on the human rights of key populations (KPs)—especially to health, non-discrimination, access to information, and to equal and meaningful participation in political and public affairs—by placing them at the center of the global HIV response. Such rights, and the demand for more transparency, accountability, and participation (TAP), have been recognized as both a necessary social justice imperative, and as a way to build more responsive, inclusive, and sustainable health systems. This article will argue that embracing TAP as key guiding principles of the global HIV response (especially in low- and middle-income countries) could have the potential to create the conditions for KPs to have their human rights fulfilled, and to expand their participation in the decision-making processes that guide the efforts against the epidemic. It will then propose a number of avenues for further engagement between different communities of practice in terms of research, agendas, and policy and practices that could be beneficial in maximizing the impact of the global efforts to end HIV/AIDS.

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Introduction

During the last United Nations (UN) General Assembly High Level Meeting on Ending AIDS in 2016, then-UN Secretary General Ban Ki-moon presented a report requesting that the international community strengthen its support for human rights-based interventions as fundamental components of the fight against the HIV/AIDS epidemic.[1] He highlighted the importance of promoting gender equality and empowering the people most affected by the disease, that is, key populations (KPs).[2] In this article, the term 'key populations' refers to individuals and groups (organized or not as a civil society organizations) of: men having sex with men (MSM), transgender persons (TG), people who use drugs (PWUD), and sex workers and their clients.

According to the World Health Organization (WHO), KPs are extremely socially vulnerable individuals and communities, which often experience an increased impact from HIV/AIDS due to their limited access to public health services and their lack of voice in public affairs.[3] Additionally, because of social barriers, stigmatizing policies, and punitive laws that keep KPs away from services—different forms of violence, discrimination, criminalization, and marginalization—they are most likely to be exposed to HIV and to remain excluded from participating in, and benefiting from, the policies that should address their needs.[4] Along these lines, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), underscore that beyond overcoming stigma and discrimination against KPs, their engagement and participation is critical to a successful HIV response everywhere, since they are both key to the epidemic and key players in the response.[5]

For decades, the international community—pursuant to international declarations and resolutions, such as the Declaration of Alma-Ata, the Paris AIDS Summit Declaration of 1994, various UN resolutions on human rights, the Declaration of Commitment on HIV/AIDS of 2001, and the Political Declarations on HIV and AIDS of 2006, 2011, and 2016—has reaffirmed the need to include the people that are themselves affected in the processes that lead to the design and implementation of the policies and strategies aimed to improve health outcomes and address HIV.[6] Such recognition is commonly known as the GIPA Principle, which is an acronym for 'Greater Involvement of People Living with HIV/AIDS.' Moreover, the recently approved Sustainable Development Goals (SDGs) include the achievement of "responsive, inclusive, participatory and representative decision-making at all levels" as a means to promote good governance and achieving sustainable development in a transparent, accountable, and inclusive manner.[7]

International organizations and donors, such as the UN, GFATM, and WHO, among others), are working to fulfill such commitments by creating and promoting spaces for KPs to participate both at the international and national levels. In many contexts, civil society organizations and key populations have been critical actors in calling for health programs, access to treatment, investments, political leadership, and human rights protection for addressing the HIV epidemic. These contributions have allowed the global fight against HIV to achieve major victories in the last decade: the global coverage of antiretroviral (ARV) therapy expanding, and the number of people who die from AIDS steadily decreasing.[8]

However, global efforts against HIV have now reached a historical juncture: HIV infection rates are on the rise in many parts of the world, while mounting challenges could further compromise the fight against the epidemic.[9] If these remain unaddressed, there is a risk of losing what has been achieved in the last decade and failing to meet the so-called Fast Track targets to end AIDS by 2030.

On the one hand, the effectiveness and legitimacy of the HIV response is weakening as KPs have no real ownership and their human rights continue to be violated, posing a long-term sustainability threat to the response.[10] Even when KPs now have more spaces for participation, for example via the Global Fund's processes, this has not translated into any substantial change or more prioritization of KP's needs in the HIV response.[11] On the other hand, the long-term sustainability of the HIV response is at stake. First, because available financial resources needed to cope with the HIV epidemic

are either dwindling or not being allocated efficiently to reach KPs.[12] And second, because a big part of the resources are getting lost to corruption, mismanagement, and/or poor service delivery. [13] This means that by failing to respond and support those who need it the most, the international community will not see the end of the epidemic.

To counter these problems, civil society organizations, advocates, activists, and KPs' organizations have been advocating worldwide for more transparency, accountability, and participation (TAP) not only in the health and HIV sectors, but more generally in political decision-making processes, as those impact KPs' daily lives. Advocating for human rights to access health care, to be informed, and to participate meaningfully in public decision-making, has proven to be both a necessary social justice imperative and a way to build more responsive health systems.[14] Empowering KPs to have a say in how public resources are allocated and to monitor service delivery will help ensure the long-term effectiveness and sustainability of the response to the epidemic.

This paper will first describe the most important challenges that are affecting the effectiveness and sustainability of the global response against HIV/AIDS. Second, it will explain why we need to advance human rights-based TAP programming, and why they need to strengthen social movements of KPs, based on the lessons learned from communities' participation in health policymaking and implementation. Lastly, it will introduce how cross-cutting TAP-based alternatives may lead to a more resilient, inclusive, and effective response against the HIV epidemic.

The global HIV response at risk: issues around sustainability and effectiveness

In the past three decades, the global HIV response has achieved major milestones, such as the reduction in the number of people who die yearly from AIDS and the expansion of the global coverage of ARV therapy.[15] Many of these successes have been made possible thanks to the engagement and mobilization of KPs and communities affected by HIV. Despite these successes, there has been no decline in new HIV infections among adults since 2010, and over 2.1 million people were newly infected with HIV worldwide in 2015.[16] Social and structural factors—including poverty, gender inequality, violence, stigma, and discrimination—are key drivers of the HIV epidemic that continue to undermine the effectiveness of proven HIV interventions.[17] This has led to a renewed call to intensify global HIV efforts within the UNAIDS "Fast-Track Strategy" that aims to end the epidemic by 2030 and ensure gains are sustained. It is therefore necessary to increase investments aimed at sustaining HIV prevention and treatment activities to stop the spread of the epidemic, as well as to establish responsive and inclusive monitoring mechanisms for accountability at all levels.

Financial constraints

In recent years, international funding for the HIV response has experienced significant constraints as development agendas change in response to changing donor priorities. As countries shift from lower- to middle-income countries, these donor recipient countries are being urged to increase their domestic investments to finance broader health services, including HIV.[18] However, available data both at the international and national levels show evidence that resources are not only becoming scarce, but they are often allocated inadequately by not addressing KPs' needs and grievances.[19] Furthermore, even if domestic investments made by national governments increase, such resources are difficult to track and monitor due to inefficient, opaque, and non-accountable governance structures and processes that are highly susceptible to corruption.[20] The impact of such losses is so big that it is impossible to determine with precision the overall costs of corruption in the health sector worldwide, but some estimates point out that around 10–25% of the annual global health expenditure (about US$7.2 trillion in 2010) is lost due to corruption and mismanagement.[21]

On the other hand, there has been an increase in the proportion of global HIV/AIDS investment coming from within affected countries. Domestic

spending by low- and middle-income countries now comprises the majority of all HIV expenditure.[22] For example, African countries have increased their domestic resources to respond to HIV by 150% in the last four years.[23]

This transition from international to local financing to sustain the HIV response is also likely to shift power from international donors to local actors and authorities. As such, with less foreign assistance, national governments will become less accountable to international donors, redirecting demands for accountability towards beneficiaries in their home countries. Conversely, there is mounting fear on the future of HIV programs for KPs in the near future. If international resources from bilateral and multilateral donors, crucial to supporting the HIV response worldwide, are already becoming scarce, those allocated for KPs and human rights interventions—for which available resources are already limited—will be most affected as a result of more countries transition to domestic financing.[24]

Failing to reach KPs and the limited protection of their human rights. Globally, there is clear evidence of the violation of KPs' human rights.[25] The lack of protection directly increases their vulnerability to HIV, fueling stigma, discrimination, and violence.[26] Harmful beliefs, gender norms, and practices are rooted in a lack of understanding and correct information about the disease and how it is transmitted. Also, HIV is incorrectly associated with behaviors that are perceived as immoral and even criminal (such as sex work, homosexuality, and drug use).[27]

For some people, an HIV-positive diagnosis could mean a progressive loss of civic, political, social, economic, and cultural rights. In extreme cases, this results in social exclusion and marginalization of KPs and people living with HIV that could lead to mental health illnesses, loss of self-esteem, and diminished chances of employment, housing, and education. Moreover, HIV-related taboos, stigma, and discrimination from politicians, public servants, and health professionals discourage or directly obstruct individuals living with HIV from accessing and making use of health and social services.[28]

In addition, further legal restrictions directly affect KPs' human rights. For example, laws limiting persons living with HIV from their rights to freedom of association and access to information (due to sexual orientation or gender identity, for example) mean that KPs may be barred from getting proper health information or even from discussing issues related to HIV in public. Thus, without such rights, participating in HIV/AIDS-related policymaking and in politics becomes very difficult, and forming support or advocacy groups can lead to penalties or prosecution.

The combined results: Uncertainty, unsustainability and ineffectiveness of current HIV strategies. Evidence demonstrates that the harm caused by stigma and discrimination—themselves paramount to social justice and human rights issues—worsens the advance of the epidemic and the financial sustainability of the response.[29] Such forms of structural violence make it difficult for lifesaving care to reach those KPs most at risk with prevention and treatment. And because the epidemic is highly concentrated among these vulnerable groups, not supporting them puts the whole HIV response at risk.[30]

Data collected and published by UNAIDS shows that of the total population believed to be living with HIV (around 37 million individuals worldwide), 54% still do not know their status.[31] These undiagnosed cases not only jeopardize the lives of those individuals because they are not receiving proper care and support for HIV (and other opportunistic diseases like tuberculosis or salmonella), but also increase the chances of passing on the disease to others.

Moreover, the increasing financial constraints that affect the response, limits the funding needed to sustain HIV prevention and treatment programs, resulting in a negative impact over the whole response to HIV and AIDS.[32] This would have a greater impact over community responses and programming for and led by KPs.[33] UNAIDS predicts that failing to secure such funding would mean at least new 17.6 million HIV infections and 10.8 million AIDS-relat-

ed deaths globally until 2030.[34]

According to the International Council of Human Rights (2009) and the Office of the United Nations High Commissioner for Human Rights (2013), corruption disproportionately impacts people that belong to groups that are exposed to social marginalization by reinforcing the exclusion and the discrimination to which they are already exposed.[35] Corruption, broadly defined as the "the misuse of entrusted power for private gain," is not only one of the biggest barriers for sustainable development, but can also reinforce marginalization and discrimination.[36] A few examples: if corrupted public officials deviate resources meant for the construction of a public hospital, all potential beneficiaries are affected, but this is most harmful for those groups that already have restricted access to existing hospitals; if HIV policies are formulated by corrupted lawmakers in the interests of a particular group (such as religious lobby groups), these can be framed ignoring the needs of certain communities (such as LGBT persons or sex workers).

Thus, it is critical that those most profoundly affected by the epidemic are given a voice and access to the necessary public information to participate, but also to demand from government the creation of an enabling environment (that is, legal, political, and socioeconomic conditions) that allows and facilitates community monitoring.[37]

Transparency, accountability, and participation principles as drivers of change in the health sector

After analyzing the increasing problems and contextual factors that are affecting the governance of the global response against the HIV epidemic, it is clear that addressing the several barriers that impede KPs from seeing their human rights realized is of high importance. However, without addressing the lack of transparency, accountability, and participation (TAP) in the health sector, and the harm caused by corruption, the international community will not succeed in achieving the structural changes required to ensure the long-term sustainability and responsiveness of the HIV interventions.[38] This section will first frame a working definition of TAP, followed by an analysis of the way in which initiatives based on such principles have been applied in practice, and what has influenced their success or not.

TAP in theory: What these principles mean in relation to the human right to health

TAP refers to the combination of transparency, accountability, and participation, three concepts that are different, yet interconnected and interdependent. Transparency usually refers to the level or extent in which the key elements of decision-making by governments and other entities (such as objectives of policy, decisions taken and their rationale, data and information, among others) are provided to the public in a comprehensible, accessible, and timely manner.[39] Accountability can be broadly defined as the obligation governments have to demonstrate and take responsibility in front of their constituents, for their performance in light of assigned responsibilities, commitments, and expected outcomes. Hence, accountability includes achieving objectives in relation to their mandates, and the fair and accurate reporting on the administration and management of public budgets in line with laws, rules, and standards.[40] And finally, participation is defined in relation to three civic rights: the right of every citizen to take part in the conduct of public affairs, the right to vote and to be elected, and the right to have access to public services.[41]

Although there are no single definitions of these terms, there is an emerging development consensus acknowledging that transparency, accountability, and participation are principles that have intrinsic ethical and instrumental value: based on human rights principles and norms, and as means to improve state responsiveness and 'good governance' more broadly.[42] The international community, thanks to the efforts of actors such as the United Nations Development Programme (UNDP), the World Bank, and civil society organizations like Transparency International, has recognized that access to information and citizens' engagement in public decision-making are crucial

components to achieve sustainable development.[43] States are believed to be more capable of meeting the needs of their citizens when their processes are guided by principles of TAP, being able to find more efficient and legitimate solutions to failures in service delivery and fight corruption.[44]

Along these lines, TAP can therefore be defined as principles based on human rights: the right to publicly available information about the actions of those in government (transparency, or the right to information); the right to demand compliance and answerability from state actors, and to hold them responsible for their decisions and actions (accountability as a human right principle); and the right to raise one's voice and see one's interests reflected in political decision-making and public policies. TAP also includes rights around service delivery: the right to participation in public affairs, voting rights, and the right of equal access to public service.[45] In 2015, world leaders adopted the 2030 Agenda, endorsing the new Sustainable Development Goals (SDGs). Notably, Goal 16 refers to governance and the commitment to "build effective, accountable and inclusive institutions at all levels," with experts calling for a "data revolution," capturing a conviction that better, more readily available data will help accelerate development outcomes.[46] TAP principles can appear very broad, but if they are framed or contextualized in relation to a particular societal or developmental goal, they become more tangible. For example, using a TAP-based approach in relation to the human right to health could mean ensuring that national health strategies and plans of action would not only lead to the opening of health data to the public, but also to getting citizens' inputs in setting priorities, making decisions, and planning, implementing, and evaluating strategies to achieve better health care.[47]

TAP in practice: different approaches, evidence, and lessons learned

In practice, TAP has been interpreted and applied in two main different ways, depending on whether they are initiated by states or by civil society. Governments, apart from holding elections, usually translate TAP into policies aimed to prevent, deter, and punish corruption, as corrective means to promote accountability and justice.[48] However, the UN Human Rights Council assures that, while reactive punitive approaches are necessary to fight corruption and mismanagement, they fail to bring justice for those affected by the results of corruption.[49] Another way of looking at this government-led type of TAP initiatives is by assessing participation. For example, international donors such as the World Bank and the International Monetary Fund provide loans to indebted countries on different conditions, one of which is the extent to which local civil society organizations have participated in the creation of their respective national strategies to combat poverty (Poverty Reduction Strategy Papers or PRSP).[50]

In the context of the HIV response, civil society organizations have led demands for transparency, accountability, and participation by challenging traditional top-down and over-medicalized approaches to health. Yet TAP principles in the context of HIV have been interpreted in the latter sense by focusing on the participation aspects. In their efforts to increase a sense of ownership, international organizations and donors such as the UN, the Global Fund, and WHO, among others, have been creating and promoting different spaces for KPs representatives to participate in policy debates and discussions (such as participation of civil society delegations in their meetings, consultations by UN bodies and human rights mechanisms, and the establishment of country coordination mechanisms (CCMs) with mandatory participation of KPs to manage resources from the Global Fund, among many others). Similar initiatives and spaces of this nature also exist at regional and national levels (such as consultations with civil society organizations and KPs' representatives made by the Organization of American States (OAS) or the African Union (AU), or at national AIDS Commissions/Councils).

As opposed to state or government-led initiatives, civil society-led TAP initiatives focus on increasing social accountability, defined as the extent and capacity of citizens to hold the state and service providers accountable and make them

responsive to their needs.[51] Thus, aiming at progressively enhancing communities' participation in public affairs, conducting activities such as: establishment of multi-stakeholder policy dialogues or consultations, empowering civil society via capacity building, advocacy for the institutionalization of information access, citizen education in public decision-making, and monitoring the delivery of public services. These types of initiatives are based on evidence that patients benefit from being more engaged in public affairs when it concerns access to (or quality of) healthcare, but there are concerns regarding its effectiveness and final impact on health policies or health outcomes.[52]

Many cases show that enhancing communities' participation in social accountability processes can increase access and coverage to quality health care services.[53] However, when assessing the impact of increased information and transparency on citizen engagement and service provision, the main finding is that such interventions can work in some contexts, but not all. Studies show that the success of a particular TAP initiative may depend on the consideration of several factors such as: the perceived legitimacy and ethical components of these TAP initiatives; the inclusion of the needs and further involvement of governmental officials, health care experts, and professionals; citizens' expertise and overall capacities to operate in a particular system; the way in which their concepts, and operationalization strategies and tactics, are defined and agreed by relevant stakeholders; their continuity over time; and the reliability and accessibility of the data used by the actors involved, among others.[54]

Nonetheless, the lack of evidence of success in achieving the specific TAP objectives of such initiatives does not necessarily mean a lack of intrinsic value for the advancement of human rights, or their further potential benefits in improving service delivery, including health care.[55] A lack of evidence for effectiveness could signify the need for additional research or the inclusion of such lessons learned.[56] Promotion of TAP and keeping civil society organizations and KPs engaged in public affairs must be sustained and enhanced, as their relevance and connection to human rights remain valid and critical.

The way forward: Enhancing TAP as means to promote human rights of KPs and improving the HIV response

Enhancing community access to information and participation in health care policymaking has the potential to improve equitable access, quality, and coverage for health care. Efforts to address the HIV epidemic require that KPs are able to overcome exclusion and can become active participants in the formulation of inclusive and effective health and HIV policies.[57] In all regions of the world, there are positive examples of community-led responses to HIV that advance health and promote human rights in the context of HIV.[58] However, these experiences remain limited in scope and coverage and are often underfunded and marginal.

Efforts to expand the HIV response and to reach the 2030 targets will require scaling up TAP initiatives in the context of HIV. TAP initiatives designed and implemented with a high involvement of KPs could allow them to: demand compliance with the international commitments made by their governments to fight the epidemic; participate meaningfully in the formulation of inclusive and effective health policies; track-down the allocation, disbursement, and use of public financial resources; monitor public contracting (from planning to implementation); access national and local financial resources from their governments; request the publication of health related information and the prices of medicines; and take actions to sanction non-performance or corrupt behavior by those in power.

If future HIV-related TAP interventions are to be successful and hold up to their potential, they should be: contextually grounded, formulated, and agreed-upon by relevant stakeholders; focused on empowering KPs with the technical expertise required for them to become agents of positive social change in their own communities; and aimed at achieving gradual long-term goals aimed at achieving systemic change instead of trying to "fix" service delivery. The following sections will explore the steps that could lead to the formulation of TAP programming in the HIV response, based on the collected evidence of TAP initiatives in the health sector.

Build the field: Establishing HIV-TAP communities of practice

Having been in existence for nearly 20 years, current TAP initiatives have both diversified and specialized in different fields, ranging from multi-stakeholder initiatives by sector—such as the Extractive Industries Transparency Initiative (EITI), the Construction Sector Transparency Initiative (CoST), and the Global Initiative for Fiscal Transparency (GIFT)—to the establishment of international standards—like the International Aid Transparency Initiative (IATI) and the Open Government Partnership (OGP)—and innovation fund mechanisms seeking to harness the potential of new technologies—such as the Transparency and Accountability Initiative, the Global Partnership for Social Accountability (GPSA), and Making All Voices Count (MACV).[59] This means that, even when they may seem different in nature, there are plenty of experiences and lessons that can be incorporated into the fight against HIV/AIDS.

As a first step, spaces and opportunities should be created for the formulation of joint strategies to tackle the lack of TAP in the health sector specifically, which is increasingly affecting the fight against HIV. Establishing international, regional, and local platforms formed by the different stakeholders involved in the HIV response—such as non-governmental organizations, KPs' organizations, pharmaceutical companies, and private health care providers, universities, and research institutes, international organizations, and governments—could enable the sharing of technical knowledge and the framing of common challenges and objectives.

Ideally, such platforms would need to be open to actors that are not directly working on HIV/AIDS, to foster cross-cutting creative collaborations between different professional sectors. Building such bridges to connecting different fields of expertise and social movements under the TAP umbrella can also catalyze innovation and potentially lead to the formulation of new frameworks, tools, and methodologies for the advancement of human rights and enhance KPs' participation in the HIV response.[60]

As an example, there are opportunities for the HIV response to be strengthened by harnessing the potential of "open data"—machine-readable information that anyone can freely access, use, modify, and share—and learn from the "open government" social movements advocating to expand demand for and access to public information, particularly from governments.[61] According to WHO, opening access to sound and reliable health data and information to the public domain is an essential feature of any effective health system.[62] Accessing this information enables individuals and communities to promote their own health, participate effectively in decision-making, claim quality services, monitor progressive realization of their rights, expose corruption, and hold those responsible to account. Recent evidence shows that these types of initiatives have a direct positive impact when applied to procurement processes in health, such as achieving better value for money, and lead to innovations in the monitoring of health care service delivery (including HIV interventions).[63]

Furthermore, public information needs to be presented in ways citizens can easily comprehend and analyze in relation to their needs, and with a clear understanding of the risks associated with the liberation of such data (for example, violation of privacy rights and possible misuse or misinterpretation of data).[64] To mitigate such risks, alliances can be formed between KPs and *infomediaries* (that is, agents who can take complex data and translate, package, and contextualize it for use by wider segments of society, such as international organizations, NGOs, information and communications technologies (ICT), and open data experts and activists, journalists, and watchdogs), to fill gaps in the supply and demand chain of information. In the case of the HIV response, *infomediaries* would ensure that KPs use government-published data effectively and in a responsible and well-informed manner.[65]

Building "cross-sector" alliances and communities of practice, shared between the KPs engaging in the HIV response and *infomediaries,* could also help in bridging those conceptual gaps and increasing the limited capacities that KPs and communities

experience when trying to engage meaningfully in complex decision-making processes. For example, if a sex worker living with HIV wants to engage with the National AIDS Council, this person would need to not only overcome the stigma and discrimination attached to his or her medical condition and/or behavior in order to participate, but would also need to be fully prepared with the right knowledge and tools to do so effectively. Providing spaces and resources for knowledge exchange could lead to the development of shared agendas, and new narratives and practices around TAP principles in the context of the HIV response could be truly beneficial to enhance its sustainability and effectiveness. *Infomediaries* could employ user-centered approaches to develop technologies and tools to facilitate open data collection and analysis (for example, new software applications for mobile phones and tablets), which could allow KPs to better harness and benefit from the "data revolution."

KP-led TAP mechanisms key to financial sustainability and effectiveness

Along with including TAP strategies in the response, and raising the awareness about the importance of such principles to overcome the main challenges of the HIV response, further steps need to be taken to enhance KPs' participation. As the people affected by HIV and the potential agents of change, KPs' participation can revitalize the effectiveness of the global efforts against HIV. Their input is necessary to adequately set the priorities and strategies of effective HIV programming.

Given increasing financial pressure, KPs need to have a say in how donors will transition out of their countries, how their governments will channel public budgets to fund national HIV plans, and how to ensure that the promises made for 2030 become a reality.[66] This would require further cooperation from the different actors involved in health governance. States must fulfill their human rights obligations by repelling discriminatory regulations, and take steps to have transparency and social accountability mechanisms in place where KPs can participate. The international community, and donors in particular, should stress their role to support governments and KPs in advancing human rights.

Furthermore, international donors and funders need to better plan their strategies and consult KPs as they transition out from middle-income countries, to avoid creating further gaps in the funding of HIV prevention and treatment services. Their support would also create pressure for governments to: increase funding to sustain the HIV response under specific funding streams and budget lines in their national health strategies and programs to address HIV; increase efficiency, transparency, and accessibility of information for constituents on how national resources are being spent; ensure inclusivity and effectiveness in the planning phase of budget allocation and contracting; and monitor implementation of their national HIV plans by including citizens and KPs.

Conclusion

Achieving the Sustainable Development Goals and the end of AIDS before 2030 requires placing human rights and TAP principles on the agenda's main priorities, as a social justice imperative, and as tools to improve the sustainability and impact of public health care delivery. By fully endorsing TAP while funding from international donors remains in place, KPs could prepare to harness the potential of new technologies, open data, and open governments. This will aid them to demand well-funded and inclusive national responses against HIV, to adequately monitor budgets and progress of governments' political and legal commitments to respect their human rights, and to participate meaningfully in decision-making.

Evidence shows that in order for the HIV response to become more effective and sustainable, it is necessary to overcome inequality and discrimination against KPs. Thus, policies should focus on prioritizing KPs needs and human rights and targeting the underlying causes (or social determinants) that drive the epidemic. Comprehensive health care must become accessible and affordable for all people without discrimination of any kind, yet meaningful involvement of KPs in the governance structures of the HIV response (particularly

at the national level) is a key element of the solution but remains unattended.

Promoting alliances across different development sectors, and particularly with activists focused on access to information, would help to promote TAP in the HIV response. The goal is to find ways in which data can be collected, analyzed, and made accessible to fit the needs and rights of KPs. Financial and health data must be fully accessible to KPs and NGOs in user-friendly formats, as a way to better monitor government actions, curb corruption, and successfully advocate for change.

The international community needs to find strategies to ensure and maintain HIV interventions—both prevention and treatment—in the immediate future and even beyond 2030, by remaining well-funded by governments, the private sector, and international donors in a transparent and accountable manner. International investments in human rights-based programming should continue as long as stigma and discrimination of KPs remain. Further, local and international HIV programming should be budgeted annually by all governments, and integrated within integral health policies (including sexual and reproductive health) until the epidemic is finally controlled.

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A Reporting System to Protect the Human Rights of People Living with HIV and Key Populations

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Abstract

People living with HIV and key populations face human rights violations that affect their access to health services, relationships in their communities, housing options, and employment. To address these violations, government and civil society organizations in Ghana developed a discrimination reporting system managed by the Commission on Human Rights and Administrative Justice that links people living with HIV and key populations to legal services. This article presents findings on how Ghanaian stakeholders built this reporting system and discusses preliminary data on its impact. To organize our analysis, we used a conceptual framework that outlines the legal frameworks that protect human rights, the institutions that promote access to justice, and the mechanisms that link people living with HIV and key populations to legal services. Using in-depth interviews, we show that targeted technical assistance increased stakeholders' knowledge of issues that affect people living with HIV and key populations, strengthened these stakeholders' commitment to address discrimination, streamlined case management systems, and improved relationships between civil society and the government. Through case review, we find that most discrimination happens when accessing government services, inside communities and families, and in the workplace. Finally, we describe implications for other human rights commissions that are considering using a reporting system to protect human rights, including using legal frameworks, developing case management systems, and working with civil society.

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Introduction

People living with HIV and key populations, including men who have sex with men, sex workers, and people who inject drugs, commonly experience human rights violations, such as community or family exclusion, police or vigilante assault, the denial of basic services, and the non-consensual disclosure of sensitive health information.[1] As a result, they are often unable to access critical services, including health, education, security, and employment.[2] These human rights violations are the result of stigmatizing behaviors and discriminatory actions on the part of families, communities, employers, and government institutions, and they contribute to poor uptake of health services by people living with HIV and key populations.[3]

Legal protections are an important tool to ensure the fulfillment of human rights, as they provide a framework for restitution and justice when necessary.[4] To this end, governments have adopted and ratified international agreements that create binding legal obligations to protect human rights. The norms and protections provided in the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination against Women, and the International Covenant on Economic, Social and Cultural Rights and other global and regional human rights instruments have been interpreted as applying to people living with HIV and members of key populations.[5]

Further, several resolutions and declarations specifically address human rights violations against people living with HIV and key populations. For instance, the 2011 United Nations' Political Declaration on HIV requires member states to proactively "create enabling legal, social and policy frameworks in each national context in order to eliminate stigma, discrimination and violence related to HIV … provide legal protections for people affected by HIV … and promote and protect all human rights and fundamental freedoms."[6] This declaration—together with the 2001 Declaration of Commitment on HIV/AIDS and the 2006 and 2016 Political Declarations on HIV and AIDS—calls on member states to protect the human rights of people living with HIV and key populations.[7]

Building on these commitments, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has outlined seven key programs to reduce stigma and discrimination and increase access to justice.[8] Strengthening legal support services is one of these key programs, though only 55% of countries reported having such services in 2013.[9]

In 2012, the government of Ghana and civil society organizations (CSOs) established a web- and SMS-based discrimination reporting system to allow people living with HIV and key populations, and the CSOs that represent and support them, to report cases of discrimination in housing, government services, health, education, employment, and other relevant areas to the Commission on Human Rights and Administrative Justice (CHRAJ). As it receives these cases, CHRAJ can mediate, investigate, or adjudicate them.[10] The Health Policy Project, a USAID- and PEPFAR-funded technical assistance project, supported the system's development.[11]

The reporting system is based on a conceptual framework that outlines the necessary policy, legal, organizational, and relational components. It theorizes that three key elements—(1) legal and policy frameworks, (2) institutions that promote access to justice, and (3) mechanisms to link people living with HIV and key populations to legal services—are necessary to ensure that a discrimination reporting system protects the human rights of people living with HIV and key populations.[12]

The conceptual framework defines legal and policy frameworks as including constitutional, legislative, policy, and case law provisions. These legal provisions describe the theoretical basis for protecting the human rights of people living with HIV and key populations, though they do not outline practical measures for ensuring that human rights are respected.

Practical measures are defined by the institutions that promote access to justice. According to the framework, CSOs and government agencies may play one of three roles: managing the logistics of the discrimination reporting system as a "clearinghouse" of cases; connecting complainants to the system; or helping complainants resolve the issue directly.

These institutions must work together to ensure that mechanisms are in place for complainants to access justice. The mandates and responsibilities of various organizations define which organizations take on which roles to ensure access to justice. The existing connections and skill sets of these organizations must also be taken into consideration when designing reporting and case management systems.

The elements of the conceptual framework are described in an earlier article; the present study outlines findings from the framework's implementation. It shows how institutions interpret their role in upholding human rights and how relationships between various actors affect opportunities for access to justice.

We begin by describing the intervention and discussing our data collection efforts, which were based on in-depth interviews and capacity assessments. We then analyze the situation at baseline, according to the elements of the conceptual framework. Third, we describe the intervention, including the elements of the reporting system. Fourth, we use the conceptual framework to analyze the effectiveness of Ghana's discrimination reporting system, including a review of case trends and progress. Finally, we identify implications for other institutions, including national human rights institutions, that protect the human rights of people living with HIV and key populations.

Evaluation methodology

In April 2012, the Health Policy Project conducted 18 in-depth interviews of representatives from civil society, government, and international organizations that support the human rights of people living with HIV and key populations. Through these interviews, we developed data on the baseline policy and legal environment for people living with HIV and key populations, institutions that promote access to justice, and mechanisms linking people living with HIV and key populations to legal services. In June 2015, three years after the start of the specific interventions described below, we conducted 21 in-depth interviews with similar key informants to understand how the interventions had affected the three areas of the framework.

We also conducted baseline and endline capacity assessments using the USAID Organizational Capacity Assessment methodology as a structure.[13] We modified this capacity assessment tool to focus on four key technical and relational areas related to CHRAJ's capacity to work with people living with HIV and key populations. Those four areas are (1) knowledge of issues that affect people living with HIV and key populations, (2) case and information management, (3) relationships with human rights and HIV organizations, and (4) CHRAJ's institutional commitment to supporting people living with HIV and key populations. We conducted the baseline assessment in October 2012 and the endline assessment in June 2015. P-values were calculated using the Fisher's exact test, due to small sample sizes.

We coded the interview data using the elements of the conceptual framework. We aggregated quantitative scoring data from the capacity assessments using Excel. Finally, we obtained case analysis data from the reporting system in September 2015 and anonymized it by removing names and assigning unique identifiers. We report this data using categories identified in the reporting system.

There are a few limitations to our evaluation approach. First, the interviews and organizational capacity assessments were done at two discrete points in time. As a result, we interviewed different people at these organizations in 2012 and 2015, who may or may not have held the same views as their predecessors. To mitigate this limitation, we kept a list of people we interviewed in 2012 and attempted to track them to their new jobs during the interviews we conducted in 2015, if the new organization was also involved in human rights or HIV programming. Second, cases reported to CHRAJ are self-reported, resulting in some level of selection and recall bias. These biases are inherent in any evaluation that relies on self-reported data.

Baseline results

Ghana has ratified several important human rights treaties that support rights relevant to HIV,

including the rights to privacy, education, work, security, the highest attainable standard of health, and participation in public life.[14] Since these treaties do not carry the force of law in Ghana, human rights protections for people living with HIV and key populations are mostly found in constitutional provisions, legislation, and policies.[15] Little case law defines how constitutional provisions apply to people living with HIV or key populations.[16] Only the right to confidential HIV services has been upheld in case law.[17] The Criminal Offenses Act prohibits "sexual intercourse with a person in an unnatural manner" and living "wholly or in part on the earnings of prostitution."[18] These prohibitions have numerous legal and real-world consequences for key populations.[19]

In Ghana, institutions that promote access to justice can be grouped into two main categories: CSOs and government agencies (including security services).[20] Before the intervention, some human rights CSOs provided legal- or community-based support for people living with HIV and key populations who experienced discrimination.[21] According to interviewees, this support focused on peer education and strengthening community-based networks. Though most CSOs could not provide people living with HIV and key populations with legal services, the Human Rights Advocacy Centre had a network of pro bono lawyers and a legal aid desk which provided limited legal services, subject to the availability of volunteer lawyers. CHRAJ has a mandate to protect the human rights of Ghanaian citizens, but had not focused on issues affecting people living with HIV and key populations. The Ghana AIDS Commission recognized that the government should systematically address human rights violations against people living with HIV and key populations, but it did not have the mandate or capacity to do so. The Ghana AIDS Commission signed a memorandum of understanding with CHRAJ in 2012 to report, and act on, cases of discrimination against people living with HIV and key populations. Security services, such as the police and the military, are critical to ensuring human rights by arresting perpetrators and supporting people living with HIV and key populations when they are assaulted or blackmailed.

According to interviewees, CSOs were unaware that CHRAJ's mandate included human rights protection. Most CSOs thought that CHRAJ was solely an anti-corruption agency or worked on high-level political issues. CSOs focused on HIV and key populations had these impressions of CHRAJ because they had never worked with the commission. While they did want to engage with CHRAJ, they were unsure how to initiate such engagement. CHRAJ did, however, have strong relationships with schools, churches, and other civic institutions and had conducted human rights trainings and outreach for these entities. CHRAJ had not used these tools to reach out to people living with HIV or key population groups.

Based on this analysis, a consensus among stakeholders emerged: CHRAJ would be the institutional home for a discrimination reporting system that would help complainants resolve issues through the commission's case management process and would refer cases to police and human rights organizations as appropriate. Civil society would connect complainants to the system.

Intervention description

Using results from the baseline in-depth interviews, we, along with stakeholders from civil society and government agencies, developed the discrimination reporting system between April 2012 and December 2013. During this time, we created the system's website and SMS module, determined how the system would integrate with existing CHRAJ case management processes, identified how to address user feedback, and trained CHRAJ and CSO staff on how to use the system.

The system allows people living with HIV and key populations to report discrimination directly to CHRAJ or to a CSO. If a complainant reports a case to a CSO, the organization then forwards the complaint to CHRAJ and acts as an intermediary between the complainant and CHRAJ. Using this process, the complainant can remain anonymous if he or she wishes. If a complainant reports the case directly to CHRAJ, the commission handles all communication

and the complainant cannot be anonymous. Complainants can also report a case to CHRAJ through an SMS module of the reporting system.

Once a case is submitted, CHRAJ uses a three-step mechanism to seek redress: mediation, investigation, and adjudication.[22] In mediation, CHRAJ facilitates a negotiation between the various parties.[23] According to CHRAJ interviewees, most cases are successfully mediated. If mediation fails, the commission will investigate the case and provide a recommendation that aligns with Ghanaian law.[24] If the parties choose not to follow the recommendation, CHRAJ can go to court to enforce it.[25] Potential recourses in these cases include fines, reinstatement, sanctions, and training.[26]

The system also allows CHRAJ to refer cases to other organizations or institutions that may be better equipped to handle them. For example, CHRAJ refers assault cases to the police and works with legal service organizations, such as the Human Rights Advocacy Centre, to ensure their legal cases are reported to CHRAJ.[27]

The system was launched in December 2013. Between the launch in December 2013 and July 2015, the Health Policy Project and CHRAJ conducted four main interventions. First, they trained CHRAJ's regional and district staff and CSOs to sensitively manage cases of discrimination against people living with HIV and key populations, use the reporting system, and strengthen relationships between CHRAJ, CSOs, and potential complainants. Second, they developed a privacy and confidentiality policy which detailed how personal information would be handled within CHRAJ, including file handling procedures, data use, consent, preventing confidentiality breaches, and sanctions for non-compliance. Third, CHRAJ restructured its case management procedures to improve complainant privacy and reduce response time by appointing a specific team to handle cases that come through the reporting system, providing both a point of contact for CSOs and minimizing the number of people who see a complaint. Complaints also began to be routed through the confidential track, which had previously been reserved for corruption cases. Finally, in May 2015, the Health Policy Project, the West African AIDS Foundation, and CHRAJ conducted workshops for CSO-trained peer educators aimed at highlighting legal service options, fundamental human rights, and the types of discrimination to report to CHRAJ. These peer educators received materials about CHRAJ and the reporting system to share with their networks.

Endline results

The legal environment for people living with HIV and key populations in Ghana underwent minor changes between the baseline assessment in 2012 and the endline assessment in 2015. In particular, in 2013, the country adopted its National HIV, AIDS, and STI Policy, which prohibits discrimination against people living with HIV but does not specify a penalty.[28] The policy also highlights CHRAJ's role in instituting legal proceedings and "establish[ing] systems to provide regular reporting of cases of discrimination."[29] Finally, it calls on the government to ensure compliance with the principles of non-discrimination.[30]

In 2016, after our evaluation was conducted, however, two major changes were made to Ghana's legal and policy environment. First, the 2016–2020 National HIV and AIDS Strategic Plan was enacted. This plan describes barriers faced by people living with HIV and key populations, including the uncertain legal status of homosexuality and sex work, cultural and religious values, and weak HIV prevention efforts in prisons.[31] It also outlines several activities to mitigate discrimination and enforce human rights protections, most of which focus on information sharing, advocacy in support of rights-based frameworks, and institutional support to government agencies that interact with people living with HIV and key populations.[32] The strategic plan also codifies CHRAJ's role in protecting the rights of people living with HIV and key populations. Second, that same year, Ghana passed the Ghana AIDS Commission Act, which enumerates specific rights for people living with HIV, including the rights to non-discrimination, health, privacy, insurance, employment, education, political engagement, movement, and reproduction.[33]

This law also provides specific penalties for violations of these rights.[34] Because the law is so new, it is too early to gauge its practical effects.

The institutions that promote access to justice in Ghana were much stronger in 2015 than in 2012. Given that CHRAJ is the institutional home for the reporting system, we focused our efforts on measuring institutional capacity within CHRAJ (Table 1). CHRAJ showed a strong commitment to promoting access to justice for people living with HIV and key populations between 2012 and 2015. During this period, the commission's senior management provided resources for a privacy and confidentiality policy, focal persons to work on the discrimination reporting system, and CSOs and peer educator outreach. CSO interviewees said that CHRAJ had good staff support that encouraged people to report cases but also that CHRAJ staff needed to do more outreach to people living with HIV and key populations to maximize the full benefits of the system. CSOs also showed a strong commitment, as at least six organizations identified a focal person to support the reporting system and eleven organizations reported a case to CHRAJ.

Interviewees and the capacity assessment (Table 1) showed that by 2015, CHRAJ had more knowledge of how human rights issues apply to people living with HIV and key populations. CHRAJ interviewees said that their skills in using international and Ghanaian law to protect people living with HIV and key populations had improved, but they had not yet had the opportunity to take a case to court. In addition, CSOs reported that CHRAJ's knowledge of the types of discrimination faced by people living with HIV and key populations had improved. However, interviewees had little experience with CHRAJ staff at the regional or district levels and were thus unable to evaluate their knowledge of issues relating to people living with HIV and key populations beyond Accra.

By 2015, CHRAJ could operate the discrimination reporting system, and CSOs felt that the commission was a welcoming environment for people living with HIV and key populations to report complaints. According to CSO and CHRAJ interviewees, CHRAJ typically contacted complainants within 48 hours, rather than 10 days, which is the standard response time for complaints. The commission achieved this improvement in response speed by routing cases directly to the relevant director for approval rather than waiting for a meeting to review. As a result, cases are mediated and investigated faster. Some drawbacks, however, are common to all CHRAJ cases: for example, CHRAJ needs complainants to identify perpetrators, and it has few investigators.

Between 2012 and 2015, CHRAJ also faced challenges in meeting its infrastructure needs. For example, by 2015, the commission's phone lines had been down for over a year, and its internet was available only intermittently. CHRAJ staff relied on personal mobile phones and tablets to access the discrimination reporting system and contact complainants. Interviewees noted that privacy and confidentiality had improved within the commission: they now had a dedicated office for interviews, private data was more secure, and staff were aware of confidentiality procedures. Multiple interviewees from CHRAJ and CSOs alike said that this was a key change that helped build trust.

TABLE 1. CHRAJ capacity: Pre-intervention (2012) and post-intervention (2015)

Institutional commitment to address discrimination against people living with HIV and key populations	2.8	3.6*	0.003*
Knowledge of issues related to people living with HIV and key populations	2.3	3*	0.002*
Management of discrimination cases against people living with HIV and key populations	3	2.9	0.6
Relationships with human rights organizations	4	3.6	0.13
Relationships with organizations supporting people living with HIV and key populations	1.8	3.6*	0.000*

Self-reported by CHRAJ staff using USAID's Organizational Capacity Assessment methodology on a four-point likert scale.

* denotes p-values are significant at 0.05 level

Finally, the mechanisms linking people living with HIV and key populations to legal services improved significantly between 2012 and 2015. Most complainants reported cases to CSOs, who then referred the cases to CHRAJ via the discrimination reporting system (Table 2). CSOs would often work with complainants to make sure they felt comfortable reporting their case to CHRAJ, such as by escorting complainants to CHRAJ for in-person interviews. CSOs noted that many of the cases they referred to CHRAJ came through their peer educator networks. One interviewee felt that this targeted approach worked well, noting that "outreach and information sharing to peer educators is the key to the referral chain." Another said that "use will go up as people get redress and share their experiences."

This referral structure helped maintain face-to-face interactions while also providing access to CHRAJ's legal services. Multiple CSOs that work with people living with HIV and key populations benefited from their relationship with CHRAJ because the commission provided them with redress options. Furthermore, the Ghana AIDS Commission was critical to linking people living with HIV and key populations to CHRAJ's services, as it coordinated engagement and tracked cases.

Though all but one of our CSO interviewees had entered cases into the system, some were still having challenges understanding what types of data to enter and how to track cases. The SMS module presented even more challenges. Interviewees did not know if complainants were using SMSs to contact CHRAJ and did not think that people living with HIV and key populations knew about the SMS feature. Most interviewees thought that the SMS module required more marketing, and few CSOs told complainants about the SMS option.

Case analysis and progress

Between December 1, 2013, and September 30, 2015, people living with HIV, key populations, and CSOs reported 50 cases of discrimination to CHRAJ (Table 3). Reporting was sparse in 2014, as CHRAJ did little outreach, instead focusing on quickly and appropriately managing the few cases it did receive. Following the workshops in May 2015, reporting climbed from one–two cases per month to four–five cases in May, June, and July. CHRAJ received seven cases directly from workshop participants.

Table 3 shows that men who have sex with men and people living with HIV used the system more frequently than sex workers did. The most common types of violations reported were assault and the disclosure of confidential health information, followed by blackmail and the denial of health

TABLE 2. How are cases reported to CHRAJ?

Type	Number	Percentage
CSO-reported through reporting system	28	56%
Reported in person	11	22%
Self-reported through reporting system	10	20%
Self-reported through SMS	1	2%
Total	**50**	

TABLE 3. Complainant profiles

Group	Number
People living with HIV	22
Men who have sex with men	21
Sex workers	7
Total	**50**

care or employment (Table 4).

Our review of these cases revealed that discrimination took place in different environments. The first environment was in the family, especially during divorces, when a relative would threaten to disclose someone's HIV status to gain access to land or money. Domestic violence and abuse, especially following disclosure to spouses, was also common.

During the reporting period, CHRAJ mediated non-consensual disclosure cases. Since disclosure was not explicitly illegal during this time, legal action was rarely a possibility. Resolved cases typically included a written understanding between the two parties or an apology. CHRAJ referred assault cases to the police for criminal investigation, while providing emotional support and guidance to the complainant.

The community was the next critical environment for discrimination. Men who have sex with men often reported cases in which their neighbors or landlords discovered that they have sex with men or identify as gay. These men were often threatened with eviction or blackmailed for consumer goods, such as phones, computers, and bicycles. In addition, men who have sex with men were commonly assaulted by young men. CHRAJ referred assault cases, which fall outside of its mandate, to the Domestic Violence Victim's Support Unit of the Ghana Police Service, which is trained to handle them. For housing discrimination cases, on the other hand, CHRAJ got involved by mediating between the landlord and complainant. These mediation sessions served to remind the landlord of his or her obligations under the law. Community-based discrimination also included witchcraft allegations and the non-consensual disclosure of HIV status. These cases were mediated; actions included community discussions and, in the case of witchcraft allegations, multiple mediation sessions leading to a written agreement where the respondent agreed not to continue the allegation.

Human rights abuses also occurred at work. Most such cases involved sex workers who were assaulted by clients. These cases were rarely brought to the police, however, as police are known to abuse sex workers.[35] Employment discrimination was not as common as other types of discrimination. These cases included both large private employers and small market stalls. CHRAJ addressed these cases through police referral, mediation, and the filing of lawsuits against employers.

Discrimination by government institutions was also a widely reported human rights abuse. Five cases of discrimination involved police stations imprisoning men who have sex with men who had reported assault or blackmail, as well as dismissing their cases without investigating. A few cases included health center staff disclosing someone's HIV status to family members. CHRAJ handled these cases quickly through mediation. Outcomes included returning private property to men who have sex with men who had been blackmailed, convincing health centers to waive improper fees for drugs, raising health facility managers' awareness of non-consensual disclosure issues, and reinstating a student who was expelled from school.

As of September 30, 2015, 21 cases were resolved or referred to another entity. Of the ten cases that were completed, six were resolved through mediation. For the three cases that CHRAJ closed after investigating, the commission issued written findings to the complainant and respondent. Elev-

TABLE 4. Commonly reported human rights violations

Type of violation	Number
Assault	13
Disclosure of health information	14
Blackmail	9
Denial of health care	4
Denial of employment	4

en cases were transferred to other entities—namely, the police and human rights organizations.

Twenty-nine cases were ongoing as of September 2015, with all but three of them having been submitted in the previous six months. Most of these cases were in the investigation stage (Table 5). Investigations require interviewing witnesses, collecting statements, obtaining documentation, and writing recommendations; as a result, they can take many months to complete. The complexity of a particular case drives how quickly it is resolved. In some cases, mediation resolved misunderstandings and solved the problem quickly, while others required the courts' intervention to clarify the law.

Given that stakeholders designed the system to include reports from CSOs, we also analyzed how cases were reported to CHRAJ. As Table 2 shows, CSOs reported 56% of cases through the reporting system, while 22% of complainants filed their cases in person at CHRAJ's offices. In-person reporting includes those people who were escorted by CSOs. Most surprising, however, is that 20% of complainants reported directly to CHRAJ through the web-based reporting system without a CSO acting as an intermediary; this figure is unexpected, considering that internet penetration in Ghana was only 17.1% in 2012.[36] The SMS module accounted for only one case.

Implications for other countries

Our analysis of interviews and case data reveals some key lessons for other countries' national human rights institutions, AIDS commissions, CSOs, and technical assistance providers working to improve access to justice for people living with HIV and key populations.

First, while the legal basis for redress is important, it is not strictly necessary. There are numerous unclear provisions in Ghana's legal framework for people living with HIV and key populations. With the right set of tools, however, a government institution with strong community-based partners and a mandate to protect human rights can overcome these gaps. CHRAJ has done so by reaching out to CSOs, providing options for mediation, and directly questioning the actions of government institutions. Mediation is especially critical if there is no explicit legal basis for redress, as filing a lawsuit and obtaining a legal remedy can take years in contexts with a weak judiciary. Nonetheless, legal action is necessary in some cases to clarify frameworks, prevent future violations, and obtain redress where mediation has failed.

Second, developing the capacity of systems and structures is critical. Since CHRAJ already had well-developed case management systems, we sought to adapt those systems to the specific needs of people living with HIV and key populations, such

TABLE 5. Case progress

Case status	Number
Completed by CHRAJ	10
mediated	6
investigated	3
withdrawn by complainant	1
Ongoing	29
in mediation	2
under investigation	26
in litigation	1
Transferred	11
to civil society	10
to police	1

as by improving privacy and response speed. Both CHRAJ's privacy and confidentiality policy and its confidential case routing track improved these areas. Given that people living with HIV and key populations have well-developed social networks in Ghana, word-of-mouth reports of poor service could negatively affect service uptake.

Case management systems, however, are only as good as the people handling the cases. CHRAJ staff were trained, mentored, and coached on how to provide sensitive services to people living with HIV and key populations. As noted earlier, CSO interviewees said that CHRAJ's services were welcoming and that the interviewees would continue to refer cases to CHRAJ. In addition, CHRAJ staff conducted outreach to people living with HIV and key populations in order to build relationships and understand how to relate to different types of clients.

Capacity and infrastructure challenges within CHRAJ and CSOs did, however, hinder full adoption of the reporting system. Infrastructure-related barriers, such as poor phone lines and internet access, led to inefficiencies in accessing the reporting system and responding to complainants. Moreover, human resource gaps, such as the lack of trained district- and regional-level staff and of case investigators, negatively affected the system. Also, many CSO staff were unfamiliar with web-based systems and needed significant training to report and manage cases. National human rights institutions must account for these increased infrastructure and training needs in order to effectively run a web-based reporting system, perhaps by budgeting for infrastructure upgrades, hiring new staff and trainers, and planning for increased engagement with civil society.

Third, people living with HIV and key populations must be linked to legal services by a trusted mediator. CSOs' activation of social networks was critical to linking key populations to CHRAJ's services. Since many of these networks are underground, CHRAJ alone could not reach them. These strategies were made possible by a planning and feedback process that allowed CSOs and CHRAJ time to understand how each other worked. More outreach to these networks through peer educators and peer-led groups would better link people living with HIV and key populations to CHRAJ's services. National human rights institutions and CSOs in other countries should consider other creative, context-specific ways to improve trust between people living with HIV and key populations and legal service providers.

A key innovation from this study is the focus on relationship building over technical solutions. Yes, the reporting system is a piece of technology; it is, after all, a website with reporting and feedback functions. The system, however, works only if stakeholders share the goal of improving human rights protections for people living with HIV and key populations, bring their various skills to the table to achieve that goal, and commit to building relationships to strengthen the system. In Ghana, stakeholders from civil society and the government were engaged throughout the process to plan, design, implement, and monitor the system. Their input and engagement allowed CHRAJ to reach people living with HIV and key populations through peer education networks, improved users' experiences with the reporting system, and ensured that cases were reported and tracked.

National human rights institutions face a decision concerning SMS modules. Though most Ghanaians own phones with SMS capability, we found that most complaints arrived to CHRAJ via CSO referral. CSOs showed little interest in the SMS module, as they rarely told potential complainants about it. Improved marketing by both CHRAJ and CSOs could have bolstered uptake of the SMS module, though stakeholders—in light of limited resources—chose to focus on social network activation instead. The SMS module could have increased reach beyond those peer networks. In this particular context, however, improved marketing of the SMS module would have been at the cost of peer-network relationship building.

Conclusion

We have shown that a reporting system can provide a critical link between people living with HIV, key populations, civil society, and national

human rights institutions. In Ghana, we used legal and policy frameworks, supportive institutions, and mechanisms linking people living with HIV and key populations to legal services to create a system that provides real redress for human rights violations. Other national human rights institutions can use our framework and experience to determine if a discrimination reporting system is the right solution for the human rights challenges faced in their countries.

Ethics statement

A research proposal was submitted to the RTI International Institutional Review Board. The board determined that our research did not involve "research with human subjects," per 45 CFR 46.102, and that its approval was not necessary.

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As the HIV Epidemic among Young Women Grows, Can We Look to the SDGs to Reverse the Trend?

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Abstract

To end the growing HIV epidemic among young women, human rights violations must be addressed. The Sustainable Development Goals have the potential to help, but only if political barriers are overcome and a rights-based approach is integrated.

Introduction

We have long known that biomedical interventions alone will not curb the HIV epidemic among young women and girls in sub-Saharan Africa. The history of the global response to HIV is ripe with political failures to address deep-seated human rights violations. Gender inequality—which ranges in its manifestations from persistent failures to recognize the sexual and reproductive health and rights of women to economic injustices perpetuated through law—allows HIV to flourish among young women and girls. This correlation between human rights violations and poor health outcomes for women and girls was not addressed by the Millennium Development Goals (MDGs), which were aimed at eradicating poverty and did not adequately measure the drivers of HIV among young women. The promise of the Sustainable Development Goals (SDGs), in this respect, is to reduce the interrelated factors that cause or contribute to gender inequality, while also reducing gender inequality's impact on health and HIV.

This paper attempts to interrogate the promise of the SDGs, specifically SDG 5. SDG 5 presents us with an opportunity to better address the challenges that contribute to women's and girls' vulnerability to HIV, for by zeroing in on these

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indicators through a legal framework, we can generate action and accountability around the human rights of young women and girls.

The paper also describes our experience developing a proposed methodology for SDG indicator 5.6.2. This indicator—which measures the number of countries that have laws and regulations guaranteeing access to sexual and reproductive health care, information, and education for women and girls—is unique in that it represents the first attempt to measure the number of countries in compliance with the Programme of Action of the International Conference on Population and Development (ICPD) and the Beijing Platform for Action. As such, it presents an opportunity to better address the challenges that contribute to young women's and girls' vulnerability to HIV by zeroing in on the existence of laws and policies that directly or indirectly affect the health of this population. This has the potential to generate action and accountability by states and other relevant actors vis-à-vis young women and girls affected by HIV—assuming that the process is not hampered by methodological flaws.

We begin with a discussion of the environmental factors that enable the spread of HIV among young women and girls in sub-Saharan Africa. We then briefly discuss the missed opportunities associated with the MDGs. Next, we show that the human rights framework is critical to the promise of advancing the sexual and reproductive health of women and girls, before moving on to a lengthier discussion of the SDGs, particularly SDG indicator 5.6.2. We conclude with a discussion of the political dynamics of the SDG process and proposals aimed at securing comprehensive and accurate data on the indicators.

Factors that drive the HIV epidemic among young women and girls

The HIV epidemic has been devastating for young women and girls. The root causes of this devastation are complex, multifactorial, and interrelated—and include converging epidemics such as sexually transmitted infections (STIs), sexual and physical violence, and drug addiction, as well as more macro-level issues such as economic injustice, structural inequalities, inadequate political participation, and the widespread failure to recognize and protect reproductive rights. For example, in the early years of the United States' HIV epidemic, women and girls living with HIV were overlooked and neglected both politically and medically; the situation improved only after prolonged advocacy efforts.[1] In other parts of the globe, health systems have frequently violated women's rights rather than addressing their needs, with coercive practices such as forced sterilization and abortion documented in Kenya, South Africa, China, and Cambodia.[2]

This is all the more tragic because the burden of HIV, particularly in sub-Saharan Africa, falls disproportionately on young women and girls, who not only have greater biological vulnerability to the disease but are also affected by a lack of access to preventive and medical services, as well as by the relative powerlessness that stems from restrictive gender norms and diminished legal status. Moreover, as the global epidemic has progressed, its toll on young women has become particularly apparent. In 2015, UNAIDS estimated that 2.3 million women between the ages of 15 and 24 were living with HIV worldwide—making this population 60% of all young people (aged 15–24) living with HIV. This trend can also be observed in new infection rates, which are particularly dire in sub-Saharan Africa: in 2015, women accounted for 56% of new infections among adults 15 years and older, with women aged 15–24 making up 66% of new infections among young people.[3] The remainder of this section provides a brief overview of the overlapping inequalities that drive the HIV epidemic among women and girls.

Gender inequality and its effects on economic security, educational access, and health

Despite the widespread ratification of international treaties and conventions that promote gender equality, gender inequality persists in sub-Saharan Africa and around the world. This has obvious economic ramifications—for example, the gender wage gap in sub-Saharan Africa is among the highest in the world, and women hold diminished status in many economies in this region.[4] While this alone increas-

es the vulnerability of women and girls by making them dependent on male relatives for financial support, its impact becomes even more severe when one considers the ripple effects on educational access. Education is important: not only do women with higher educational attainment tend to delay sexual debut and marriage, but increased educational attainment is also linked to increases in self-efficacy, economic stability, and negotiation of safe-sex practices.[5] And because all of this is considered protective against HIV, the fact that many families from the low-income states of sub-Saharan Africa do not have the financial means to send their daughters to school is troubling from a health perspective.

There is also an endogeneity effect at work: women's unequal status in the labor market relegates them to caregiving work (also considered their traditional role in some states), but the HIV epidemic has now made the burden of caregiving so great that its physical, social, and psychological impacts make women more vulnerable to HIV. Women and girls account for 66–90% of all AIDS caregivers worldwide and two-thirds of all caregivers for people living with HIV in southern Africa—with the burden of this caregiving exacerbated in rural and resource-poor settings.[6] The effects of this distribution of care work are tremendous: young girls who may otherwise have been fortunate enough to attend school are now often absent because they are needed at home; when the economic demands of caregiving become particularly acute, some of these girls may resort to work outside of the formal economy in order to provide for their families. Still others may turn to sex work or transactional sex, placing them at an even higher risk of contracting HIV.[7] In this way, then, the severe burdens of caretaking can themselves contribute to propagating the epidemic.

Gender inequality and its more direct effects on women's health

Gender inequality also has more direct effects on health, with one of the clearest examples being the pervasive problem of violence against women and girls. According to the World Health Organization, approximately 35% of women worldwide report having experienced sexual or physical violence over the course of their lifetimes, and about one-third of women in relationships report that their partner physically or sexually abuses them.[8] Regularly experiencing violence decreases women's ability to negotiate safe-sex practices and seek HIV testing or counseling—and, unsurprisingly, studies in India and Tanzania have shown an association between intimate partner violence and the prevalence of HIV infection among women (though it is important to note that other studies have demonstrated that this finding holds true only in some settings).[9] In addition, many women who are HIV positive are reluctant to disclose their status to their partners for fear of reprisals.[10]

Various studies demonstrate additional connections between gender inequality and women's health. For example, a recent study in Tanzania demonstrated that some men's perception of women as sexual objects encouraged them to demand sex from their wives, while frequently engaging in extramarital sex—behaviors that put married women at increased risk of contracting HIV from their husbands.[11] Moreover, the same norms that encourage sexual submission in women also result in women having less autonomy to mediate safe-sex practices—and this dovetails in unfortunate ways with reliance on male-controlled prevention methods such as condom use.[12] Only recently have promising advances been made in the field of microbicides, which have the potential to become an effective female-controlled prevention strategy.[13]

Gender inequality in health systems

When health systems reflect prevailing gender norms, this creates further inequities. This can be seen in a number of contexts, including in the mistreatment that women experience during facility-based childbirth (a consequence of, among other things, the insidious ways in which patriarchal norms contort the doctor-patient relationship).[14] But for our purposes, it is most clearly illustrated by the practice of coerced sterilization, which is typically justified by either the prevention of vertical transmission or the discriminatory belief that women with HIV are unfit to be mothers.

These kinds of rights violations have been documented in Namibia and South Africa and tend to affect women who are marginalized and living in places with weak or nonexistent surgical consent laws. Common practices include sterilizing women who are undergoing other procedures, requesting their consent during labor, obtaining consent from male relatives, withholding treatment until consent is given, and offering cash or nutrition in exchange for undergoing sterilization. In some settings, women are also subject to breaches of confidentiality (for example, disclosure of their HIV status to governmental authorities) and to open hostility from health care workers, who are rarely held responsible for their actions.[15]

While these are some of the most dramatic examples of health system failures, there are other, subtler examples as well, including an overemphasis on programs designed to prevent mother-to-child transmission of HIV. These programs have been extremely successful at preventing vertical transmission but often neglect the health care needs of women living with HIV, especially once the window for vertical transmission has closed. Nor are these programs immune to the problems discussed above, as they, too, often undermine women's rights by failing to respect confidentiality, obtain informed consent, or provide adequate medical treatment.[16]

In a broader sense, these kinds of health system failures—which are not only failures of care but also acute human rights violations—reinforce the need for states to adopt laws and regulations that safeguard the sexual and reproductive health and rights of women.

The promise of international human rights in advancing the sexual and reproductive health of women and girls

Ensuring the realization of sexual and reproductive rights is a fundamental aspect of achieving sustainable development. Sexual and reproductive rights are grounded in a constellation of fundamental human rights guarantees, including the rights to life, health, privacy, information, freedom from discrimination, and freedom from cruel, inhuman, and degrading treatment, among others.[17] These rights are found in national laws and constitutions, as well as in foundational and universally accepted human rights documents; they are also defined and expanded on in later international and regional human rights treaties, interpretive statements, and political consensus documents.[18]

Global and regional human rights treaties—including the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa—provide for specific protections of the human rights of women and girls. Further, a series of documents adopted at United Nations (UN) conferences, most notably the 1994 ICPD Programme of Action, link governments' duties under international treaties to their obligations to uphold sexual and reproductive rights.[19] Under international human rights law, states are required to take steps to progressively achieve the full realization of the right to sexual and reproductive health. As highlighted in the Committee on Economic, Social and Cultural Rights' General Comment 22, "States parties must move as expeditiously and effectively as possible towards the full realization of the highest attainable standard of sexual and reproductive health … using all appropriate means, particularly including, but not limited to, the adoption of legislative and budgetary measures."[20] States are obliged to ensure that laws and policies are in place to guarantee access to sexual and reproductive health and rights. There is, therefore, a direct connection between human rights law and what SDG indicator 5.6.2 seeks to measure: laws guaranteeing access to sexual and reproductive health care.

The Beijing Platform for Action builds on the 1994 ICPD consensus, which was agreed on by 179 states and renewed most recently at ICPD+20, in 2014.[21] The Beijing Platform for Action guarantees women the right to sexual and reproductive health services and information and, in its robust description of what that entails, defines a baseline of adequate sexual and reproductive health care,

information, and education. The Beijing Platform for Action also aims to improve women's sexual and reproductive health and education through a number of recommended policy changes, including increases in the education and training of women; increases in women's access to appropriate, affordable health care services and information; and initiatives to improve women's STI and HIV care and education.

These international consensus documents and subsequent jurisprudence and commentary from human rights mechanisms have elucidated the parameters of the right to sexual and reproductive health care, education, and information. This right extends throughout the woman's life cycle—including in connection with pregnancy and childbirth, contraception and family planning, abortion and post-abortion care, comprehensive sexuality education, and sexual health and well-being.

Notably, UN treaty monitoring bodies—which are committees of independent experts appointed to monitor states' implementation of the core international human rights treaties—have developed strong human rights standards on women's and girls' right to safe pregnancy and childbirth, situating it within the rights to life, health, equality and non-discrimination, and freedom from cruel, inhuman, and degrading treatment. This guarantee encompasses women's rights to the full range of services in connection with pregnancy and the postnatal period, as well as the ability to access these services free from discrimination, coercion, and violence.[22] Additionally, women and girls must be able to exercise reproductive autonomy in determining the number and spacing of their children, have adequate information about maternal health care, and be empowered to utilize maternal health services.[23] As a result, states have a duty to prevent and address maternal and perinatal mortality by guaranteeing antenatal, perinatal, and postpartum care; combat early and high-risk pregnancy and early marriage; provide prevention services, testing, and treatment for HIV/AIDS during pregnancy; and ensure access to education and employment for pregnant women and girls, while also ensuring access to infertility information and services to all women.[24]

Moreover, human rights treaty monitoring bodies have consistently found that women and adolescents have the right to access contraceptive information and services and have recognized the correlation between the unmet need for contraception and high rates of teenage pregnancy, abortion, and maternal mortality.[25] These bodies have also noted the obstacles to ensuring women's access to contraception information and services, including unaffordability, third-party authorization requirements, and restrictions on access on the basis of marital status or age.[26] They have recognized that these barriers amount to potential violations of the rights to non-discrimination and health and have mandated that states ensure women's access to a full range of high-quality contraceptive and family-planning information and services.[27]

The right to abortion requires states to guarantee access to safe and legal abortion information and services, including post-abortion care. Treaty monitoring bodies have consistently recognized the connection between restrictive abortion laws, high rates of unsafe abortion, and maternal mortality.[28] As a result, they have called on states to decriminalize abortion, at a minimum, in circumstances in which pregnancy poses a risk to a woman's life or health, is the result of rape or incest, or involves severe fetal impairment.[29] Moreover, they have recognized that bans on abortion are incompatible with human rights guarantees.[30] Additionally, treaty monitoring bodies have indicated that legal abortion services must be accessible in practice and that the denial of such services or the imposition of barriers to access undermines women's reproductive autonomy and can amount to violations of the rights to health, privacy, non-discrimination, and freedom from cruel, inhuman, and degrading treatment.[31] In this light, they have urged states to establish clear guidelines that indicate the conditions under which abortion is legal and to eliminate barriers to access, including third-party authorization requirements (such as spousal consent), mandatory waiting periods, and biased counseling requirements.[32] Moreover, states should regulate conscientious refusals of care to ensure that they do not limit women's access to reproductive health

services and should ensure that such refusals can be invoked only by individuals and not institutions.[33] Treaty monitoring bodies have also indicated that states must guarantee the availability of confidential and adequate post-abortion care and must ensure that such care is not conditioned on the patient's admitting to having procured abortion services illegally (which can later be used to prosecute the patient). Such circumstances may amount to cruel, inhuman, and degrading treatment.[34]

Comprehensive sexuality education—which includes education about STI and HIV prevention—is embedded in these foundational rights. Notably, the right to health requires states to remove all barriers interfering with access to health education and information, including all barriers to sexuality education, such as parental consent requirements.[35] UN treaty monitoring bodies have recognized that sexuality education contributes to the prevention of HIV/AIDS, teenage pregnancy, unwanted pregnancies, abortions, and maternal deaths.[36] They have also established that states should ensure adolescents' access to information on sexual and reproductive health by implementing sexuality education programs in schools, as well as in other settings in order to reach children who are not in school.[37] Additionally, treaty monitoring bodies have indicated that sexual and reproductive health information should be comprehensive and scientifically accurate.[38] Notably, sexuality education programs should include information on preventing unwanted pregnancy, sexual and reproductive health and rights, the risks of unsafe abortion, the legality of abortion, and the prevention of STIs, including HIV.[39] They should also aim to transform cultural views and taboos about adolescent sexuality and gender equality and should address other topics relating to sexual and reproductive health and well-being.[40] Related to the SDGs on health (SDG 3) and education (SDG 4), comprehensive sexuality education is critical because it allows individuals to make informed decisions relating to reproduction and sexuality, enabling their autonomy.

Moreover, human rights standards indicate that adolescents and youth are entitled to special measures of protection to ensure that they are able to exercise their human rights, including their sexual and reproductive rights.[41] The Convention on the Rights of the Child acknowledges that adolescents have the evolving capacity to make decisions about their own well-being, and adolescents with the capacity to make intelligent decisions about their health must be given the autonomy and "freedom to seek, receive and impart information and ideas of all kinds."[42] The convention avows that states should grant children the right to consent to sexual health interventions—including education and services for STIs and HIV, contraception, and safe abortion—without parental guidance; these commitments have recently been reaffirmed in the Committee on the Rights of the Child's General Comment 20, which discusses the evolving standard for consent in matters related to adolescent health.[43] Moreover, human rights treaty monitoring bodies have called on states to ensure adolescents' access to sexuality education and information, eliminate third-party consent requirements in connection with sexual and reproductive health information and services, remove laws criminalizing consensual sexual behavior between adolescents, and prohibit harmful traditional practices that affect the right to health, such as female genital mutilation and early marriage.[44]

Taken together, the multitude of treaties and documents guaranteeing sexual and reproductive rights also protects the right to enjoy sexual experiences autonomously and free from coercion. This includes freedom from gender-based violence. The interconnectedness of violence and sexual and reproductive health is addressed in both the ICPD Programme of Action and the Beijing Platform for Action, the latter of which affirms the right to make reproduction-related decisions free from discrimination, coercion, and violence.[45] Measuring the degree to which UN member states have incorporated policies against gender-based violence into law is crucial for determining the level of sexual and reproductive health guarantees for citizens. Together, these norms and principles provide a framework on which to anchor the vision and goals for global development. SDG indicator 5.6.2

measures the number of countries with laws that guarantee access to these defined rights.

The Millennium Development Goals and women's rights: A missed opportunity

As things stand now, it is clear that global efforts to measure progress on women's rights have shed little light on the mechanisms driving the current HIV/AIDS epidemic among young women and girls in sub-Saharan Africa. At the Millennium Summit in 2000, UN member states developed eight quantifiable and time-bound targets—the MDGs—to operationalize the Beijing Platform for Action and related UN General Assembly commitments. These targets were developed to drive and measure progress at the national level.[46] MDG 3 focused on gender equality and women's empowerment but was mainly measured by gains in enrollment in primary education and the number of women holding elected office; it made no attempt to measure violence against women or address discriminatory laws.[47] Similarly, MDG 6, which focused on HIV/AIDS, malaria, and other diseases, pledged to halt and start reversing the spread of HIV/AIDS by 2015; to achieve, by 2010, universal access to HIV/AIDS treatment for all those in need of it; and to halt by 2015 and start to reverse the incidence of malaria and other major diseases. The only three indicators related to adolescence were to reduce HIV prevalence among populations aged 15–24 years; increase condom use during sexual intercourse with non-regular partners; and increase the proportion of the population aged 15–24 with comprehensive correct knowledge of HIV/AIDS. Overall, then, the MDGs did nothing to support collective efforts to close the glaring gap around adolescent data on health or the structural drivers of HIV in young women and girls.

The MDGs measured complex, interrelated issues (such as HIV and maternal and child health) as separate "silos," while failing to address other areas, including universal access to sexual and reproductive health.[48] They did not measure human rights advances or violations, or the effectiveness of governance and accountability measures in ensuring progress.[49] Nor did they adequately measure inequalities: child mortality and maternal mortality targets and indicators measured average reductions and not quintiles, despite the fact that measuring the latter would have revealed the overarching failure to improve the situation of women in the fourth and fifth quintiles in any context.[50] Despite the mobilization they generated at the time, the MDGs represented a disregard for the lived experience of the most disadvantaged. Donor, outcome-based programming resulted in incentivizing health services only for those who were less marginalized and easier to engage.[51]

The Sustainable Development Goals: Will they do better?

After the expiration of the MDGs, the international community sought to adopt a more comprehensive set of goals. UN General Assembly Resolution 70/1, entitled Transforming Our World: The 2030 Agenda for Sustainable Development, sets out 17 goals and 169 targets over the next 15 years to achieve sustainable development.[52] The 2030 agenda's vision of sustainable development, and the actions required to achieve it, are grounded in universal respect for international law, human rights, the rule of law, justice, gender equality, and the empowerment of women and girls.[53] The agenda emphasizes the responsibilities of states, in conformity with the UN Charter, to respect, protect, and promote human rights and fundamental freedoms for all, without distinction as to race, color, sex, language, religion, political or other opinion, national or social origin, birth, disability, or other status—and recognizes that gender equality and the empowerment of women and girls will make a crucial contribution to progress across all goals and targets.[54]

The global indicator framework. In line with the agenda, the Inter-Agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) developed 230 global indicators to assist in measuring progress in the implementation of the SDG targets.[55] The indicators were considered at the 47th session of the Statistical Commission, which

convened in March 2016. During the session, the commission also recognized that the development of the indicator framework is a technical process that will need to continue over time, making use of expertise in related fields.

The tier system. In its report to the Statistical Commission, the IAEG-SDG proposed that the global indicators be grouped into three "tiers," based on their level of methodological development and the overall availability of data. Tier I indicators would be those for which an established methodology exists and data are widely available; tier II indicators would be those for which a methodology has been established but data are not easily available; and tier III indicators would be those for which an internationally accepted methodology has not yet been developed.[56] During the 48th session of the Statistical Commission, the IAEG-SDG reported on progress made in developing the global indicators, as well as plans to develop methodologies for tier III indicators (including work on definitions and standards), to be agreed on at the international level to guarantee international comparability. UN Women and the World Health Organization then sought experts to help develop the methodology for SDG 5. At the time we became involved in this process (and at the time of writing), SDG 5 was a tier III indicator.

SDG 5. SDG 5 aims to achieve gender equality and empower all women and girls. Its nine interrelated and mutually supportive targets are in service of this goal. These gender equality objectives also underpin the SDG Declaration and all other goals and targets, which place the elimination of inequality and discrimination at the center of the development agenda.[57] (See, in particular, SDGs 3, 4, 10, and 16—though it is important to note that there are inter-linkages and synergies among all the goals and targets, which are global in nature and universally applicable.[58]) It should also be noted that while SDG 3—which is to ensure healthy lives and promote well-being for all at all ages—is clearly relevant to the struggle against HIV, achieving SDG 5 is no less crucial to preventing the spread of this disease. As discussed at length above, gender inequality contributes, in many overlapping ways, to the spread of HIV in sub-Saharan Africa; this linkage makes it abundantly clear how much is at stake, in health terms, in empowering women and girls.

Target 5.1 of SDG 5 is to "end all forms of discrimination against all women and girls everywhere." The indicator proposed by the IAEG-SDG to track progress in the implementation of this target over the next 15 years is "whether or not legal frameworks are in place to promote, enforce, and monitor equality and non-discrimination on the basis of sex."[59] As noted above, gender discrimination and acute human rights violations also occur within health systems, making this focus on legal frameworks equally vital for the sexual and reproductive health of women.

Indicator 5.6.2 attempts to address this by aiming *to increase the number of states with laws and regulations that guarantee women aged 15–49 access to sexual and reproductive health care, information, and education*. Because of our expertise in sexual and reproductive health and rights and HIV, we agreed to work on the methodology for this tier III indicator.

Indicator 5.6.2 is integral to the achievement of all of SDGs. The principle of universality within the 2030 agenda calls on states of all income and development levels to take action to achieve sustainable development and, in so doing, address issues ranging from poverty and hunger to climate change and inequalities—both within and beyond their borders.[60] Without laws and regulations that guarantee access to sexual and reproductive health services, information, and education, this commitment will remain unmet. It is clearly critical to the elimination of HIV/AIDS in women.

Target 7 of SDG 3, the health and well-being goal, mandates that states ensure universal access to sexual and reproductive health care services, including for family planning, information, and education, and also requires the integration of reproductive health into national strategies and programs.[61] The health goal also includes targets related to maternal mortality, HIV/AIDS, and harmful practices such as genital mutilation and

child, early, and forced marriage (targets 3.1, 3.3, and 3.7, respectively). SDG 4, on education, requires that education promote gender equality, that all girls complete primary and secondary education, that women have equal access to tertiary and vocational education, and that states eliminate gender disparities in education (targets 4.7, 4.1, 4.3, and 4.5, respectively). Reproductive and sexual rights are necessary components of these objectives as well.

All of that being said, in developing a methodology with which to measure laws and regulations, we must pay special attention to states with plural or multiple legal systems that allow various sources of law to govern simultaneously.[62] Plural legal systems may include customary law, religious law, and tradition or practice. Customary and religious laws enjoy the status of binding sources of law or practice in the vast majority of countries in Africa, and in a number of countries in Asia and the Americas as well.[63] Legal pluralism can, in certain circumstances, permit religious, traditional, and customary law or practice to contradict national or civil law. Of course, common and civil law can also be discriminatory. States avoid compliance with international law in various ways, including reservations to international conventions or the failure to domesticate international law. States may also enact constitutional protection for plural legal systems. For example, national legislation may set the age of marriage at 18, while constitutionally protected religious and customary laws may set lower age limits. We therefore included questions in our methodology—discussed in more detail below—intended to capture these legal loopholes. There are also some countries with gender discrimination in civil or national law related to marriage, adoption, and inheritance.[64]

As noted by the Global Strategy for Women's, Children's and Adolescents' Health (2016–2030), launched by the UN Secretary-General in 2015 to create a roadmap for achieving the health-related SDGs, it is critically important for us to develop a methodology that can effectively measure member states' legal commitments to guaranteeing sexual and reproductive services and education.[65] While a number of sources and databases exist to measure individual components of sexual and reproductive health care within states, few have built-in engagement with states—meaning that most existing sources would be inadequate without substantial revisions to, and expansions of, their data collection processes. Although country-level research on the components of SDG 5.6.2, validated by qualitative interviews and analysis of law and policy, might be the soundest approach, the SDG process has limited financial resources and requires that member states buy in to the methodology. A survey that can be administered to member states in a timely way and that provides usable and reliable results may therefore be the most acceptable method by which to track SDG progress. We were asked to develop such a survey while simultaneously exploring other paths. In the following section, we discuss the survey methodology we proposed to effectively measure these outcomes among member states.

Our proposed methodology for SDG indicator 5.6.2: The number of countries with laws and regulations that guarantee women aged 15–49 access to sexual and reproductive health care, information, and education

Our work in developing a methodology for indicator 5.6.2 revealed the challenges of integrating a rights-based approach into the SDGs. The process was hampered by weak and ineffective coordination and collaboration mechanisms among the UN agencies responsible for developing indicators—and there was also an overemphasis on "silo-ing" these SDG indicator development processes, despite the avowed inter-relatedness of the SDGs. Similarly, despite the obvious need to incorporate human rights standards into the indicators, there was a clear preference for measuring procedural guarantees rather than implementation or access (indicator 5.6.2 was confined to measuring the existence of laws and regulations rather than evaluating their implementation in practice). These limitations were communicated to us by UN representatives, who cited limited resources, a lack of cooperation from other UN agencies, and the likelihood that

too onerous a methodology would be rejected by member states.

More specifically, there was also a strong preference by UN representatives for a "yes/no" survey administered only to member states. This was problematic on at least two levels. First, a binary survey instrument of this kind—while simpler to administer and methodologically more sound in terms of data analysis—is constitutively incapable of capturing the breadth and complexity of the issues at stake and cannot yield adequate or accurate information. This is particularly true in this indicator's case, given the lack of operationalization of key terms (for example, "regulations," "guarantee," "address"), the politicization of crucial information (for example, the unwillingness to include information about abortion), and other serious validation challenges. Second, the richest source of information on how states are complying with the international standards addressed herein is not the states themselves but reports and commentary by human rights bodies and civil society organizations. The myriad ways that member states avoid compliance with laws guaranteeing access to sexual and reproductive health care, information, and education can be discovered in treaty body comments and questions, as well as in the concomitant shadow reports prepared by members of civil society. Excluding these voices from the reporting process, we argued, would be a serious mistake.

We sought to propose a more effective strategy for compiling and validating data—and, in so doing, made several recommendations, including for an expert panel and the inclusion of voices from civil society. Our original questionnaire—which covered the breadth of ICPD issue areas (including implementation)—was quickly deemed unmanageable by UN representatives. They stated that member states would reject the indicator if we pressed forward with a "burdensome" process. By the time we had finished our work, the UN questionnaire had been reduced to five issue areas: (1) pregnancy/childbirth, (2) contraception/family planning, (3) abortion, (4) sexuality education/information, and (5) sexual health/well-being (all of which, it should be noted, are clearly relevant to the ongoing struggle against the HIV epidemic in sub-Saharan Africa). Other, more specific questions about HIV were deemed to be already covered by other SDGs, despite our stated concern that other indicators did not take into account the existence of relevant laws. Our questions on marginalized and vulnerable groups, adolescents, and gender-based violence were cut. We argued strenuously for the inclusion of questions examining the status of ratification of relevant rights treaties, as well as relevant observations and commentary.

To ensure the reliability of the survey across states, we recommended that staff with comparable positions in similar government entities provide answers to the questions. UNFPA would identify categories of country-level staff appropriate for survey completion and do the same for nongovernmental organizations and civil society groups on the ground. Then, UNFPA staff would administer the survey, working in conjunction with country-level staff and civil society groups to provide complete answers. In order to accurately assess validity, we proposed an expert panel like the one that has been established for the Global Strategy for Women's, Children's and Adolescents' Health to further the 2030 agenda.[66] In that case, the World Health Organization set up a nine-member panel whose participants represent diverse regions and backgrounds—ranging from human rights to humanitarian work to statistics—to "monitor and review" progress in connection with the Global Strategy for Women's, Children's and Adolescents' Health. We suggested establishing an analogous panel here that includes a similarly diverse group of experts on sexual and reproductive health, information, and education, all of whom are knowledgeable about human rights standards. This expert panel would assess the validity of the survey's content and review all questions for clarity before the administration of the survey.

To measure "construct validity"—or the extent to which the results of the study are found to be consistent with existing data—the expert panel, in conjunction with UNFPA staff, would also

compare findings from the survey with existing data from states. For example, spikes in adolescent maternal mortality might correspond with regions governed by plural legal systems. Additionally—given that many states have a patchwork of laws and regulations on sexual and reproductive health issues, which can be confusing and contradictory and which may prevent clear or accurate answers to the questions in the survey—civil society groups would also participate in the survey.

Though there are existing data sets that match sections of our survey, nothing exists that comprehensively covers the substance of this indicator. This survey would therefore represent the "gold standard" of what a state would need to do to achieve progress on the target. In the survey analysis, a grading system would be established based on this "gold standard," and each state would be assigned a grade representing its level of compliance with the human rights obligations connected to this indicator. The expert panel would also assess whether the state took the necessary measures to ensure compliance; this assessment would include a review of any concluding observations, decisions, communications, reports, and recommendations issued by UN and regional treaty monitoring bodies. The "gold standard" would be satisfied if the state can provide evidence that it has taken all necessary measures to address the concerns raised by UN and regional human rights bodies.

We exited the indicator's development process toward the end of 2016. We understand that the indicator is still tier III, that boys and men have been added, and that there are now 33 questions in the survey. We also understand that UNFPA is piloting the survey through six of its offices. The process, however, taught us about the tensions between the SDG objectives and reality, particularly in the realm of human rights. The historic inclusion of an SDG indicator to measure the existence of legal protections is a step in the right direction; however, the methodology, as it currently stands, might weaken the reliability of the results. Every component of this proposed indicator refers to an important dimension of the human rights and future of young women and girls affected by HIV. Without the guarantees this indicator seeks to measure, we will not stem the epidemic of HIV among young women and girls.

Conclusion

The HIV epidemic has been devastating for women and girls—and, as things stand now, global efforts to measure progress on the rights of women and girls have shed little light on the causes of the current HIV epidemic among young women and girls in sub-Saharan Africa. The SDGs have the potential to do better, but our work on indicator 5.6.2 illustrates the real difficulties of integrating a rights-based approach into the SDGs. One of the clearest hurdles—seen in the preference for collecting solely procedural information, and only from member states—is the lack of an effective accountability mechanism for ensuring state compliance with SDG commitments. What we urgently need, then, is to overcome these political barriers so that we can incentivize a response to HIV prevention and eradication that prioritizes the human rights of women and girls.

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Where Public Health Meets Human Rights: Integrating Human Rights into the Validation of the Elimination of Mother-to-Child Transmission of HIV and Syphilis

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Abstract

In 2014, the World Health Organization (WHO) initiated a process for validation of the elimination of mother-to-child transmission (EMTCT) of HIV and syphilis by countries. For the first time in such a process for the validation of disease elimination, WHO introduced norms and approaches that are grounded in human rights, gender equality, and community engagement. This human rights-based validation process can serve as a key opportunity to enhance accountability for human rights protection by evaluating EMTCT programs against human rights norms and standards, including in relation to gender equality and by ensuring the provision of discrimination-free quality services. The rights-based validation process also involves the assessment of participation of affected communities in EMTCT program development, implementation, and monitoring and evaluation. It brings awareness to the types of human rights abuses and inequalities faced by women living with, at risk of, or affected by HIV and syphilis, and commits governments to eliminate those barriers. This process demonstrates the importance and feasibility of integrating human rights, gender, and community into key public health interventions in a manner that improves health outcomes, legitimizes the participation of affected communities, and advances the human rights of women living with HIV.

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Introduction

In 2015, Cuba became the first country to be officially validated by the World Health Organization (WHO) for the successful elimination of mother-to-child transmission (EMTCT) of HIV and syphilis.[1] Since then, several other countries and territories have been successfully validated, including Thailand, Belarus, Anguilla, Montserrat, Cayman Islands, Bermuda, St. Kitts and Nevis, and Antigua and Barbuda for dual elimination, Armenia for EMTCT of HIV, and Moldova for elimination of syphilis. Over 80 countries are considering applying for, or are in the advanced stages of validation.[1]

The WHO-led process of EMTCT validation is a unique disease elimination certification process that proves the feasibility and value of the integration of human rights standards and community participation into public health interventions.

From both public health and human rights perspectives, this WHO EMTCT validation process is remarkable for several reasons. First, validation involves the fulfillment of epidemiological and public health criteria that illustrate the successes of global and national efforts to address vertical transmission of HIV and syphilis. This biomedical criterion relates to the reduction in the number of new babies born with HIV below a threshold low enough that it no longer constitutes a public health problem.[2] This criterion is also being applied to EMTCT of syphilis, which can be prevented through simple, low-cost screening and treatment of pregnant women. Since the antenatal services to prevent mother-to-child transmission of HIV and syphilis are similar, dual elimination is being pursued to harmonize improvements in maternal and child health.[3]

Second, EMTCT certification also includes—for the first time in history—human rights, gender equality, and meaningful community engagement as key factors in evaluating whether a country should receive certification for a health achievement. The inclusion of these factors among the validation criteria is a reflection of the increased understanding that the realization of human rights can foster the achievement of public health goals. It also signals that the respect and fulfillment of these principles are critical goals in themselves.

Historically, public health approaches to disease control and elimination have focused on biomedical and technical approaches rather than addressing human rights and social determinants of health.[4] However, in the context of HIV, networks of people living with HIV, and particularly, networks of women living with HIV have consistently identified gender inequality and human rights abuses, including discrimination, as obstacles to treatment, care, and support, and have called for greater focus on human rights, gender equality, and community engagement.[5]

These efforts recognize that human rights, gender equality, and community engagement are essential factors that influence: how health systems are shaped both at community and country level; the national and international legal and policy environment within which these systems operate; and the overall social and economic context of people's access to and use of these services.[6]

Earlier in the HIV epidemic, access to medicines for EMTCT came to epitomize the struggle for human rights in the context of HIV in South Africa and globally.[7] The refusal of the South African government to provide access to antiretroviral treatment for EMTCT was challenged before the court by civil society. In a landmark ruling, the Constitutional Court of South Africa held that the constitutional rights of pregnant women living with HIV were being violated by the failure to provide them with anti-retroviral medicines.[8]

While countries across the world have been implementing EMTCT programs since the late 1990s to early 2000s, global efforts to accelerate the elimination of vertical transmission of HIV gained momentum in middle- and low-income countries around 2009, when UNAIDS published its Business Case as part of the Outcome Framework.[9] This joint publication with WHO, UNICEF, and UNFPA laid the groundwork for the elimination of vertical transmission, including its definition and its indicators. The biggest impetus for the development of rights-based validation of EMTCT was the launch of the Global Plan Towards the Elimination

of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive ("Global Plan"), initiated by UNAIDS and PEPFAR. The Global Plan was launched in July 2011 at the United Nations General Assembly High-Level Meeting on AIDS in New York. It prioritizes 22 countries with the highest number of pregnant women living with HIV in need of services. These countries are Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, the Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, the United Republic of Tanzania, Zambia, and Zimbabwe. Together, these countries accounted for 90% of the total number of pregnant women living with HIV that needed services to prevent mother-to-child transmission of HIV in 2009. The goals of the Global Plan were to reduce the number of new HIV infections among children by 90%, and to reduce the number of AIDS-related pediatric and maternal deaths by 50%. This plan was "global" in nature, and it galvanized leadership, engaged front-line communities, and stimulated innovative approaches and new technologies to prevent, diagnose, and treat HIV.[10] It called for the respect and fulfillment of the rights of women living with HIV, and for community empowerment and engagement.[10] It brought together a diverse set of stakeholders, including governments, funders, the private sector, networks of women living with HIV, civil society, and many more; seized political momentum for planning and action; and set bold targets enabling accountability.[11]

Countries which had reduced vertical transmission of HIV to negligible levels seized the momentum generated by the Global Plan to ask for avenues to officially recognize their achievements. WHO understood the potential of such process not only for recognizing achievements but also for maintaining and encouraging continuous efforts towards EMTCT. In response to these calls, WHO thus developed a process through which countries could be validated as having eliminated vertical transmission of either HIV, syphilis, or both. Tools to guide the validation process and to conduct country assessments were developed and a governance mechanism at global, regional, and country levels was formulated. In light of the serious human rights violations that have been reported in maternal and child health care settings, including rampant discrimination and involuntary sterilization, networks of women living with HIV and UNAIDS advocated the inclusion of rights-based elements to be integrated into EMTCT validation criteria and processes.[12]

This article describes the human rights, gender equality, and community mobilization principles, norms, and approaches that are included in the EMTCT validation tools and process. It also provides insights into the implementation of these principles, norms, and approaches during the validation process. Finally, the article reflects on the benefit and impact of this first-ever rights-based process for the validation of disease elimination.

Conceptual elements of the rights-based validation process

The criteria to validate EMTCT of HIV and syphilis were developed to apply across a wide range of epidemiological and programmatic contexts, including the assessment and evaluation of appropriate health services infrastructure, staff capacity and training, laboratory preparedness, and high quality monitoring and surveillance systems.[13] In addition to these, rights-based conceptual elements of the validation entail the inclusion of human rights, gender equality, and community engagement among the required validation criteria through such elements as informed consent, respect for privacy, confidentiality and autonomy, and decriminalization of HIV non-disclosure, exposure, and transmission. It also includes the manifestation of these principles in the validation process itself, such as inclusion of human rights experts in the validation committees, as well as participation of women living with HIV in each step of the process.

These key elements of the validation are outlined in "Global Guidance on Criteria and Processes for Validation of Elimination of Mother-to-Child Transmission of HIV and Syphilis," which describes the minimum global processes and criteria that countries should present to achieve valida-

tion of EMTCT, and is intended for national and regional validation committees as they prepare or review national submissions requesting validation. While the human rights, community engagement, and gender equality validation process requires the engagement of specific actors and expertise, and collection of particular information, it is seen as an integral part of the overall validation process. The first edition of this global EMTCT guidance document was released in 2014 by WHO, while the second edition was developed by WHO and the Global Validation Advisory Committee (GVAC) in 2017.[14] While both editions are inclusive of rights-based principles, the second edition is much more comprehensive and explanatory in regard to the operationalization of human rights, gender equality, and community engagement principles.[15]

Consistency with international, regional, and national human rights standards

Besides the various health system criteria, a key consideration for the validation of a country is that the interventions to reach the targets have been implemented in a manner consistent with international, regional, and national human rights standards.[11] The rights-based elements and requirements of the validation process are captured in the tool and guidance on Elimination of Mother-to-Child Transmission of HIV and Congenital Syphilis: Assessment of Human Rights, Gender Equality and Community Engagement Dimensions of National Programmes, which was developed in collaboration with the International Community of Women Living with HIV (ICW) and Global Network of People Living with HIV/AIDS (GNP+).[16] They were invited into this process to develop a clear framework and criteria for human rights, gender equality, and community engagement standards by which to evaluate EMTCT programs for validation. The standards were developed in direct consultation with networks of women living with HIV and other experts on human rights, gender equality, and community engagement.

This tool and guidance is one of four core assessment tools to be used by all EMTCT stakeholders throughout the validation process; the others include the evaluation of national programmatic elements, the laboratory services, and the quality of data. Human rights issues being investigated and evaluated through the validation process include: whether or not vertical transmission of HIV is criminalized; whether health care settings are free from mandatory or coerced testing and treatment, forced and coerced abortion, contraception and/or sterilization; and whether informed consent, confidentiality and privacy, and equality and non-discrimination are respected, protected, and fulfilled. The validation process also recognizes inclusion and meaningful participation as a human rights concept in programmatic efforts. As an illustration, the process investigates whether certain population groups, such as migrants or sex workers are systematically included in EMTCT programs and the provision of services.

Gender equality

The criteria for EMTCT validation also include a gender equality-related component, which recognizes that gender norms and practices can significantly shape sexual and reproductive health and rights of women, and health outcomes for their children. In particular, it recognizes that the promotion and achievement of gender equality can significantly influence the opportunities of women and girls to access necessary information and services, make autonomous decisions about their sexuality and reproduction, and protect themselves against HIV and sexually transmitted infections (STIs). The assessment of this gender equality criteria includes the investigation of the steps taken by the state to address gender-based violence and to ensure adequate access to justice, remedies, and redress for women, including in the context of EMTCT.

Community engagement

The validation process aims to give significant recognition to the content and meaning of the right to participation and to the principle of "Greater involvement of people living with HIV" (GIPA).[17] This principle recognizes that meaningful participation of people living with HIV, and

in particular, women living with HIV, affects the exercise of their right to health and well-being. Meaningful participation helps to ensure that women living with HIV and infected with syphilis get the treatment they need to keep themselves well and their children free from infection; it also results in better, more effective programs.[18] This validation criteria hence investigates whether the involvement of women, in particular women living with HIV, is multi-dimensional, and includes their participation in the formulation of health laws and policies, program development, and implementation, service delivery, and advocacy.

Progressive realization

In the revised validation process, which incorporates lessons learned from practical implementations, WHO proposes criteria for validation of three levels of achievement—bronze, silver, and gold—on the path to elimination. The term "validation" is used to attest that a country has successfully met criteria for EMTCT or for one of the three levels of achievement on the path to EMTCT of HIV and/or syphilis. This second edition of the global guidance presents a new approach to recognizing high-burden countries that may not have reached elimination targets but are on the path to elimination.[19] The path to elimination comprises three tiers of accomplishment, each with its own set of process and outcome indicators. These three levels are designed for countries with a high prevalence of HIV and/or syphilis that have made tremendous strides in preventing MTCT but cannot as yet reach elimination targets due to the high prevalence of HIV and syphilis in antenatal care attendees. Moving to a higher tier brings a country progressively closer to meeting the WHO criteria for achievement of elimination.[20]

This approach is easily translatable to the principle of "progressive realization" of socioeconomic rights that recognizes that states will be in a position to immediately and completely fulfill all these rights. This principle, however, implies that steps toward the full realization of socioeconomic rights, including the right to the highest attainable standard of health, which relates directly to EMTCT, must be deliberate, concrete, and targeted as clearly as possible toward meeting a state's human rights obligations "to the maximum of its available resources."[21] It thus requires all countries to show concrete efforts in moving toward full realization of rights within their means and without deliberate backsliding.

Due diligence

States have an obligation to exercise due diligence to prevent, investigate, and, in accordance with national legislation, punish acts that violate human rights, whether those acts are perpetrated by the state or by private persons. In the context of EMTCT, this can be of vital importance—where, for example, discrimination or violence render some individuals unable to realize their rights on an equal basis with others, including those women living with HIV, or women engaging in sex work.[22] The due diligence standard has been also applied increasingly in the context of elimination of gender stereotypes, as well as in the context of provision of health care for marginalized populations, such as migrants and refugees, that can have a great relevance when countries are applying for validation.

Rights-based procedural elements of the validation

A rights-based approach to health interventions is not only grounded in the content but also essential to the process by which validation is granted. The EMTCT validation provides an important and innovative platform for interrogating and addressing human rights issues, in particular during the in-country assessment missions and during the final consideration of the validation report and findings.

Such procedural elements are related to:

- operationalizing of human rights in country reviews, through a systematic and analytical inclusion of the human rights-based criteria into the validation reports;
- inclusion of human rights expertise and civil society representation in national-, regional-,

and global-level program and data reviews and within the validation committees, including the national and Regional Validation Committees (RVC), where such mechanisms exist, and in the Global Validation Committee (GVAC).

- strong community engagement throughout the validation assessment; and
- integration of human rights into the maintenance of the validation.

Operationalizing of human rights in country reviews

The methodology for the human rights assessment of country validation includes three complementary processes: 1) a desk review to assess national legal framework relating to EMTCT against applicable international and regional human rights and gender equality standards; 2) semi-structured interviews with women living with HIV, key officials with human rights, gender equality and community engagement functions, civil society and community-based organizations representatives, and HIV and EMTCT program managers and service providers; and 3) invitation of shadow reports by civil society organizations, including networks or groups of women living with HIV who use EMTCT services to provide their views on human rights, gender equality, and community involvement issues. Findings from the desk review, interviews, and shadow reports are compiled into a report. The drafters of the report, who may be from ministries of health or EMTCT programs, are encouraged to document how they have engaged and consulted community in the collection and preliminary examination of data, particularly around human rights, gender equality, and community engagement. However, not only the drafters of the report need to demonstrate thorough investigation of the fulfillment of human rights standards. The RVC, where such mechanisms exist, and the GVAC must also evaluate the content of the report from a human rights perspective and where possible embody the core principles of GIPA and gender equality.[18] WHO Headquarters and Regional Offices function as validation secretariats for these Committees, in partnership with UNAIDS, UNFPA and UNICEF.[23] For example, it is recommended for the validation team assessing the country report to arrange to meet independently with human rights experts and networks of women living with HIV at the country level in order to evaluate the claims in the report. Critically, these bodies need to provide clear rights-based feedback to countries about required areas of improvement and, where necessary, encourage them to take specific steps to remedy laws, policy, and practices which have resulted in human rights violations. They are also expected to call countries to demonstrate progressive improvements on key issues related to gender equality and community engagement in order to achieve validation or alternatively to maintain the validation once achieved.

Inclusion of human rights expertise and civil society representation in the validation committees

The validation process consists of a series of national-, regional-, and global-level program and data reviews. Once the reports prepared at the country level are submitted to the RVC, the RVC convenes a team to undertake an initial assessment of whether the report confirms that the country has met with the fundamental requirements for validation across the four assessment tools. Once the report passes the RVC assessment, it is submitted to the GVAC along with the RVC assessment. The GVAC then prepares a global validation report based on a critical review and assessment of the information, outcomes, processes, and recommendations identified in the regional report. Ultimately, it is the WHO global secretariat, in collaboration with UNAIDS, UNFPA, and UNICEF who reviews the GVAC's critical assessment and recommendations and make the final determination on whether the country has achieved validation of EMTCT of HIV and/or syphilis including recommended follow-up actions for maintenance of EMTCT validation status. Subsequently, WHO headquarters monitors maintenance of EMTCT of HIV and syphilis annually through routine global reporting mechanisms already in place, and with additional reports

from validated countries. As a result, not only the drafters of the initial report need to demonstrate thorough investigation of the fulfillment of human rights standards, but the RVC (where applicable) and the GVAC must also evaluate the contents of the report from a human rights perspective and, where possible, embody the core principles of GIPA and gender equality.[24]

A rights-based consideration of the validation reports requires that the membership of the national, regional, and global validation committees consist of independent and multidisciplinary experts, including human rights experts, representatives of networks of women living with HIV, as well as advocates from civil society that work with at-risk and vulnerable groups.[25]

In practice, however, resource limitations may jeopardize consistent use of in-country evaluation teams, and in some cases the assessment may need to be conducted remotely by members of the GVAC.[26] This may lead to limitations on the involvement of human rights and community experts in the validation process, which may influence the final findings of the report. There are countries, however, where significant efforts have been made to provide meaningful participation of human rights expertise and communities in the process. In Cuba, for example, five municipalities were selected for site visits, which included visits to civil society organizations, including networks of people living with HIV. Three members of the validation team were specialists in human rights, and community engagement and civil society representatives were included in meetings with national ministry of health officials at the beginning of the validation process. The inclusion of human rights experts and community members ensured that human rights issues, such as adolescents' access to services and institutionalization practices and community participation in program development, were raised and adequately addressed.[27]

Ensuring community engagement throughout the validation assessment

The validation process requires countries to ensure that representatives of civil society, including women living with HIV, are involved in each level of the validation process. This element of the process can serve as an important accountability mechanism for comprehensively evaluating human rights concerns in the context of EMTCT in the country. Furthermore, the procedural criteria of community engagement can encourage governments to systematically involve communities in the process, that can create previously non-existent mechanisms for monitoring and multi-stakeholder discussions on human rights and gender equality in relation to EMTCT. In Thailand, for example, strong success with community engagement became one of the key factors that enabled the country's success in validation.[28]

At the national level, community consultations, focus group discussions, and other methods such as interviews with key community members and human rights experts creates the community engagement element of the process. In addition, the possibility of submission of shadow reports to the RVC or the gathering of their own data around key issues, by community groups, including networks of women living with HIV, provide independent input to the validation process.

Although only a few countries have gone through the nascent process of validation, it is clear that the process would benefit from the establishment and requirement of minimum standards of community engagement within the process to further guide and encourage countries to gather data and feedback from community groups in the preparation of their reports. Such minimum standards could include ensuring that community-based organizations and networks of people living with HIV are not tokenized within the process of report preparation, and that their concerns, voices and lived experiences are heard.

Integrating human rights in the maintenance of the validation

The validation criteria also include the demonstration that the country is committed to maintain the validation status of EMTCT of HIV and/or syphilis, including through sustained attention to respecting, protecting, and fulfilling human rights

as part of EMTCT efforts. This includes ensuring that the incidence of vertical transmission remains low, health systems continue to be maintained and strengthened, human rights and gender equality barriers are addressed and community engagement sustained.[29]

Countries need to show evidence that they are consistently meeting the EMTCT criteria over time, and that they are addressing the recommendations received. For example, in at least three of the validated countries, urgent timelines were set for removal of laws criminalizing HIV non-disclosure, exposure, and transmission, and for ensuring access to HIV services for adolescents. A country may have their validation rescinded if they do not comply with recommendations.

Greater transparency around the specific recommendations issued by the GVAC in this process—for example, making the recommendations public or sharing them with all involved in the validation process, including community-led groups—would strengthen accountability within this mechanism and empower community and advocacy groups to hold EMTCT programs accountable at the country level.

Benefits and impact

Adequate attention to human rights, gender equality, and community engagement considerations has the potential to serve as an important tool for community-led accountability dialogues and advocacy to challenge human rights violations and improve program quality. The validation process can provide a critical point of engagement for women living with HIV to advocate for stopping practices that violate human rights. These human rights considerations, based on recommendations considered in final country decisions, include:

- addressing criminalization of HIV non-disclosure, exposure, and transmission, and its impact on EMTCT efforts,
- removing age-related legal barriers to services by acknowledging adolescents' rights to make decisions according to their evolving capacity and best interest,
- removing mandatory testing and treatment requirements,
- safeguarding privacy and confidentiality,
- eliminating stigma and discrimination in health care settings, and
- ensuring systematic and sustained community engagement in EMTCT.

GVAC chooses from the following options: 1) unqualified endorsement of the EMTCT programs and services, 2) endorsement of the programs and services with clear recommendations for strengthening of components that might pose a current or future threat, or c) determination of insufficiencies that preclude EMTCT validation or which must be remedied before reapplication or revalidation. Recognition that countries may achieve process and target indicators for EMTCT and still not be validated if there are grave or systematic recent or ongoing human rights violations is an important motivator for due diligence in pre-empting and addressing such violations.[30]

Importantly, the mere inclusion of human rights in the EMTCT validation demonstrates clear commitment to realizing that long-term public health benefits can only be achieved if rights are upheld, and those most affected are meaningfully engaged as partners in promoting their own and community health.[31]

In addition, the EMTCT validation process requires assessment of whether the least-performing geographic unit meets the criteria of providing access to EMTCT services for all, including the most vulnerable and marginalized. Challenges related to access of key and vulnerable populations to services are taken into consideration during validation missions and case reviews to ensure that the validation process and tools are applied in a manner that is consistent with the guidance. Among the countries that applied for validation, many faced challenges in ensuring equitable access to antenatal care to undocumented internally displaced people, external migrants, refugees, or ethnic minority groups. The importance of leaving no one behind in EMTCT

program efforts was a key feature in each of the validated countries, many of which demonstrated the provision of free antenatal (inclusive of HIV and syphilis screening and treatment) and outreach services to these populations.[32]

Another vital benefit of the process is that it galvanizes the direct engagement of women living with HIV.[33] As countries undertake initial self-assessment as they prepare an application for validation, the data-gathering tool and process encourages both self-reflection and information gathering from community-led organizations and feedback from EMTCT program participants. This process has the potential to open new dialogue or strengthen existing dialogue and collaboration between service providers and community-led organizations, which can lead to the establishment of people-centered, quality services.

Conclusively, one of the most important benefits is that the validation process and the recommendations from the GVAC can create a de facto accountability mechanism through which community-led organizations can hold programs accountable. Reporting back to the GVAC on upholding such recommendations is an important precursor for action, and creates the space for human rights activists and communities to engage in advancing human rights and removing some of the barriers to the full realization of the right to health.

As more countries achieve validation, the expected impacts will multiply and include rights-based approaches to responding to diseases, and ensuring equitable access to services that are acceptable and of good quality, for all, most marginalized and key communities included. The validation of EMTCT of HIV and syphilis may be expanded in the near future to include elimination of other diseases, as hepatitis B, further amplifying the potential benefits and impacts beyond the HIV and STI responses.

However, as an increasing number of countries apply for validation, there is a risk that human rights, gender equality, and community participation criteria might be seen as secondary to biomedical and epidemiological data on elimination. Therefore, maintaining and strengthening a rights-based EMTCT validation for the future will require continued commitment by WHO, UNAIDS, and states, as well as vigilance from civil society to protect the uniqueness of this process.

Conclusion

The WHO-led EMTCT validation is a unique and innovative channel to engage governments in addressing human rights violations and barriers in their countries, and fulfill their public health and human rights commitments towards HIV, particularly addressing the rights and health of women and children. It is a singular tool for creating important dialogue among various stakeholders within the country, and ensuring the meaningful participation of affected populations in program monitoring and evaluation. The inclusion of validation and sustainability criteria in relation to human rights, gender equality, and community participation in the EMTCT validation process allows for an ongoing dialogue, encourages and assesses advances, and ensures guarantees about no retrogression. It represents an important innovation in disease elimination validation and is already providing important lessons for other disease elimination efforts, including hepatitis, Zika, and Ebola.

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The Cholera Epidemic in Zimbabwe, 2008–2009: A Review and Critique of the Evidence

C. NICHOLAS CUNEO, RICHARD SOLLOM, AND CHRIS BEYRER

Abstract

The 2008–2009 Zimbabwe cholera epidemic resulted in 98,585 reported cases and caused more than 4,000 deaths. In this study, we used a mixed-methods approach that combined primary qualitative data from a 2008 Physicians for Human Rights-led investigation with a systematic review and content analysis of the scientific literature. Our initial investigation included semi-structured interviews of 92 key informants, which we supplemented with reviews of the social science and human rights literature, as well as international news reports. Our systematic review of the scientific literature retrieved 59 unique citations, of which 30 met criteria for inclusion in the content analysis: 14 of the 30 (46.7%) articles mentioned the political dimension of the epidemic, while 7 (23.3%) referenced Mugabe or his political party (ZANU-PF). Our investigation revealed that the 2008–2009 Zimbabwean cholera epidemic was exacerbated by a series of human rights abuses, including the politicization of water, health care, aid, and information. The failure of the scientific community to directly address the political determinants of the epidemic exposes challenges to maintaining scientific integrity in the setting of humanitarian responses to complex health and human rights crises. While the period of the cholera epidemic and the health care system collapse is now nearly a decade in the past, the findings of this work remain highly relevant for Zimbabwe and other countries, as complex health and rights interactions remain widespread, and governance concerns continue to limit improvements in human health.

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Introduction

The 2008–2009 cholera epidemic in Zimbabwe resulted in 98,585 reported cases and 4,287 reported deaths, making it the largest and deadliest in the history of Zimbabwe.[1] The initial outbreak was notable for its high cumulative case fatality rate (4.3%) that persisted over a protracted duration (10 months). It was then followed by a second wave of infections lasting through June 2011.[2] The epidemic emerged within months of two violent rounds of presidential elections that pitted President Robert Mugabe of the Zimbabwe African National Union-Patriotic Front (ZANU-PF), in power since 1980, against the primary opposition leader, Morgan Tsvangirai, of the Movement for Democratic Change (MDC).

In December 2008, in response to the epidemic, Physicians for Human Rights dispatched an emergency delegation to Zimbabwe to investigate the country's health infrastructure and to document possible ongoing human rights abuses.[3] The organization's investigation revealed multiple such abuses as well as the true scale and scope of the epidemic. These findings have been supported by other reports.[4] Most critically, ZANU-PF's loss of municipal elections in Zimbabwe in 2005 led party leaders to refuse to fund municipal budgets for cities where it had been defeated, including in Harare, the capital.[5] These retaliatory cuts led to a cessation of water purification for the city and, eventually, the redirection of raw human sewage into the city's main reservoir.[6]

In this paper, we contextualize the Zimbabwean epidemic within a broader conceptual framework that outlines the role of political institutions in mediating cholera outbreaks. Using data from Physicians for Human Rights' 2008 investigation, as well as supplementary information from the social science and human rights literature and from international news reports, we describe the human rights abuses that contributed to the epidemic in relation to a larger pattern of human rights violations by ZANU-PF leaders under the Mugabe regime, including the politicization of water and sanitation. Then, through a systematic review and content analysis of peer-reviewed scientific literature, we explore the extent to which these abuses, including ZANU-PF's role in perpetrating them, were discussed or not discussed in scientific discourse.

With regard to the scientific literature on the cholera epidemic, it is striking how few authors directly noted the political or human rights aspects of the crisis. This seeming reluctance of the scientific community to fully address the political determinants of the epidemic exposes challenges to preserving scientific integrity in the setting of humanitarian responses to complex health and human rights crises. The imperative to seek access to vulnerable populations in such settings limits many partners from discussing the political and human rights aspects of these crises, even when they are well documented by other sectors, including human rights organizations. In the case of Zimbabwe, both the Zimbabwe Association of Doctors for Human Rights and the Zimbabwe Health Students Network had reported on abuses in this period and were active participants in the research effort described here.

While Zimbabwe's cholera epidemic and health care system collapse is now nearly a decade in the past, our findings remain highly relevant for Zimbabwe and other countries in the region and beyond, as complex health and rights interactions remain all too common, and governance concerns continue to limit improvements in human health.

Methods

We utilized a mixed-methods approach that combined qualitative research from a primary investigation by Physicians for Human Rights in 2008 with a review of the social science and human rights literature and of international news reports. We then performed a systematic review and content analysis of articles published on the epidemic in peer-reviewed scientific journals.

Qualitative assessment: Physicians for Human Rights' investigation

Physicians for Human Rights sent a team of four investigators, including the second and third au-

thors of this paper, to Zimbabwe for seven days in December 2008 to conduct an emergency health and human rights assessment. Investigators comprised two physicians with expertise in public health and epidemiology and two with primary expertise in human rights. The team conducted a series of key-informant interviews and several focus group discussions, speaking with a wide range of stakeholders in urban and rural areas of four provinces (Harare, Mashonaland Central, Mashonaland West, and Mashonaland East); they interviewed a total of 92 participants. Participants included health care workers in private and public hospitals and clinics, medical students from Zimbabwe's two medical schools, representatives from local and international nongovernmental organizations, representatives from United Nations agencies, Zimbabwean government health officials, members of parliament, water and sanitation engineers, farmers, and schoolteachers.

The qualitative domains of the interview instrument were adapted from health and rights instruments used in similar circumstances by Physicians for Human Rights, the Center for Public Health and Human Rights at Johns Hopkins University, and the School of Public Health at the University of the Western Cape, South Africa. Survey instruments, research protocols, and consent processes were reviewed and approved for adoption in Zimbabwe by Physicians for Human Rights' Ethics Review Board – Human Studies Research, which has been operating since 1996 in accordance with the US Code of Federal Regulations, Title 45, Part 46. Local authorities were not approached in the beginning out of concern for the safety of participants.

After explaining the purpose of the investigation and the intent to conduct advocacy based on the findings, Physicians for Human Rights' investigators asked participants for their informed verbal consent. All participants were aged 18 or older. Verbal, rather than written, consent was obtained to safeguard participant confidentiality: consent was not formally recorded in association with any identifying information for participants to ensure their safety in the event that research materials were intercepted by authorities while in the country.

Every effort was made to ensure participants' protection and confidentiality and to reduce potential adverse consequences, such as political reprisal. Measures included data encryption and de-identifying the participant's name, profession, residence, hospitalization, history of arrest, and information pertaining to family members and co-workers. Interviews took place in private settings and were never conducted if interviewers judged that risk to the participant was too high or that the participant's ability to assess risk was impaired. Interviewers were careful not to publicize their presence in Zimbabwe or the purpose of their visit.

We supplemented qualitative data from this investigation with a review of social science, international news, and human rights sources to be able to present a comprehensive overview of the specific political and social determinants of the epidemic within the country's wider human rights context.

Systematic review and content analysis: Discussion of political determinants in peer-reviewed scientific literature

We conducted a systematic review of articles published in peer-reviewed scientific journals between August 2008 and May 2013. We performed this review through the PubMed and Web of Knowledge databases using the search term "cholera AND Zimbabwe." This search yielded 59 unique citations, including commentary/editorial pieces, news updates, and original research articles.

All 59 articles underwent a full text review. We included English-language articles for which the 2008–2009 Zimbabwean cholera epidemic was a major subject of discussion (rather than a peripheral example) and for which mention of at least one causal factor for the epidemic was provided. These inclusion criteria yielded 30 articles: 5 commentary/editorial pieces, 12 news updates, and 13 original research articles. The articles came from 22 peer-reviewed journals.

We further evaluated these 30 articles using a basic content analysis for inclusion of subject matter addressing the political dimensions of the epidemic, including Mugabe, his ZANU-PF political party, and the 2008 Zimbabwean presidential

elections. The analysis involved searching the body of the text (excluding references) for the four terms and their etymological variants: "Mugabe," "ZANU," "election," and "politic." Representative quotations involving assertions of causality in the epidemic were extracted and tabulated.

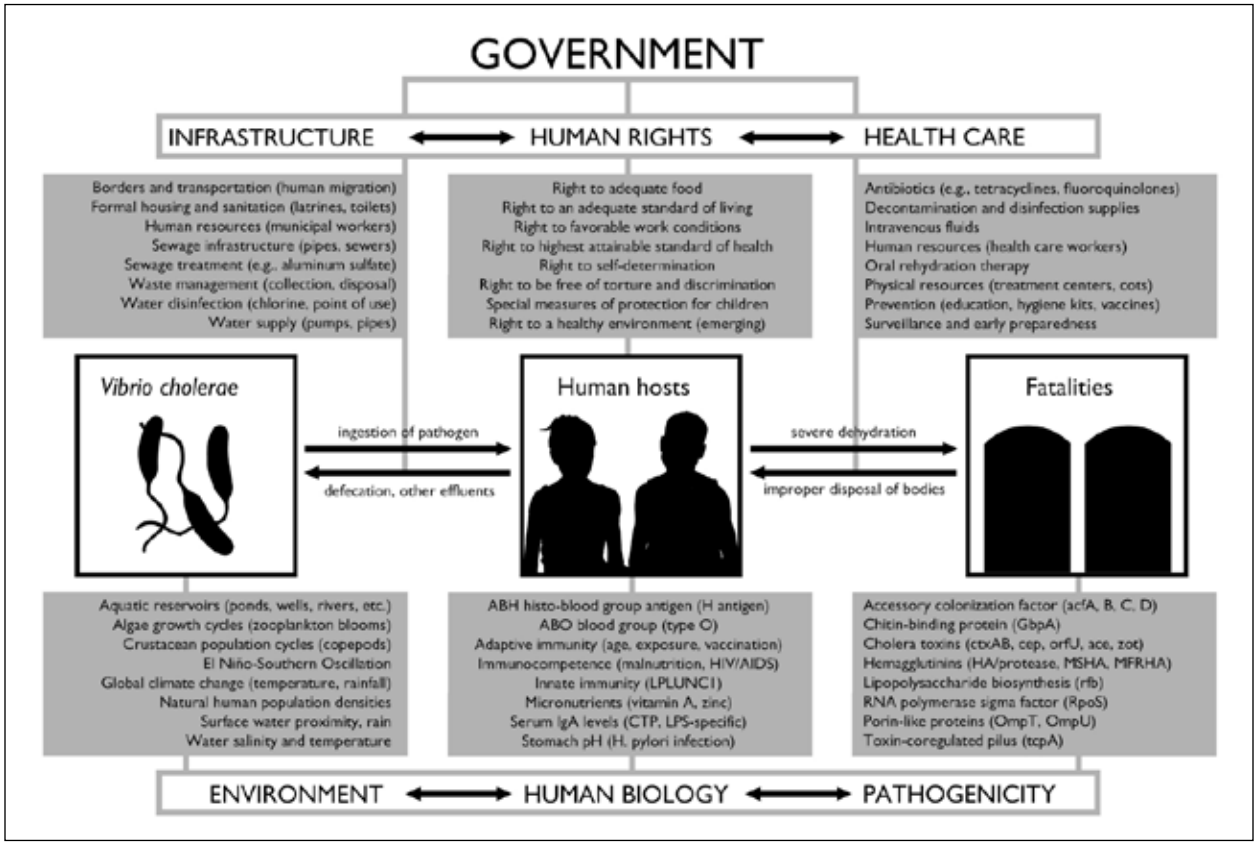
Findings

This section presents our findings regarding the political and social determinants of the epidemic based on our in-country investigation and our supplementary literature review. In doing so, it utilizes a framework that we developed to understand cholera epidemics as a product of compromises in infrastructure, human rights, and health care and their interactions with the environmental, human biological, and pathogenic factors of the disease (Figure 1).

Infrastructure: The politicization of water and sanitation and the origins of the epidemic

Recent literature has highlighted the essential role of water and sanitation infrastructure in preventing and combating cholera.[7] This relationship has been established since the earliest days of modern epidemiology, when John Snow identified the contaminated "Broad Street pump" as the source of the 1854 London outbreak. Maintaining proper infrastructure remains the most effective public health mechanism for combating the fecal-oral route of transmission on which the cholera pathogen, *Vibrio cholerae*, depends.[8]

FIGURE 1. A conceptual framework for understanding cholera



Six major mediators of cholera epidemics are highlighted in this model: (1) environmental factors potentiate the presence of the pathogen (*Vibrio cholerae*) in the ecosystem, while an individual's (2) human biological variables and (3) realization of human rights determine his or her unique susceptibility to contracting the pathogen and becoming a host. (4) Infrastructural advances serve to mitigate possibilities for individuals to come into contact with the pathogen in their environments or to introduce it into their surroundings once infected. Overall fatalities depend not only on the (5) pathogenicity of the particular cholera strain but on (6) health care delivery and other upstream drivers. The government, which is responsible for developing infrastructure, protecting human rights, and providing health care for its citizens, occupies a central role in the model.

A breakdown in the most basic elements of water and sanitation infrastructure underpinned the cholera epidemic in Zimbabwe. On May 9, 2005, just weeks after parliamentary elections in which the MDC opposition party had made a strong showing, ZANU-PF issued a national directive to overturn the 1976 Water Act and bring municipal water authorities across the country under the Zimbabwe National Water Authority. This directive came at a politically charged time, weeks before ZANU-PF's execution of Operation Murambatsvina ("Drive Out Trash" in Shona language), which displaced more than 700,000 Zimbabweans—many of whom supported the opposition party. This government-sanctioned action was widely interpreted as a response to the MDC's success in the election.[9]

The decision to usurp municipal authority over water, which had been under the control of the MDC in many areas of opposition support (including Harare), had major implications: (1) it immediately deprived MDC-controlled city councils of an important source of revenue, which they had been using to fund civic projects and maintain infrastructure; (2) it provided the cash-strapped ZANU-PF regime with a new stream of revenue (confirmed as a major motivation behind the move by one of our government informants); and (3) it allowed the ZANU-PF to assume control of another essential element for life—the government had a history of politicizing access to food amid famine through the national Grain Marketing Board (Table 1).[10]

In nationalizing water services, ZANU-PF claimed to be taking a step toward relieving Zimbabweans of "persistent water woes."[11] Instead, it raised water rates for residents while simultaneously neglecting infrastructure and diverting revenue to military and security forces.[12] This approach predictably led to widespread service disruptions, resident discontent, and water-borne disease, particularly in and around Harare. In March 2006, there were 27 cholera-related deaths as civil groups in Harare warned of a "cholera time bomb" should the Zimbabwe National Water Authority not make essential repairs to the deteriorating water system. The water agency did not heed these calls: in August 2007, reports surfaced of it pumping raw sewage into Lake Chivero, the main source of water for Harare, a claim that was later confirmed by agency representatives who were quoted in regional media.[13] Water supply became increasingly erratic while quality deteriorated. In March 2008, Mugabe suffered a definitive defeat by MDC opposition leader Morgan Tsvangirai, further inflaming the political situation in the country.

The 2008–2009 cholera epidemic began in late August in Chitungwiza, a high-density center outlying Harare that was also part of the Lake Chivero catchment area.[14] Chitungwiza, a stronghold of MDC support, had been a target of ZANU-PF's Operation Murambatsvina two years before, through which over 45% of the city's million informally settled inhabitants had seen their homes and possessions seized or destroyed by ZANU-PF forces.[15] The failure of ZANU-PF to maintain basic infrastructure, particularly in areas of opposition support, continued as the epidemic began to take root. On November 29, 2008, Harare residents reported a complete cut in water supply, as the Zimbabwe National Water Authority had ceased pumping water from its main treatment plant after running out of aluminum sulfate, one of four chemicals it had been using to treat the water. Multiple sources we spoke with, including two members of parliament, confirmed that ZANU-PF leaders continued to willfully neglect their responsibility in repairing infrastructure, even after the epidemic began.

Human rights: Decades of politically motivated abuses against a vulnerable population

Despite the country having signed and ratified both major international human rights covenants—the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights—ZANU-PF, under Mugabe's leadership, has engaged in human rights abuses since its earliest days in power.[16] A review of the chronology of the actions, motivations, and consequences surrounding many of the regime's human rights violations reveals a common theme: the targeted intimidation and punishment of op-

TABLE 1. Chronology of politically motivated human rights abuses in Zimbabwe

Time		Action	Presumed motivation/ cause	Human rights violations	Consequence
1980	March	**General election: ZANU-PF (63.0%), ZAPU (24.1%)**			
		ZANU-PF uses coercive tactics to help elect Mugabe prime minister	To suppress ZAPU opposition party and leader, Nkomo	Right to vote	Set precedent for voter intimidation
1983–1984		Mugabe fires Nkomo from cabinet (1983), ordering targeted killings of Ndebele civilians (estimated at around 20,000)	Ndebele seen as ethnic minority group supporting ZAPU and Nkomo	Rights to enjoy one's culture, to equal protection, to life, to safety	Set *gukurahundi* ("storm that destroys everything") policy to obliterate opposition
1985	June	**Parliamentary election: ZANU-PF (77.2%), ZAPU (19.2%)**			
	July	ZANU-PF makes parliamentary election gains, denies any cabinet seats to ZAPU	To bring Zimbabweans under ZANU-PF	Rights of participation in civil society and politics	ZAPU, defeated, agreed to unify with ZANU-PF (1987)
1987		Mugabe amends Constitution to make himself executive president, abolishing prime minister position	To consolidate Mugabe's powers in face of opposition	Rights of participation in civil society and politics	Mugabe gained executive, judicial, and legislative power
1990	March	**Presidential election: Mugabe (83.05%), Tekere (17.05%)**			
1992–1993		**Cholera outbreak (7433 cases, 5.8% case fatality rate) – first recorded in Zimbabwe**			
1995	April	**Parliamentary election: ZANU-PF (81.4%), ZANU-Ndonga (6.9%)**			
1996	March	**Presidential election: Mugabe (92.8%), Muzorewa (4.8%), Sithole (2.4%)**			
		Mugabe indefinitely arrests new opposition leader, Sithole, before vote and wins election	To quash opposition	Rights to a fair trial, to trial within a reasonable time	Poor voter turnout (32.3%) despite youth militia coercion
1999	January	**Cholera outbreak (5637 cases, 6.8% case fatality rate)**			
2000	February	**Constitutional referendum on land reform: no (54.3%), yes (45.7%)**			
	March	Mugabe permits fast-track "land reform" in form of violent land invasions of white-owned farms to award to "war veterans"	Mugabe needed political win after creation of MDC, a new opposition party, and referendum defeat	Rights to safety, to life, to compensation for expropriation of property	Sowed the seeds of ensuing agricultural and economic collapse, famine
	June	**Parliamentary election: ZANU-PF (48.6%), MDC (47%)**			
		Mugabe denies food to members of opposition amid food shortage	MDC made major gains in elections	Rights to food, to equal protection	Set precedent for politicization of food
2001	May	Mugabe begins replacing judiciary, chief justice resigns	Court ruled against farm invasions	Right to an impartial tribunal	Loss of judiciary independence
2002	January	**Cholera outbreak (3125 cases, 6.1% case fatality rate)**			
	February	Parliament passes law limiting freedom of press, burns and closes independent newspaper offices	To suppress criticism of Mugabe before elections	Freedom of press, of thought and conscience	Mugabe gained power over media, control of discourse
	March	**Presidential election: Mugabe (56.2%), Tsvangirai (42.0%)**			
	April	Food shortages lead to famine, Mugabe refuses to intervene	Retaliation for opposition support	Rights to food, to equal protection	Continued policy of politicizing food aid
2003	June	Tsvangirai and other MDC leaders are arrested by Mugabe and charged with "treason"	Tsvangirai was gaining popularity, leading mass strikes	Rights to trial within a reasonable time, to just cause	Reinforced policy of *gukurahundi*, political intimidation
2005	March	**Parliamentary elections: ZANU-PF (59.4%), MDC (39.5%)**			
	May 9	Mugabe nationalizes municipal water sources under the Zimbabwe National Water Authority with exception of Bulwayo (considered too much of an MDC stronghold)	To undermine the MDC's authority, gain access to major source of revenue	Rights to self-determination, to highest attainable living conditions	Deprived MDC of revenue, set the stage for collapse of water infrastructure
	May 25	Mugabe launches Operation Murambatsvina, destroying the homes of >700,000 (mostly MDC supporters)	To target informal settlements in the city that were areas of MDC support	Rights to adequate housing, to physical integrity and safety, to compensation	Dispossessed MDC supporters, forced them into rural areas of ZANU-PF support

position leaders and their supporters, along with the consolidation of power necessary to ensure the party's continued reign in the country (Table 1).

The 2008–2009 cholera epidemic was no exception to this theme. Emerging in a presidential election year, as did the previous cholera epidemic in 2002, the outbreak was the culmination of a series of politically motivated human rights violations that had intensified after the 2005 parliamentary elections. These violations had in fact become official policy under Operation Murambatsvina. Such policies were specifically directed at areas of MDC support, including Glenview, Chitungwiza, and Dzivarasekwa—districts that were among the most affected by the epidemic.[17] While such a link may be dismissed as merely coincidental by those unaware of ZANU-PF's human rights record, it is consistent with the Mugabe regime's denial of food aid to areas of opposition during famines.[18] An earlier example would be the killings of more than 20,000 civilians in Matabeleland (where Mugabe's major opponent at the time, Joshua Nkomo, was drawing much of his support) in the 1980s through its policy of *gukurahundi* ("storm that destroys everything").[19]

Health care: The economic collapse of a system and exacerbation of an epidemic

While the failures in water and sanitation infrastructure served to initially precipitate the epidemic and permit it to spread rapidly across the country, the failures of the health care system played a role in extending and exacerbating it. The Zimbabwean government's public health response was characterized by early denial of the epidemic, suppression of health information, inadequate resourcing of health care centers, and abandonment of other health care priorities. As a result of these failures, the epidemic assumed a high initial case fatality rate, over five times the international standard of <1%.[20]

Cholera broke out in Zimbabwe following the 2008 elections and amid an economic crisis that led to the hyperinflation of the Zimbabwean dollar (inflation surpassed 2,000,000% in July 2008) and successive devaluations of the currency.[21] The economic crisis was the result of ZANU-PF's poor economic governance, fiscal indiscipline, and destruction of property rights following the implementation of the *jambanja* ("direct action") policy in 2000.[22] *Jambanja* called for the seizure of thousands of white-owned farms despite a consti-

TABLE 1. *continued*

Time		Action	Presumed motivation/ cause	Human rights violations	Consequence
2006		ZANU-PF treasury continues injecting huge sums of money into economy, inflation reaches 1,000%	To pay down large debts from ZANU-PF's lavish spending	Right to promotion and protection of economic interests	Currency became worthless, economy begins to collapse
2007	March	Tsvangirai is arrested and brutally tortured by ZANU-PF forces and denied treatment	To scare Mugabe's opposition into pulling out of election	Rights to physical integrity and safety, to health	Continued political intimidation of MDC supporters
	August	ZINWA is reported to be dumping raw sewage into Lake Chivero, Harare's main water supply	Result of willful neglect of water infrastructure	Rights to health, to water	Contaminated water supply to Harare, already intermittent
2008	March	**Presidential elections: Tsvangirai (47.9%), Mugabe (43.2%) – first round**			
		Parliamentary elections: ZANU-PF (45.9%/46.2%), MDC-T (42.9%/43.3%) (House of Assembly/Senate)			
		Mugabe embarks on campaign of violence and intimidation after initial round of elections in areas of MDC support	To suppress the MDC vote in the second round of the election	Rights to vote, to physical integrity and safety	Tsvangirai forced to withdraw from second round to avoid more violence
	May	Economy bottoms out, inflation reaches 1,000,000%	Result of 10 years of misgovernance	Right to protection of economic interests	Zimbabwe adopted dollar as currency
	June	**Presidential elections: Mugabe (85.5%), Tsvangirai (9.3%) – second round**			
	August	**Cholera outbreak (98,585 cases, 4.3% case fatality rate)**			

tutional referendum opposing such action and a constitutional court ruling against it.[23] The violent land seizures undermined business confidence in Zimbabwe and gutted one of the country's most productive sectors after the ousted farmers were replaced largely by those lacking the skills, resources, and access to credit to continue producing agricultural surpluses. Zimbabwe subsequently became the target of international sanctions that were targeted mainly at individuals and entities believed to be the most responsible for undermining democratic processes within the country.[24]

While *jambanja* sowed the initial seeds of Zimbabwe's economic collapse, ZANU-PF's economic policies sealed its fate. Through increased spending on military and security forces to appease party loyalists, ZANU-PF racked up huge deficits, which were financed by having the Reserve Bank of Zimbabwe print new money under the direction of the bank's governor and the minister of finance. This money was then injected into the economy at unprecedented rates, fueling hyperinflation.[25] Furthermore, ZANU-PF maintained a series of fiscal mandates, such as a fixed exchange rate and excessively high reserve requirements for banks, which made participating in Zimbabwe's formal sector virtually impossible. Zimbabweans, who had enjoyed a relatively high standard of living in southern Africa, were impoverished by these policies, and several million (including many skilled workers such as health care professionals) were forced to leave the country in search of work and food security.

ZANU-PF's primary focus on power—as opposed to governance—was highlighted during the cholera epidemic. When the outbreak began to surface amid Zimbabwe's economic crash, ZANU-PF initially suppressed information about it.[26] When it became difficult to hide the burgeoning disaster, ZANU-PF fabricated data and refused offers of assistance by local physicians.[27] Georges Tadonki, head of the United Nations Office for the Coordination of Humanitarian Affairs in Zimbabwe at the time, was wrongfully terminated for blowing the whistle on the impending epidemic by United Nations country chief Agostinho Zacarias, who was later found to be colluding with ZANU-PF.[28] The Zimbabwe Association of Doctors for Human Rights informed us that when the association offered help to the Harare City Council in treating cholera victims, the City Council responded, "We have the situation under control." The MDC had lost its leadership of the council when Emmanuel Chiroto, who had been elected to serve as mayor in June 2008, was forced into hiding after his home was bombed and his wife presumably murdered by ZANU-PF supporters.[29] Instead of making an early appeal for international aid, which would have injected essential foreign capital into the health system, Mugabe stalled for nearly four months, publicly declaring there to be "no cholera in Zimbabwe," even after his own health minister, David Parirenyatwa, had finally issued such a call.

Our investigation unveiled the near-complete cessation of public sector health care delivery in the early days of the epidemic, a time when such intervention would have been especially critical for curbing the epidemic and associated fatalities. Between September and November 2008, most wards in the large public hospitals were shuttered. The acute collapse of the health system culminated in the dramatic November 17 closure of the Parirenyatwa Hospital and the Medical School, Zimbabwe's premiere medical institutions, at the height of the epidemic due to a lack of water supply. Other hospitals became nonfunctional due to shortages in essential medicines and supplies and staff absenteeism as a result of the prohibitive costs of transportation.

Content analysis: Discussion of political determinants in peer-reviewed scientific literature

In our systematic search, we analyzed 30 articles from peer-reviewed scientific journals that addressed risk factors or described contextual factors related to the 2008–2009 cholera epidemic in Zimbabwe. The articles included 5 commentary/editorial pieces, 12 news reports and updates, and 13 original research papers (Table 2). Fewer than half (46.7%) explicitly mentioned politics as an influence, while only seven (23.3%) explicitly men-

tioned Mugabe's or ZANU-PF's involvement in water supply and sanitation disruptions, denial of the cholera epidemic, or refusal to respond to the crisis. Only two articles (6.7%) mentioned the antecedents of the 2005 and 2008 political elections. While many articles did cite the most direct causal factors responsible for the outbreak (that is, failures in basic infrastructure and health care delivery systems), few acknowledged the fundamental role of ZANU-PF, under the leadership of Mugabe, in generating these failures, despite widespread evidence in the general media, human rights reports, United Nations reports, and other fora.

Several articles focused on individual-level risk factors. For example, the attribution of a "hyper-infectious state" to ongoing transmission was reported by one group; attending "funeral feasts associated with the culture of eating together with fingers from the same bowl" was reported by another; and "eating cold food" was noted by a third group.[60] Others employed general and vague political terminology, such as describing the epidemic as "unfolding against a background of a complex political and economic crisis."[61]

Seven of the thirteen original research papers presented mathematical, epidemiologic, and economic models based on data collected from the epidemic to either characterize pathogen trans-

TABLE 2. Content analysis of indexed publications on the Zimbabwean cholera epidemic

Source	Representative assertions of causality	Mugabe	ZANU-PF	Election	Politic
Commentaries/editorials					
Clemens (2011)[30]	• "Human-to-human transmission, either directly or indirectly via contamination of food or water"				
Clemens and Holmgren (2009)[31]	• "Sanitation and hygiene are poor and healthcare is inadequate"				✓
Fisher (2009)[32]	• "Political turbulence and economic collapse … has produced a loss of infrastructure necessary to facilitate domestic food production and maintain essential services including water, sanitation and hygiene"				✓
Ncayiyana (2009)[33]	• "The country's inability to process clean, potable water for the city of Harare, nor indeed for the country as a whole" • "The Zimbabwe National Water Authority has simply shut down the regular water supply system" • "Prevailing political impasse and economic meltdown … all resulting from the Mugabe regime being permitted to maintain political control of the country against the wishes of the people of Zimbabwe"	✓			✓
Nelson (2009)[34]	• "Ubiquitous failure of the Mugabe government to provide clean water"	✓			
News reports					
Bateman (2009)[35]	• "Inadequate supplies of safe drinking water" • "Dilapidated sanitation systems" • "Public health system in 'total collapse'"				
Chambers (2009)[36]	• "9 years of political tensions … and an accompanying economic crisis" • "Violations of the right to safe and potable water, adequate sanitation and a collapsed health care system"	✓			✓
Cumberland (2009)[37]	• "Breakdown of water and sanitation infrastructure" • "Restricted availability of … life-saving treatment" • "There are few cholera treatment centres, and people can't afford to travel or are too sick to catch a bus" • "Due to damaged urban water-piping systems … further fuelled by inadequate sanitation, mainly excreta disposal"				
Euro-surveillance (2008)[38]	• "Background of a complex political and economic crisis" • "A deteriorating healthcare system weakened by lack of resources and staff strikes" • "Lack of clean water because the state-run water company has run out of aluminium sulphate"				✓
Hug (2009)[39]	• "Sewage runs through the streets" • "Water station doesn't have the parts to repair the pump needed to bring water [or] electricity to run the pumps" • "The mine workers haven't been paid in a year. Neither have the garbage collectors. The sewage facility is in a similar fix."				

TABLE 2. *continued*

Source	Representative assertions of causality	Mugabe	ZANU-PF	Election	Politic
Kapp (2009)[40]	• "Total collapse of the health and sanitation system" • "Months of political deadlock … worsened the humanitarian crisis"	✓			✓
Koenig (2009)[41]	• "Breakdown of potable water and sewage systems—a symptom of the country's economic chaos" • "Worsened … because the public health system … was severely understaffed and underfunded"				
Mason (2009)[42]	• "Breakdown in water supply and sewerage disposal in high density urban areas" • "Breakdown in health service facilities, with shortages of clinic staff" • "Failure of primary care facilities to provide even simple conditions for case management" • "Transfer of responsibility for water supply and sewerage disposal from City Councils to the Zimbabwe National Water Authority" • "The general economic crisis of Zimbabwe"				✓
Rosborough (2009)[43]	• "Fueled by a failed public water supply and sanitation system together with a crumbling national health infrastructure"				
	• "The Zimbabwe National Water Authority shut off all water supply to Harare … after running out of water purification chemicals"	✓			✓
Truscott (2008)[44]	• "Poor nutrition, sanitation, and water quality, and high rates of HIV infection and poverty in Zimbabwe have combined to push up morbidity rates" • "Collapse of state hospitals" • "The state run Zinwa water authority abruptly cut supplies to the entire capital, citing a lack of aluminium sulphate used in water purification"				
Truscott (2008)[45]	• "Widespread unavailability of clean piped water" • "Uncollected rubbish and frequent bursts in sewer pipes" • "Unofficial closure of almost all public hospitals"				
Zarocostas (2009)[46]	• "Rainy season floods" • "Collapsed water and sewerage" • "Lack of transport, food, and incentives"				✓
Original articles					
Ahmed, Bardhan, Iqbal, et al. (2011)[47]	• "Breakdown of … potable water and sanitation systems" • "Widespread contamination of available drinking-water sources" • "An example of how man-made disasters can cause degradation in the quality of life due to the destruction of well-established and essential infrastructures" • "Health facilities were found to be operating with fewer numbers of trained health personnel … result[ing] in inappropriate and ineffective management of patients"				✓
Davies (2012)[48]	• "The cholera epidemic in Zimbabwe was caused largely by the financial and political mismanagement of public health for well over a decade" • "The response of the government … ranged from complete denial to assertions that the government had the situation under control … Mugabe even alleged that the outbreak was the result of a biological weapon attack"	✓	✓	✓	✓
Grad, Miller, and Lipsitch (2012)[49]	• "Cholera spreads in areas with poor sanitation and through contaminated water, and the ideal solution is to improve infrastructure in order to provide clean water and effective sanitation"				
Islam, Mahmud, Ansaruzzaman, et al. (2011)[50]	• "Zimbabwe experienced a cholera epidemic caused by both altered and hybrid strains, possibly due to cross-border transmission from Zambia and Mozambique"				
Kim, Choi, Mason, et al. (2011)[51]	• "A weak health system infrastructure" • "Sub-optimal availability of and access to basic water/sanitation" • "Lack of political will to improve the system"				✓
Kone-Coulibaly, Tshimanga, Shambira, et al. (2010)[52]	• "The index case was a 26 year old woman from Waterfalls who came from Mozambique" • "Having a diarrhoea contact at home" • "Eating cold food" • "Having attained less than secondary education" • "Community health education campaigns were negatively affected by human and material resources constraints" • "Refuse had not been collected for years and burst sewage pipes were flowing all over in the affected areas"				
Liao and Wang (2011)[53]	• "The hyperinfectious state plays an important role in the transmission of the disease"				

TABLE 2. *continued*

Source	Representative assertions of causality	Mugabe	ZANU-PF	Election	Politic
Luque Fernandez, Mason, Gray, et al. (2011)[54]	• "The country was in economic crisis" • "The health care system had become dysfunctional" • "Water supplies were irregular and sanitation systems had collapsed" • "A lack of maintenance of the system" • "Combination of a highly mobile infectious working population coming together in the overcrowded and unsanitary conditions found in markets significantly influenced the spread of cholera into the city through person to person transmission"				
Luque Fernandez, Schomaker, Mason, et al. (2012)[55]	• "In developing countries, cholera is closely related to poor environmental status and lack of basic infrastructure. In this respect, high population densities and poor access to safe water and proper sanitation, along with other environmental conditions, contribute to the spread of cholera in Africa"				
Morof, Cookson, Laver, et al. (2013)[56]	• "Hyperinflation, inadequate finances, shortages of clinicians, medications, and supplies left Zimbabwe with an inadequate health care system and unable to respond adequately to a cholera outbreak" • "Access to … services varied nationally. Poor access to healthcare may have contributed to the unusually high proportion of community deaths."				
Mukandavire, Liao, Wang, et al. (2011)[57]	• "Environment-to-human and human-to-human modes of transmission both contributed … with the latter mode … contributing more" • "Funeral feasts associated with the culture of eating together with fingers from the same bowl…have been a major cause of cholera spread during an outbreak0" • "Water and sanitarian problems, with burst sewers, unprotected wells, and only one tanker and one borehole available to the population of 44,000" • "Water and sanitation problems, with burst sewers, unprotected wells" • "Abetted by the economic collapse in the country that left clinics and hospitals unable to acquire and stock even basic medicines and materials to provide health care, with most clinics in the rural areas closed" • "Explosive outbreaks associated with contamination of drinking water"				
Reyburn, Deen, Grais, et al. (2011)[58]	• "A concerted effort to distribute a hypothetical cholera vaccine stockpile could have potentially prevented more than a third of the cholera cases and deaths in Zimbabwe" • "There is a consensus opinion that the political situation in Zimbabwe at the time of the outbreak would have prevented mass vaccination campaigns"				✓
Youde (2010)[59]	• "Near-collapse of the country's water and sanitation infrastructure" • "Direct relationships between the policies and decisions of President Robert Mugabe and his ZANU-PF party and cholera's emergence" • "The takeover of municipal water supplies by the national government to weaken the opposition… and the government's economic mismanagement have worked in tandem to allow cholera to flourish"	✓	✓	✓	✓

mission patterns from the epidemic or assess the suitability of a reactive mass vaccination campaign post hoc. Any discussion of the concomitant political situation beyond the superficial—for example, "exacerbated by a … lack of political will to improve the system"—was missing from the analyses, which contained no mention of Mugabe, ZANU-PF, or the elections.[62]

A few authors and journals stood out in their coverage of the explicit political and human rights dimensions of the outbreak. Jeremy Youde, in the *International Journal*, detailed the root causes of the outbreak and the political factors that exacerbated it.[63] Notably, this Web of Science-indexed journal focuses on international relations, with little readership in the biomedical sciences. Interestingly, all three reports on the Zimbabwe outbreak published in the *Lancet* included an assessment of the political nature of the epidemic and the Mugabe regime's complicity in it.[64] In addition to the *Lancet*, the regional scientific literature, including two reports in the *South African Medical Journal*, was also notable for identifying the political factors behind the epidemic.[65]

Discussion

In this paper, we present a synthesis of original and supporting data documenting the major political forces behind the 2008–2009 Zimbabwean cholera epidemic, adding to the existing body of literature on the structural aspects of health care delivery as they relate to sociopolitical determinants, including human rights abuses.[66] On the basis of Physicians for Human Rights' investigation and our primary literature review, we found that the epidemic was a tragic case of a man-made disaster—an outcome of the politicization of water and aid by an authoritarian government with a long history of human rights abuses, acting in fear of opposition gains in recent elections.

We then critically assess the literature published on the epidemic in peer-reviewed scientific journals by using a systematic review and content analysis to explore the causal factors identified. Despite ample publicly available evidence linking direct actions by the Zimbabwean government under the control of Mugabe's ZANU-PF party to the initiation, propagation, and exacerbation of the cholera epidemic, only a minority (23.3%) of authors referenced Mugabe or the ZANU-PF party, and fewer than half (46.7%) explicitly mentioned the role of politics in the health system collapse. In the rare cases when such factors were discussed, authors used passive and in some cases permissive language that at times obfuscated causality, negating the central role that ZANU-PF's polices played in creating the crisis. Phraseology such as "a deteriorating health care system weakened by lack of resources and staff strikes" neglects the deliberate withholding of resources following the 2008 elections and may implicitly blame the striking health professionals.[67] Medical and nursing staff, whose government salary did not even cover the cost of public transportation to go to work, did indeed protest the collapse of Zimbabwe's health sector; they exercised their right to peaceful assembly to demand services, resources, food, water, and medicine for their patients. Several notable exceptions came from regional authors, who, not surprisingly, exhibited a more nuanced understanding of the relevant political dimensions of the epidemic. This distinction underscores the importance of regional medical literature concerning health crises with political dimensions. Of note, South Africa became involved in both mediating sanction-related discussions between Zimbabwe and the international community and in compelling a direct response after the epidemic began to cross Zimbabwe's borders.

These findings demand inquiry. Why would scientists choose not to explicitly address the political dimensions of an epidemic? Possible explanations include a lack of political or human rights knowledge outside one's disciplinary focus (which biases against addressing those issues), a belief that explicit political references in scientific literature would violate a perceived norm of neutrality, and (perhaps most commonly) deliberate avoidance of overt political analysis in order to protect one's ability to conduct future research or maintain one's personal safety.

The first example represents a narrow disciplinary focus on the part of scientists who fail to address issues outside the scope of their specific medical or public health expertise, even when such factors are directly relevant to the subject of inquiry. By neglecting to investigate or adequately address these elements when contextualizing their results, researchers oversimplify a complex system to a point at which the integrity of their observations may be compromised. Cholera—a preventable and curable infectious disease at the intersection of a wide range of social and biological mediators—is a prime example of a disease that necessitates multidisciplinary scientific inquiry, including an analysis of its political and social dimensions.

The second case of deliberate neutrality is similarly problematic. Here, cognizant investigators choose to withhold data based on an erroneous belief that revealing such evidence is tantamount to espousing an openly moral or ethical stance, thus violating a perceived doctrine of neutrality that guides scientific inquiry. Philosopher C. P. Snow, the authoritative voice of the "moral un-neutrality of science," famously challenged this belief in a 1961 issue of *Science*.[68] Nevertheless, a half century later, the belief remains pervasive, stemming from a persistent and flawed conflation of the terms "ob-

jectivity" and "neutrality." Indeed, as Snow argued, there is nothing morally neutral about the pursuit of objectivity: "The desire to find the truth is itself a moral impulse, or at least contains a moral impulse … The way in which a scientist tries to find the truth imposes on him a constant moral discipline."

The third example concerns the complicated phenomenon of the "silent witness."[69] We must not dismiss the threat to personal and professional security that academics and humanitarian workers face while practicing in politically charged environments around the world. The ability of humanitarian organizations such as the International Committee of the Red Cross and Médecins Sans Frontières to safely provide assistance in areas of conflict derives from their perceived political impartiality. One can readily infer the importance of such impartiality among humanitarian organizations in their reporting language. For example, they are often disinclined to name political entities responsible for health rights violations: "the health care system had become dysfunctional"; "water supplies were irregular and sanitation systems had collapsed"; and "a lack of maintenance of the system."[70] These tangible compromises in reporting are likely unavoidable, but they place weight on those groups less affected by such constraints to establish such causation explicitly and robustly on behalf of colleagues whose terms of engagement may make them less able to directly report on human rights and political determinants.

Conclusion

Researchers have shown the importance of understanding and addressing the political determinants of health in order to implement effective public health interventions that save lives. In this paper, we take a human rights-based approach to present findings from a primary investigation of a prolonged, high-mortality cholera epidemic in Zimbabwe, which we then utilize to frame a subsequent analysis of a systemic literature review. We found the peer-reviewed scientific literature to be lacking in appreciation of the basic human rights issues and political factors responsible for the outbreak and its subsequent pathogenicity. Using the example of the Zimbabwean epidemic, we argue that neglecting to address the political determinants of complicated epidemics can limit the integrity of scientific research. The man-made health system collapse in Zimbabwe serves as an important case study that elucidates the linkages between political violence and attendant rights abuses that ultimately led to thousands of preventable deaths from cholera.

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Medical Students' Attitudes toward Torture, Revisited

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Abstract

This paper reports the findings of a survey of medical students' attitudes toward torture and discusses variables that may correlate with those attitudes. In late 2016, 483 enrolled medical and MD–PhD students at the Weill Cornell Medical College received an anonymous, institutional review board-approved survey that included questions about torture and its effectiveness, demographic questions, inquiries about personal experiences of harassment or discrimination, and questions regarding engagement in human rights activities. Some questions were drawn from a 2008 University of Illinois survey of medical students' attitudes toward torture, the only prior such survey at a US medical university. Of the 483 students who were contacted, 121 (25%) returned completed questionnaires, with responses indicating strong opposition to torture and skepticism about its usefulness. Respondents expressed greater opposition to torture in this survey than those who participated in the 2008 survey. Respondents' involvement in Weill Cornell's human rights program was associated with significantly stronger opposition to torture, while personal experiences of harassment were associated with a trend toward weaker opposition to torture. Respondents' answers closely approximate the clearly stated ethics of the profession, suggesting that human rights education during medical school may contribute to the development of proper values in young physicians even before they proceed into practice.

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Introduction

Physicians are subject to broadly accepted standards governing ethical and professional conduct. The condemnation of physicians' direct or indirect participation in torture is one example. This is asserted by the World Medical Association, American Medical Association, American Psychological Association, World Psychiatric Association, American College of Physicians, American Psychiatric Association, and innumerable countries' medical societies.[1] However, as Steven Miles reminds us, many medical personnel continue to participate in and condone torture: "Many torture survivors report that clinicians monitored their mistreatment. The presence of a physician during torture compounds the victim's suffering by emphasizing that even the humanity of medicine is turned against the prisoner."[2] This paper explores the knowledge and attitudes of medical and MD–PhD students at one institution on matters relevant to the practice of torture and physician complicity with torture.

Many physicians and medical personnel who participate in torture do so as they succumb to conflicts between professional ethics and the demands of their work, superiors, and peers. The authorization of torture during the Bush administration by government authorities (Departments of State, Defense, and Justice) enabled its legitimization through the military chain of command. In military settings, many may fear retaliation or disciplinary consequences should they fail to follow orders. From a psychosocial perspective, Myles Balfe identifies factors that may contribute to a physician's participation in torture, such as the passionate assumption of the need to defend the United States from grave danger.[3] Balfe further notes that the capacity for rationalization (such as euphemistically referring to torture as "enhanced interrogation procedures") and cognitive distortions (such as the belief that without medical supervision, greater harm might ensue) are clear factors. Additionally, the splitting of roles such that responsibility can be diffused among many participants, each believing that their individual contribution to torture was minor or insignificant, creates an environment that enables medical personnel's participation in torture.

The present study explores future US physicians' attitudes toward the permissibility and utility of torture, as well as their beliefs about physicians' participation in torture. A previous survey of medical students' attitudes toward torture, conducted in 2008 at the University of Illinois College of Medicine-Chicago (UIC), provided a precedent for our project.[4] That six-question survey of 336 medical students across the four years of study revealed a level of support for torture that the authors reported as distressing, given medical associations' widespread condemnation of physicians' participation in torture. Specifically, the authors found that 35% of their sample would condone torture under certain circumstances; 24% agreed with the use of torture if a chance to elicit life-saving information existed; and 22% agreed that it was permissible for physicians to treat individuals so that torture could be initiated or continued. These and other findings led the authors to recommend the implementation of medical school curricular assessments to address ignorance or attitudes among students that are at odds with the universally and clearly stated ethics of the profession.

International surveys of medical students' attitudes toward torture or the mistreatment of prisoners have generally revealed a somewhat greater tolerance for such practices among medical students than in the UIC survey. For example, in a study conducted in Mauritius, 37.4% of surveyed medical students were in favor of beating individuals in police custody to obtain information, and in a study of New Delhi medical students, nearly 30% of respondents indicated approval of this practice.[5] Taken together, these studies demonstrate the importance of assessing medical students' attitudes toward such a major human rights issue.

The UIC survey has not, to our knowledge, been repeated at any other medical university in the eight years since it was administered. In addition to replicating the prior study, our project attempts to delineate personal and demographic factors that may be associated with attitudes toward torture. Clearly a question of great political, ethical, and medical sensitivity, this topic invites medical training institutions to examine curricula and human

rights educational efforts. It is important that medical students have solid grounding on matters such as torture and the obligations of the profession before they begin to practice independently in society.

Subjects and methods

The Institutional Review Board of the Weill Cornell Medical College in New York City approved this study. All enrolled four-year medical and MD–PhD students (483 total) received an email in November 2016, shortly after the conclusion of the national elections, containing links to a 28-item questionnaire (see Appendix). Their participation in the survey was anonymous and completely voluntary. Appropriate encryption procedures were employed to ensure that the identification of participant/non-participant status was impossible. Institutional review board-approved consent was obtained from all participants through encrypted procedures, and participants could access the survey only after first providing their consent.

The survey instrument contained 10 items addressing specific torture activities, justifications for torture, and ways that physicians might participate in torture. Five of these items matched questions from the 2008 UIC study. To identify factors that might influence students' attitudes, the survey also included demographic inquiries related to age, gender, ethnicity, religious affiliation, sexual orientation, and stage of medical school training; questions examining individual and family histories of exposure to trauma, harassment, or discrimination; and items surveying respondents' participation in student human rights activities at Weill Cornell, their familiarity with certain human rights statistics, and their opinions about human rights curricula in medical school. Participation in the survey was initiated by 146 students, but 19 were excluded because they did not complete any sections. Responses from six more participants were discarded, either because those respondents failed to complete the 10 torture-specific items or because they neglected to indicate their gender or age. The final sample size was thus 121 respondents.

We employed two methods to identify associations between participants' attitudes toward torture and their responses to the non-torture questions. In the first strategy, we used an aggregate metric, termed the "attitude toward torture scale" (ATS), to compare pools of participants grouped by their responses to individual non-torture questions. To calculate the ATS, we created a standardized scale of 0–4 for each of the 10 torture-specific items. Higher scores on this scale correspond to greater support for torture; "strongly agree," for example, was coded as a 4 if this response indicated the strongest support for torture (questions 1.1a-c, 1.2-1.5), whereas "strongly agree" was coded as a 0 if it instead corresponded to the greatest opposition to torture (questions 1.6-1.8). An individual's ATS was then calculated by summing that person's scores on these 10 questions. The ATS therefore ranged from 0 to 40, with a neutral position represented by 20. We performed Mann-Whitney U tests to compute p-values for the differences found between mean ATS values of paired subgroups. We employed the Bonferroni method to account for multiple hypothesis testing; differences in mean ATS values were considered statistically significant if their associated p-values fell below 0.05/N, in which N is the number of hypotheses tested. The ATS metric was developed solely for this study and has not been validated elsewhere.

Considering the 10 torture-specific items and ATS as dependent variables, the second method entailed creating a statistical model for each dependent variable as follows. We performed ordinal regressions between the dependent variable and each independent variable using the polr function of the MASS package in R. The false discovery rate was controlled at a level of 0.1 using the Benjamini-Hochberg method to account for testing multiple hypotheses. Those independent variables that did not survive the multiple hypothesis correction were then excluded. A final ordinal regression was performed on the dependent variable and all the remaining significant independent variables to arrive at a multivariate model for the dependent variable. Multivariate models were not computed for torture questions 1.6 and 1.7, as these questions were not found to have significant dependences on

any of the independent variables. Lastly, to investigate associations between individuals' attitudes toward various facets of torture, we calculated the Pearson correlation coefficient (r) for each pair of torture-specific questions.

Results

Of the 483 students who received the survey, 25.1% responded (Table 1). The lowest response rates were seen from the third-year medical school class and from MD–PhD students engaged in the PhD phase of their training. More females than males (75:46) completed the survey (the entire student body annually approximates a 50:50 male:female ratio).

The questionnaire began with ten items surveying respondents' attitudes toward torture, five of which were based on questions from the 2008 UIC study. Using a five-point Likert scale, participants were asked to indicate their agreement or disagreement with each statement. For ease of comparison between the studies at UIC and the Weill Cornell Medical College (WCM), the "strongly disagree" and "disagree" responses were pooled together, as were the "strongly agree" and "agree" responses.

A larger proportion of those surveyed in the present study expressed opposition to torture than in the 2008 UIC study (Figure 1). The most striking difference was seen in response to the statement "It is permissible for interrogators to use psychological intimidation (e.g. mock executions, sexual humiliation, religious humiliation, threatening loved ones)"; here, 93% of WCM respondents disagreed, compared to 30% of those surveyed at UIC (Figure 1A). In addition, 63% of WCM respondents disagreed that "the use of torture can be justified if the information obtained will save lives," compared to 51% of UIC respondents (Figure 1B). The item "It is permissible for physicians to treat individuals to verify their health so torture could begin or continue" garnered a disagreement rate of 83% at WCM and 58% at UIC (Figure 1C). Furthermore, 83% of

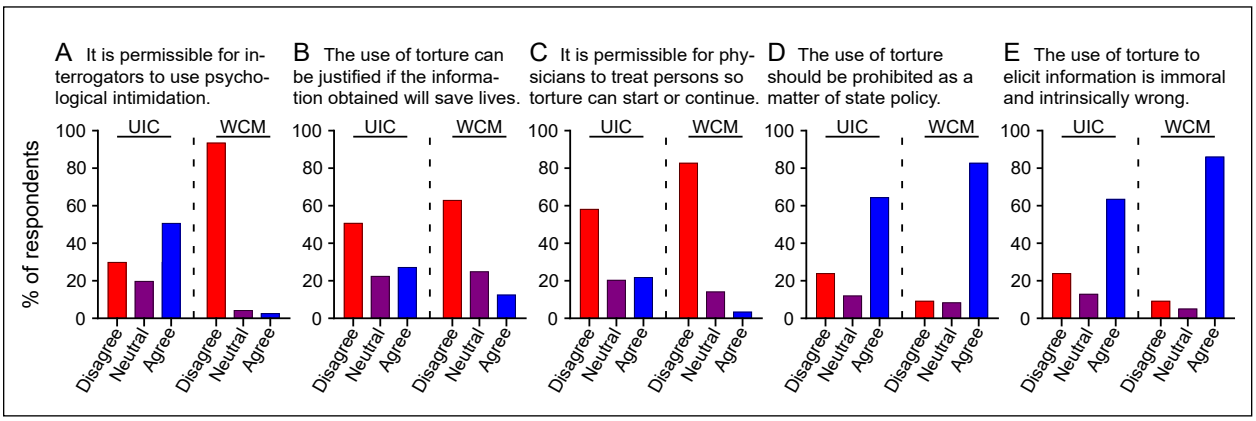
TABLE 1. Respondent demographics

Year†	Number of respondents	Response rate
1st	35	34.7%
2nd	37	40.2%
3rd	14	12.8%
4th	24	22.4%
MD–PhD	11	14.9%
Total	121	25.1%

Gender	
Female	75
Male	46
Age (yrs)	
Mean	25.4
Range	21–38

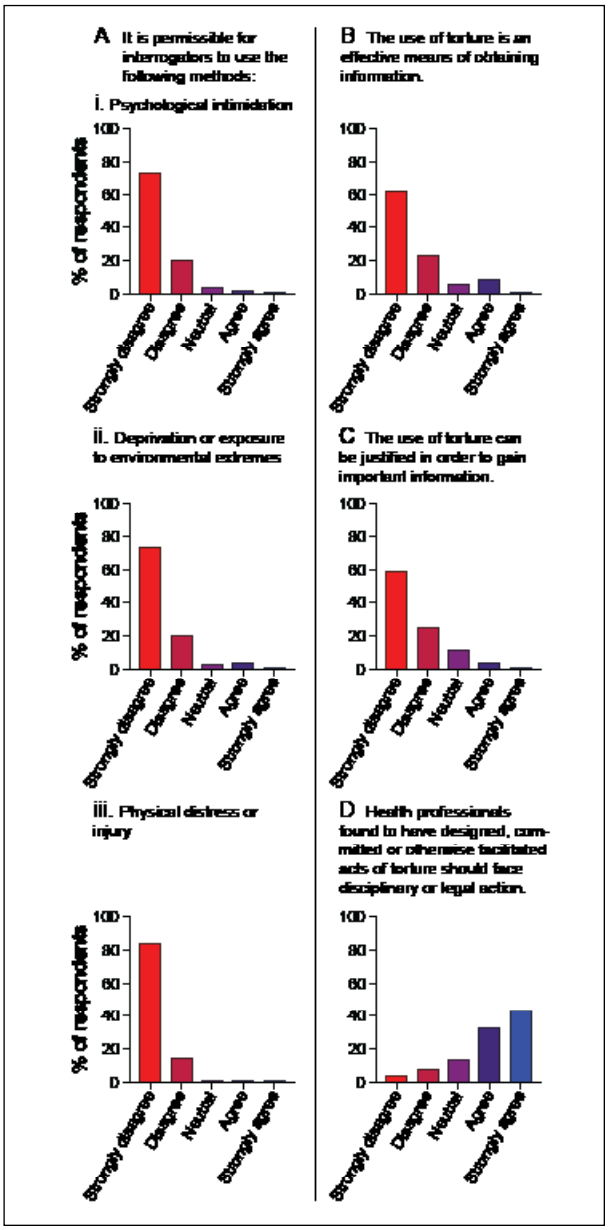
†Medical school year or MD–PhD students in PhD training

FIGURE 1. Comparison between survey results from the 2008 study at the University of Illinois College of Medicine–Chicago (UIC) and from the present study at the Weill Cornell Medical College (WCM)



WCM respondents agreed that "the use of torture should be prohibited as a matter of state policy," compared to 64% of UIC respondents (Figure 1D). Finally, for the statement "The use of torture to elicit information is immoral and intrinsically wrong," the 86% agreement rate among WCM respondents exceeded the rate of 63% reported for UIC respondents (Figure 1E). WCM respondents' answers to these two final questions were strongly correlated (r = 0.84). Interestingly, the rate of neutral responses was lower among WCM respondents than among UIC students in all but one item: "The use of torture can be justified if the information obtained will save lives."

FIGURE 2. Medical students' attitudes toward torture



Our study sought to expand upon the 2008 UIC survey in several ways. First, because torture comes in different forms, we asked participants whether it is permissible for interrogators to employ "psychological intimidation (e.g. mock executions, sexual humiliation, religious humiliation, threatening loved ones)," "deprivation or exposure to environmental extremes (e.g. exposure to extreme heat/cold/noise, sensory deprivation, sleep deprivation, starvation, or forced feedings)," or "physical distress or injury (e.g. forced positions, asphyxiation, beating, electrocution)." More than 90% of WCM respondents disagreed that any of these three interrogation classes are permissible (Figure 2A). Approximately 8% of WCM students felt neutral or agreed that psychological intimidation and deprivation or exposure to environmental extremes are permissible interrogation strategies. Interestingly, WCM students were most opposed (97.5%) to interrogators employing tactics that would cause physical distress or injury. Respondents' answers to these three questions were strongly correlated ($r > 0.7$).

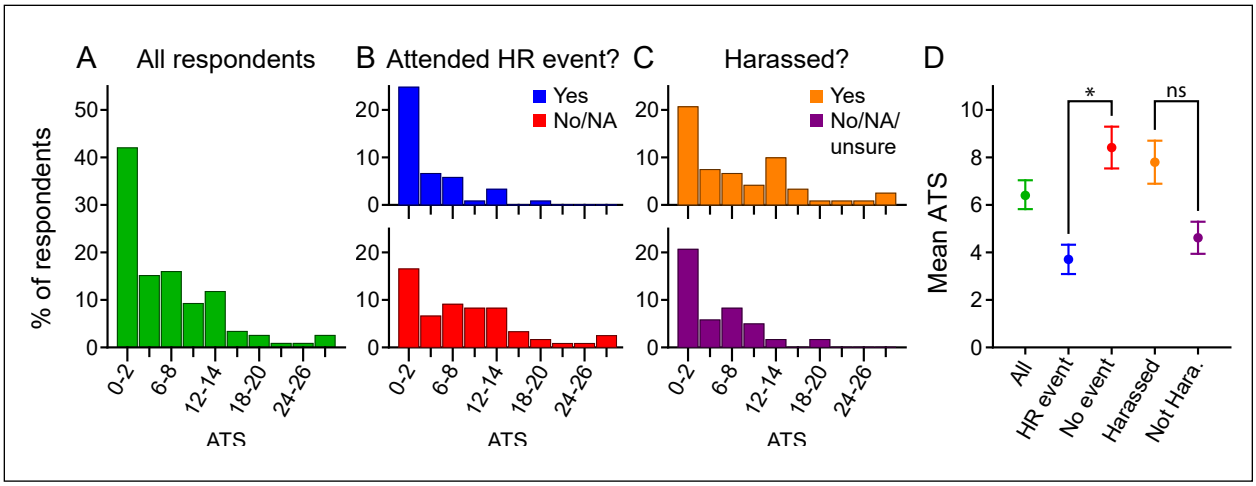
Believing that information elicited through torture is reliable will influence individuals' views on the justification of torture. Therefore, our survey also asked participants whether they agreed that "torture is an effective means of obtaining information"; more than 80% of students disagreed with this statement (Figure 2B). A similar percentage of respondents also disagreed with the premise that "torture can be justified to gain important information" (Figure 2C). Only 60%, however, disagreed with the statement that "torture can be justified if the information obtained will save lives" (Figure 1F), with 27.6% responding with a neutral answer. Participants who disagreed that torture is justified if it yields important information were also likely to disagree that life-saving information justifies torture (r = 0.75). Their responses to these two items, however, correlated less well with their belief in the effectiveness of torture as a means of obtaining information (r = 0.57 and 0.49, respectively).

Third, the 2008 questionnaire explored whether those surveyed believed it was acceptable for physicians to participate in torture. Taking this one step further, our study looked at whether respondents felt that physicians' participation in torture should warrant punishment. In this regard, 75% of WCM participants agreed that "health professionals who are found to have designed, committed, or otherwise facilitated torture should face disciplinary or legal action" (Figure 2D).

Finally, in an effort to identify factors that may inform individuals' beliefs about torture, our survey contained a number of additional questions (Appendix). Several items specifically addressed human rights issues, including whether respondents had participated in the existing programs at the medical college. Students involved with the Weill Cornell human rights program (item 5.3 of the survey) had significantly ($p < 10^{-4}$) lower mean ATS values (see "Subjects and methods" section), indicating greater opposition to torture than those who had not participated (Figure 3 and Table 2). Participants were also asked about individual or familial experiences of harassment or discrimination (item 4.3). A trend toward stronger pro-torture attitudes, as measured by mean ATS values, was seen among individuals who had experienced discrimination or harassment ($p = 0.0046$), but this trend did not reach statistical significance after applying a Bonferroni correction for multiple hypothesis testing (Figure 3 and Table 2). Strong correlations were seen between ATS values and responses to all of the torture-specific questions, with the strongest being for the item "The use of torture can be justified in order to gain important information" ($r = 0.85$).

Our multivariate regression analyses identified several additional factors that strongly predicted respondents' attitudes toward certain torture-specific items. Responses to the statement "Medical schools' curricula should include mandatory Human Rights coursework" (item 5.1) provided the strongest predictor for when individuals would express weaker opposition to torture. Those who disagreed with this statement were many times more likely to support the use of torture to obtain important information (odds ratio (OR) 42.14, 95% confidence interval (CI) {3.8,1059}) or life-saving information (OR 58.63, 95% CI {3.89,1752}), as well as the use of interrogation techniques that result in physical distress or injury (OR 18.22, 95% CI {2.22,183.7}). Conversely, those who agreed with mandatory human rights coursework were less likely to support the use of psychological intimidation (OR 0.27, 95% {0.09,0.79}), and those who strongly agreed were less likely to support the use of deprivation or exposure to environmental extremes compared to those who disagreed, felt neutral, or did not answer the question (OR 0.17, 95% CI {0.05,0.5}). The

FIGURE 3. A comparison of attitude-toward-torture scale values (error bars indicate standard error of the mean, and the asterisk denotes $p < 10^{-4}$)



conclusions we can draw are limited, however, as only four individuals disagreed that medical school curricula should include mandatory human rights coursework.

Interestingly, students who were trained by the Weill Cornell Center for Human Rights to perform forensic evaluations of asylum seekers (item 5.3) were less likely to agree that obtaining life-saving information justifies the use of torture (OR 0.4, 95% CI {0.20,0.78}) or that it is permissible for physicians to treat individuals so that torture can begin or continue (OR 0.28, 95% CI {0.13,0.61}). We also found that the importance of an individual's belief system and experiences of harassment or gender-based discrimination yielded predictors of that person's attitude toward certain torture-specific items (data available upon request). Other factors, including ethnicity and age, were not found to be significant predictors for responses to individual torture questions (additional information available upon request).

Discussion

As part of their education, medical students would benefit from understanding that participation in torture may take active and passive forms.[6] Helping design torture programs that leave no physical evidence, such as those designed by James Mitchell and John Jessen for the US Department of Defense, would be considered active participation.[7] Passive physician participation can include ignoring torture when it occurs, deliberately failing to diagnose injuries caused by torture, and covering up occurrences through non-documentation or the alteration of medical records. When doctors condone and participate in torture, a demoralizing impact is felt both by victims and by staff—and given the respected authority of physicians, a strong message of support for torture may be inferred. The same can be said of physicians' participation in certain activities in correctional institutions, where human rights abuses often occur and where a doctor's behavior and attitude may convey tolerance for insensitive, inhumane conduct.[8] Given the parallels between torture and correctional medicine abuses, both topics should be central to any medical school's human rights curriculum.

Our results support the implementation of human rights educational programs in medical school curricula. However, beyond the one item in our survey that asked about support for disciplinary or legal action for physicians who have participated in torture (Figure 2D), we have not addressed an important aspect of the issue: professional accountability. The settlement, in August 2017, of a lawsuit brought by the American Civil Liberties Union (on behalf of three men who were kidnapped by the CIA in 2002 and tortured according to a protocol designed by psychologists Mitchell and Jessen) sends a clear message: health care personnel who violate professional codes of conduct may indeed be held accountable for their actions. The two psychologists had been paid millions by the CIA to design and implement an "enhanced interrogation program" to deal with post-9/11 terrorism suspects.[9] Whether a physician contributes actively to the conduct of torture, in the manner of Mitchell and Jessen, or passively, as might a prison MD who fails to contravene a course of solitary confinement, awareness that their actions or inaction will be scrutinized may help combat misbehavior.

TABLE 2. Mean attitude-toward-torture scale values

Condition	Number of respondents	Mean ATS ± SEM†
All	121	6.43 ± 0.61
WCCHR event[a]	51	3.71 ± 0.62
No WCCHR event[b]	70	8.41 ± 0.88
Harassed[c]	69	7.80 ± 0.91
Not harassed[d]	52	4.62 ± 0.68

† SEM = standard error of the mean. [a] Attended a human rights event hosted by the Weill Cornell Center for Human Rights (WCCHR). [b] Did not attend or left this question blank. [c] Respondent or family member experienced harassment (bullying/cyberbullying, stalking, intimidation, threats, etc.). [d] Was not harassed, was unsure, or left this question blank.

A recent global survey by the International Committee of the Red Cross reported that 46% of Americans approved of torture to obtain information from enemy combatants, with only slightly more than half indicating that torture was "wrong." Only Israelis, Palestinians, and Nigerians matched Americans in their endorsement of torture. By comparison, over 80% of Afghans and Colombians surveyed disapproved of torture.[10] The results of our survey of medical students at one American university reflect strongly divergent attitudes toward torture compared to this global survey.

Conclusive findings from our survey are limited by several factors. Our study, like the 2008 survey, was conducted at a single institution. The number of respondents (121) is relatively small, although our response rate of 25.1% is comparable to other survey response rates of physicians and medical students: 24% of medical students and 18.9% of medical residents completed the 2012 Canadian National Physician Survey, and 27% of medical students responded to Australia's 2013 National Mental Health Survey of Doctors and Medical Students.[11] The more robust response rates of first- and second-year students (34.7% and 40.2%, respectively) suggest that the pre-clinical years, before students disperse to disparate locations with different schedules, might be a more optimal time for surveying students.

The response rate of our study may have been affected by the very subject matter, torture being an uncomfortable topic for many. Questions about personal or familial experiences of discrimination, harassment, being a victim of a crime, or experiencing sexual or physical abuse may similarly have been too off-putting for some students.

Responses to some of our survey items may have been influenced by our detailing specific torture methods that were not made explicit in the UIC questionnaire (Figure 1A). Similarly, we attempted to ascertain whether respondents believed that torture is an effective way to obtain information, a question that was not included in the UIC study.

Although temporal, geographic, and compositional differences limit comparisons of responses to similar and identical questions between the 2008 UIC survey and our own, some limited observations seem merited. A trend toward stronger anti-torture attitudes was seen among students in 2016 (Figure 1). Why might such a trend be taking place? General contributing factors might include formal and informal human rights educational initiatives that have arisen in the intervening years; continued writing about Abu Ghraib and the role of medical personnel; the ongoing horrific human rights crises in Syria and in other countries; increased awareness of all human rights abuses, including torture; and the agitating polemics of the most recent presidential campaign, in which torture specifically and an atmosphere of hostility toward immigrants fleeing oppression generally may have seeped into the consciousness of medical students.[12]

Using the ATS metric, we examined whether students' participation in the school's student-run asylum clinic, the Weill Cornell Center for Human Rights, affected their views on torture.[13] Founded in 2010, this voluntary program attracts students interested in human rights activism and trains them in providing pro bono medical, mental health, and gynecologic evaluations to individuals seeking asylum in the United States. Between one-quarter and one-third of Weill Cornell students will have participated in this program by graduation. In the course of these evaluations, students have helped examine more than 300 asylum seekers, the majority of whom are survivors of torture, and have absorbed their histories. In our study, students who had participated in the human rights program had significantly lower (more opposed to torture) mean ATS values than students who had not been involved (Figure 3 and Table 2).

The medical education experience can be isolating for many students. Human rights education, formalized or not, can ameliorate such isolation and can enhance a student's preparedness for his or her life as a physician. A 2010 study documented deficits in medical students' knowledge of torture that could be remediated through a structured curriculum.[14] The experiences of Croatian medical students during the Croatian War of Independence (1991–1995) bears on the value of human rights experiences in medical school. As has been described:

> *Our experience during the five years of the wars… showed that the best option for the medical students was to continue their studies and engage very actively in a number of activities where their education and medical experience were important …Psychologically, intensive engagement in extracurricular activities related to their profession was of enormous benefit to the students … They became a symbol of safety, consolation, and help in many complicated situations.*[15]

Of course, torture is only one of many human rights issues that physicians will encounter in their careers. However, learning about torture equips clinicians to attend to victims of other abuses, including victims of human trafficking; domestic abuse; child abuse and child labor; bullying; religious, political, and ethnic persecution; LGBT discrimination; and, as previously mentioned, human rights abuses in prisons. Specifically, being able to elicit painful and difficult histories, developing empathy, and recognizing human resilience are skills that will serve all physicians in all settings.

Acknowledgments

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Ethical approval

Ethical approval for this study, protocol number 1507016384, was received from the Weill Cornell Medical College Institutional Review Board on November 19, 2016.

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APPENDIX

Medical Students' Attitudes toward Torture survey

The numbering of the questions discussed in Figures 1 and 2 of the main text correspond to questions in Part 1 of the original survey as follows:

Main text figure	1A	1B	1C	1D	1E	2A	2B	2C	2D
Survey, Part 1 question	1.a	4	5	6	7	1	2	3	8

Questions 5–7 of the survey were taken verbatim from the UIC study, while questions 1a and 4 are modified versions of UIC questions.

SURVEY

Please complete the following brief, *confidential* survey. You may skip any questions you do not feel comfortable answering.

Part 1

Please note that once you select 'Submit', you cannot return to this section of the survey.

1. It is permissible for interrogators to use the following methods:

   a. Psychological intimidation (e.g. mock executions, sexual humiliation, religious humiliation, threatening loved ones).

   ☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

   b. Deprivation or exposure to environmental extremes (e.g. exposure to extreme heat/cold/noise,

sensory deprivation, sleep deprivation, starvation or forced feedings).

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

c. Physical distress or injury (e.g. forced positions, asphyxiation, beating, electrocution).

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

2. The use of torture is an effective means of obtaining important information.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

3. The use of torture can be justified in order to gain important information.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

4. The use of torture can be justified if the information obtained will save lives.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

5. It is permissible for physicians to treat individuals to verify their health so that torture could begin or continue.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

6. The use of torture should be prohibited as a matter of state policy.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

7. The use of torture to elicit information is immoral and intrinsically wrong.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

8. Health professionals who are found to have designed, committed or otherwise facilitated acts of torture should face disciplinary or legal action (e.g. loss of one's professional license).

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

Part 2

Please note that once you select 'Submit', you cannot return to this section of the survey.

1. What is your age? _____

2. What is your gender?

☐ Male ☐ Female ☐ Transgender ☐ Intersex ☐ Other

3. What is your home state (abbrev.) in the United States, or country of origin if not the United States?

_____

4. What year of medical education are you in?

☐ 1st year ☐ 2nd year ☐ 3rd year ☐ 4th year ☐ MD/PhD (if currently in PhD stage)

Part 3

Please note that once you select 'Submit', you cannot return to this section of the survey.

1. What ethnicity do you consider yourself?

☐ American Indian or Alaskan Native ☐ Native Hawaiian or Pacific Islander

☐ Non-Hispanic White ☐ African-American ☐ Hispanic/Latino ☐ Middle Eastern
☐ Asian ☐ Multiracial ☐ Other

2. Do you identify as:

☐ Heterosexual ☐ Lesbian ☐ Gay ☐ Bisexual ☐ Questioning ☐ Asexual ☐ Not Sure

3. Do you identify with any one of the following?

☐ Christian ☐ Jewish ☐ Muslim ☐ Hindu ☐ Buddhist ☐ Atheist
☐ Agnostic ☐ Spiritual ☐ Other

4. How important is this religion or belief system in your daily life?

☐ Not at all ☐ Slightly important ☐ Important ☐ Very Important ☐ No opinion

5. Have you served in the military or with affiliated organizations/contractors?

☐ Yes ☐ No

6. Has a member of your family served in the military or with affiliated organizations/contractors?

☐ Yes ☐ No

Part 4

Please note that once you select 'Submit', you cannot return to this section of the survey.

1. Have you or a member of your family ever been a victim of a crime that caused physical or emotional injury?

☐ Yes ☐ No ☐ Not sure

2. Have you or a member of your immediate family ever experienced physical or sexual abuse?

☐ Yes ☐ No ☐ Not sure

3. Have you or a member of your immediate family ever experienced harassment (including, but not limited to, bullying/cyber bullying, stalking, intimidation, threats, etc.)?

☐ Yes ☐ No ☐ Not sure

a. If you answered "yes" to question 3: Was the perpetrator(s) acting in an official capacity (e.g. security personnel, law enforcement, military, etc.)?

☐ Yes ☐ No ☐ Not sure

4. Do you believe that you or a member of your immediate family have ever experienced discrimination based on the following (select all that apply)?

☐ Race ☐ Ethnicity ☐ Nationality ☐ Religion
☐ Sexual orientation ☐ Gender ☐ Political opinion ☐ Membership in a specific group

Part 5

Please note that once you select 'Submit', you cannot return to this section of the survey.

1. Please indicate how strongly you agree or disagree with the following statement: Medical schools' curricula should include mandatory Human Rights coursework.

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

2. Have you participated in a *Weill Cornell volunteer/community service activity?

   ☐ Yes ☐ No

*Such as with the Weill Cornell Center for Human Rights (WCCHR), Weill Cornell Community Clinic (WCCC), Motivating Action through Community Health Outreach (MAChO), etc.

   a. If you answered "yes" to question 2: Please indicate which activity: _____

3. If you have participated with the Weill Cornell Center for Human Rights (WCCHR), please indicate if you attended a WCCHR-sponsored educational event (select all that apply):

   ☐ Student training ☐ WCCHR Elective ☐ SafeZone training ☐ Other

   a. If you answered "student training" to question 3: Please indicate the year you attended the student training: _____

   b. If you answered "other" to question 3: Please describe what other WCCHR-sponsored educational event(s) you have participated in _____

4. Have you participated in human rights training, education or other activities in the past?

   ☐ Yes ☐ No

   a. If you answered "yes" to question 4: Please describe: _____

5. If you have participated with the Weill Cornell Center for Human Rights (WCCHR), how many evaluations have you observed?

   ☐ 0 ☐ 1 ☐ 2 ☐ 3 or more

6. How many applications for asylum were submitted in the United States in 2015?

   ☐ < 10,000 ☐ 10,000-49,999 ☐ 50,000-249,999 ☐ >=250,000

7. How many survivors of torture are estimated to be residing in the United States?

   ☐ < 10,000 ☐ 10,000-49,999 ☐ 50,000-249,999 ☐ >=250,000

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Global Survey of National Constitutions: Mapping Constitutional Commitments to Sexual and Reproductive Health and Rights

LUCÍA BERRO PIZZAROSSA AND KATRINA PEREHUDOFF

Abstract

General Comment No. 22, issued in 2016 by the Committee on Economic, Social and Cultural Rights (CESCR), clarifies states' legal duties to respect, protect, and fulfill the right to sexual and reproductive health (SRH). Our study analyzes domestic constitutions around the world to investigate whether and to what extent the right to sexual and reproductive health is respected, protected, and fulfilled; to what extent these provisions are inclusive and non-discriminatory; and to what degree the interlinkages between this and other human rights are acknowledged. Of the 195 constitutions accessed, 27 enshrine sexual and/or reproductive health, and seven adopt restrictive approaches to this right. In the 27 constitutions, provisions most frequently enshrine respect of one's sexual health and family planning decisions, the protection of sexual health, and the provision of reproductive health care and family planning services (fulfillment). Most of the 27 constitutions fail to adequately respect reproductive health rights; to protect reproductive health, family planning, and abortion services from third-party interference; and to fulfill all dimensions of sexual health and access to abortion. Three of the 27 constitutions enshrine a universal right to SRH, and additional constitutions protect specific vulnerable groups (such as women, children) and/or restrict the scope of rights holders to couples. Among the 27 constitutions, nine explicitly link the right to sexual and reproductive health to the rights to education, science, and/or to make autonomous decisions about sexuality and reproduction. Our results can serve as a baseline measure to track constitutional reforms in pursuit of the realization of sexual and reproductive health and rights, and as building blocks for future lawmakers committed to realizing these rights through domestic legal reform.

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Introduction

The right to sexual and reproductive health has been increasingly developed in international human rights law. The United Nations (UN) human rights system has repeatedly confirmed that this is a human right, first enshrined under the right to health in the International Covenant on Social, Economic and Cultural Rights (ICESCR).[1] The scope and content of the right to health was interpreted by the CESCR in General Comment No. 14 and specifically stated that women and men have the freedom to decide if and when to reproduce and the right to be informed and to have access to safe, effective, affordable and acceptable methods of family planning as well as the right of access to appropriate health care services.

The International Conference on Population and Development (ICPD) (Cairo, 1994) transformed the discourse from reproductive control to meet demographic targets to a more comprehensive and positive approach to sexuality and reproduction, free from coercion, discrimination, and violence. ICPD forged the link between sexuality and health as human rights, where women's agency over their own bodies and sexuality are intrinsically linked to their sexual and reproductive health.[2] The Beijing Platform for Action (1995) was the first declaration to embody the concept of sexual rights, and expanded the ICPD definition to cover both sexuality and reproduction by upholding the right to exercise control over and make decisions about one's sexuality.[3] Among their many achievements, these documents recognized the duty of governments to legislate on the matter translating international commitments into national laws and policies.[4]

In 2016, the CESCR extensively addressed states' obligations to realize the right to sexual and reproductive health in its General Comment No. 22. This comment adopts a clear human rights-based approach and affirms that this right is an integral part of the right to health that has enjoyed long-standing recognition based on already existing international human rights instruments. General Comment No. 22 contains five innovative components; it:

1. adopts a life-cycle approach, reinforcing that the concept of sexual and reproductive health extends beyond the limits of "maternal health";
2. recognizes that the right to sexual and reproductive health is indivisible from and interdependent with other human rights;
3. rejects all forms of coercive practices related to this right;
4. promotes a gender-sensitive approach and recognizes that due to women's reproductive capacities, the realization of women's right to sexual and reproductive health is essential to the realization of the full range of their human rights; and
5. adopts an intersectional approach to the cross-cutting issues of equality and multiple discrimination in the design and execution of policies and programs.[5]

Despite these legal developments, much progress is needed to realize the right to sexual and reproductive health in practice. The Lancet Commission on Women and Health asserts that an estimated 225 million women globally have an unmet need for family planning, and every year, an estimated 75 million unintended pregnancies put women at risk of unsafe abortion.[6] Furthermore, unsafe abortion is estimated to cause 47,000 maternal deaths and 5 million maternal disabilities annually.[7] Maternal mortality claims the lives of 289,000 women annually while complications during childbirth result in 5.8 million serious injuries every year.[8]

Showcasing the importance of the legal arrangements, the Lancet Commission emphasizes the need for "an enabling social, legal, and regulatory environment" to respond to women and girls' health needs and rights, and the Commission on the Status of Women continues to demand that states strengthen their normative, legal, and policy frameworks.[9]

Adopting domestic laws consistent with international standards is a demonstration of the government's commitment to realizing sexual and reproductive health and rights.[10] As a recognized indicator of these rights, legal codification may be

the first step in improving the respect, protection and fulfillment of these rights in practice. Domestic constitutions are the most vital expressions of government responsibility and individual entitlements, and therefore one of the channels best suited to endorsing states' commitments to human rights. Constitutional law offers a frame for subsequent policies, programs, and services to be executed. In many jurisdictions, constitutional law supports enforcement and redress in case of violations, and is a key success factor in strategic litigation for reproductive health.[11] Pivotal cases such as the *Treatment Action Campaign v. the South African Ministry of Health* seeking access to essential medicines to prevent the transmission of HIV from mother to child during childbirth, illustrate how forceful a constitutional protection of certain rights, and specifically reproductive health, can be.[12] Legal recognition in constitutions can endure changes in government administrations and survive economic or social strife, therefore ensuring a certain degree of consistency over time.

An estimated 20 nations replace or amend their constitution annually, presenting the opportunity to strengthen state commitments to sexual and reproductive health and right. In this process, constitutional framers often seek inspiration from other jurisdictions or from international law.[13] Our objective is to survey the language and concepts used to describe the right to sexual and reproductive health in domestic constitutions from around the globe. These constitutional texts may serve as building blocks for future lawmakers committed to realizing these rights through domestic legal reform.

Methodology

We apply the human rights framework articulated in General Comment No. 22 to investigate whether and how the respect-protect-fulfill typology has been applied to constitutional rights to sexual and reproductive health; to what degree these are inclusive, non-discriminatory provisions; and to what degree the explicit interlinkages between these rights and other human rights are acknowledged.

Analytical framework

The key terms 'reproductive health' and 'sexual health' serve as the backbone of our study. General Comment No. 22 defines reproductive health as the "freedom to make to make informed, free and responsible decisions," and "access to a range of reproductive health information, goods, facilities and services to enable individuals to make informed, free and responsible decisions about their reproductive behaviour."[14] Closely linked is the concept of sexual health, defined as "a state of physical, emotional, mental and social well-being in relation to sexuality."[15]

The legal obligations to respect, protect, and fulfill sexual and reproductive health offered in General Comment No. 22 provide clear guidance to state parties using standardized terminology. The duty to respect requires states to refrain from interfering with individuals' right to exercise their sexual or reproductive health. Examples include limiting or denying access to health services and information, such as laws or practices that criminalize abortion, limit consensual sexual activities between adults, require third-party authorization for access to abortion or contraception, or exclude certain health services from publicly or donor-funded programs.[16]

Under the obligation to protect, states must protect the right to sexual and reproductive health from third-party interference.[17] Examples include protecting against private health clinics, or insurance or pharmaceutical companies that impose practical or procedural barriers to health services.[18] States must introduce laws and policies that prohibit third parties from acting in a way that harms integrity or undermines the enjoyment of rights; for example, they must ensure that all adolescents, despite marital status, have access to age-appropriate information about sexual and reproductive health, including family planning.[19]

The responsibility to fulfill mandates that states "adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to ensure the full realization of the right to sexual and reproductive health."[20] States must take steps to

ensure universal access to sexual and reproductive health care, including emergency contraception and access to safe abortion services. States are required to provide comprehensive education about sexual and reproductive health for all and to take measures to eradicate social barriers that prevent individuals from autonomously exercising their right to sexual and reproductive health.[21]

In relation to the specific aspects of family planning and abortion, General Comment No. 22 recognizes abortion services as an integral part of the right to health and notes that states have an obligation to repeal or eliminate laws, policies, and practices that criminalize, obstruct, or otherwise undermine an individual's or a particular group's access to health facilities, services, goods, and information, including abortion.[22]

The duties to respect, protect, and fulfill are intrinsically linked to states' immediate legal obligation to eliminate discrimination against individuals and groups in relation to sexual and reproductive health. Discrimination undermines individual autonomy in matters of sexuality and reproduction, and impairs one's equal access to the range of sexual and reproductive health information, goods, and services.[23] Although the principles of equality and non-discrimination are grounded in Article 2(1) of the ICESCR, General Comment No. 22 further emphasizes that equality between women and men is a cross-cutting objective that requires the removal of direct and indirect discrimination and the assurance of formal and substantive equality.[24] The comment mandates that tailored attention and greater resources are devoted to traditionally neglected groups in order to address systemic discrimination. Intersectional discrimination may disproportionately affect groups such as, but not limited to, poor women, persons with disabilities, migrants, indigenous or other ethnic minorities, adolescents, LGBTI persons, and people living with HIV/AIDS. General Comment No. 22 also engages with the specific needs of intersex and transgender people in relation to their sexual and reproductive health.[25]

Furthermore, General Comment No. 22 recognizes that the right to sexual and reproductive health requires states to address the underlying social determinants of health; it is indivisible from and interdependent with other human rights and cannot be achieved without the realization of this wider range of rights that are enshrined in ICESCR and other instruments.[26]

Search strategy

Our study investigates whether and how the right to sexual and reproductive health is introduced into domestic constitutional law. In March 2015 and again in April 2016, we searched the constitutions of 195 member states of the World Health Organization (WHO) available on the Comparative Constitutions Project website for the key words 'reproductive,' 'reproduction,' 'sexual,' family planning,' and 'abortion.' We excluded provisions concerning the use of genetic or reproductive material; the economy and reproduction of material and immaterial conditions; the reproduction of art, culture, or sound; the protection and reproduction of the (natural) environment; the delegation of competences or jurisdiction of authority; and proceedings for sexual harassment or crimes.

Melton and colleagues suggest that constitutional text that uses once-only words and that is focused by topic rather than complex cross-referencing are most important for clear interpretation.[27] We minimized this risk by identifying well-defined terminology and concepts in the right to sexual and reproductive health within constitutional commitments in order to maximize their clarity and comparability between jurisdictions.[28]

We applied the tripartite typology to categorize constitutional provisions for the right to sexual and reproductive health and the specific concepts of family planning and abortion. We then analyzed these provisions through the lens of equality and non-discrimination, searching within constitutions for universally applicable provisions, special attention to vulnerable groups, language that restricts the scope of rights holders, and any acknowledgement of multiple discrimination. We also report on any explicit interlinkages in constitutions between the right to sexual and reproductive health and other human rights.

Results

Twenty-seven domestic constitutions (shown in Figure 1) enshrined at least one aspect of the right to sexual and reproductive health; these laws were most often found in the pan-American (n=9 constitutions) and African (n=8) regions.

Right to sexual health

Respect for sexual health was framed as the positive right to make decisions about or to exercise sexual rights in two constitutions and as a negative right to sexual integrity or sexual safety in three constitutions (Table 1). In terms of rights protection, states must guard against sexual exploitation, abuse, or violence in 13 constitutions, and four constitutions oblige states to punish such acts.

Right to reproductive health

Four constitutions require the state to respect reproductive health (see Table 1). Reproductive health is protected in two constitutions. Seven constitutions include the explicit state duty to provide for reproductive health care.

Four constitutions have specific provisions related to budget allocation and all such references are in relation to reproductive health care. The Brazilian constitution states that the "government shall promote full health assistance programs for children, adolescents" and in order to do that there will be an allocation of a percentage of public health funds to assist mothers and infants.[29] The constitutions of Fiji, South Africa, and Zimbabwe establish that the state must take reasonable legislative and other measures, within the limits of the resources available to it, to achieve the progressive realization of the right to health, including reproductive health. In an effort to enhance state accountability, the constitution of Fiji demands that if the state claims that it does not have the resources to implement the right, it is the responsibility of the state to show that the resources are not available.

Family planning and contraception

Three constitutions address the duty to respect family planning decisions (see Table 1). No constitution protects the right to family planning. A state duty to fulfill family planning is enshrined in three constitutions. Portugal's constitution offers a

FIGURE 1. Twenty-seven countries (shown in black) have adopted constitutional provisions that reflect different aspects of the right to sexual and reproductive health

notable example of state responsibility to fulfill access to family planning information and methods (emphasis added):

> *In order to protect the family, the state shall particularly be charged with: (d) with respect for individual freedom,* ***guaranteeing the right to family planning by promoting the information and access to the methods and means required*** *therefore, and organizing such legal and technical arrangements as are needed for motherhood and fatherhood to be consciously planned.*[30]

Portugal's constitution charges the state with guaranteeing family planning through access to information and the means to act on that information.

Family planning resembles an individual obligation or duty towards national population control objectives in the constitutions of China, Vietnam, and Turkey.

Abortion

Three countries have specific constitutional provisions about abortion: Kenya, Swaziland, and Somalia (see Table 1). Although the provisions frame abortion primarily in negative terms such as "unlawful," "illegal," or "not permitted," all laws recognize various grounds on which abortion may be permissible.[31] No constitution recognizes the duty to protect or fulfill abortion services as a component of the right to sexual and reproductive health.

Non-discrimination, equality, and multiple discrimination

Universal rights are explicitly enshrined in the constitutions of Fiji, Kenya, and South Africa, which recognize that everyone is entitled to access reproductive health care. In addition, the Bolivian constitution states that both "women and men are guaranteed the exercise of sexual and reproductive

TABLE 1. Overview of constitutional provisions for the respect, protection, and/or fulfillment of the right to sexual and reproductive health, family planning, and abortion.

	Respect	Protect	Fulfill
Right to sexual health	Right to make decisions about one's sexual life and orientation (Ecuador, 2011, Art. 66[9]) Right to exercise sexual rights ([women and men] Bolivia, 2009, Art. 66) Right to sexual integrity ([children] Belgium, 2014, Art. 22bis; Bolivia, 2009, Art. 15[I]; [students] Ecuador, 2011, Art. 347) Right to sexual safety (Ecuador, 2011, Art. 66[3])	Guard against sexual exploitation ([children and adolescents] Brazil, 2014, Art. 227; [elderly] Ecuador, 2011, Art. 38[4]; [children] Egypt, 2014, Art. 80; [children] Cambodia, 2008, Art. 48; [children] Zimbabwe, 2013, Art. 81) Protect against sexual abuse [children] Colombia, 2013, Art. 44; [children] Democratic Republic of the Congo, 2011, Art. 41; [youth] Guinea, 2010, Art. 19; [children] Timor-Leste, 2002, Art. 18(1); [women] Malawi, 2010, Art. 24[2] ; [workers] Somalia, 2012, Art. 24) Protect against sexual violence (Bolivia, 2009, Art. 15[11]; [children and adolescents] Dominican Republic, 2010, Art. 56) State obligation to prevent, eliminate, and/or punish sexual violence or exploitation (Bolivia, 2009, Art. 15[III]; Brazil, 2014, Art. 227[4]; Democratic Republic of the Congo, 2011, Art. 15; [women, children, adolescents, disabled, vulnerable] Ecuador, 2011, Art. 66[3]; [women] Malawi, 2010, Art. 24[2]). Right to confidentiality about one's sexual life (Ecuador, 2011, Art. 66[11])	The state promotes access to the means to make decisions about one's sexual life and orientation in safe conditions. (Ecuador, 2011, Art. 66[9]) The state shall guarantee permanent, timely, and non-exclusive access to programs, actions and services promoting and providing sexual health; the state shall be responsible for ensuring sexual health actions and services (Ecuador, 2011, Arts. 32 and 363) Priority and specialized care shall be received by persons in situations of sexual violence; the state shall provide special protection to persons who are doubly vulnerable. (Ecuador, 2011, Art. 35)

	Respect	Protect	Fulfill
Right to reproductive health	Right to make decisions concerning reproduction (Ecuador, 2011, Art. 66[10]; South Africa, 2012, Art. 12[2]; Zimbabwe, 2013, Art. 52) Right to reproductive health ([women] Nepal, 2015, Art. 38) Respect for reproductive rights ([all workers] Ecuador, 2011, Art. 332)	Special protection to the process of reproduction and during pregnancy ([women] Nicaragua, 2015, Art. 74) Eliminate labor risks affecting reproductive health (Ecuador, 2011, Art. 332)	State duty to provide for reproductive health care (Fiji, 2013, Art. 38; Kenya, 2010, Art. 43[1]; South Africa, 2012, Art. 27[1]; [citizens and permanent residents] Zimbabwe, 2013, Art. 76) State shall pursue policies to ensure access to necessary services and facilities during reproductive phase (Nepal, 2015, Art. 51[j][3]) State duty to develop special plans for reproductive healthcare for the poor (Paraguay, 2011, Art. 61) The state shall guarantee permanent, timely, and non-exclusive access to programs, actions and services promoting and providing reproductive health; the state shall be responsible for ensuring reproductive health actions and services (Ecuador, 2011, Arts. 32 and 363)
Family planning	Right of persons to freely and responsibly decide on the number and frequency of the birth of their children (Paraguay, 2011, Art. 61) Right to decide on family planning (couples) (Brazil, 2014, Art. 226[7]; Portugal, 2005, Art. 67[2]) Right to decide how many children to have (Ecuador, 2011, Art. 66[10]; [couples] Venezuela, 2009, Art. 76)	State prohibits any coercion on the part of official or private institutions with regards to family planning (Brazil, 2014, Art. 226[7])	Right to access to family planning education, information and capacity ([women] Ethiopia, 1994, Art. 35) Exercise the right to family planning through access to the information, methods, and means required (Portugal, 2005, Art. 67[2]; Venezuela, 2009, Art. 76) State must provide educational and scientific resources for the exercise of the right to decide on family planning (Brazil, 2014, Art 226[7]) State shall take measures to ensure the instruction of family planning and its practice (Turkey, 2011, Art. 41) Family planning is a responsibility of the state (Vietnam, 2013, Art. 40)
Abortion	Abortion is unlawful except on medical or therapeutic grounds to preserve life, physical health or mental health, in the case of rape, in the case of incest, or in the case of fetal impairment (Swaziland, 2005, Art. 15[5]) Abortion is prohibited except when there is need for emergency treatment, or the life or health of the mother is in danger, or if permitted by any other written law (Kenya, 2010, Art. 26[4]) Abortion is prohibited except in cases of necessity, especially to save the life of the mother (Somalia, 2012, Art. 15[5]).	None	None

Legend: Provision (country, year of constitution adoption or amendment, article). Rights-holders are universal unless otherwise specified in brackets before the country name.

rights," and that "everyone, in particular women" have the right to be free from sexual violence.[32]

The constitution of Ecuador addresses multiple discrimination as "persons who are doubly vulnerable," however, this is noted only in the context of priority care for people in situations of sexual violence.[33]

Special consideration for maternal health

The constitution of Ecuador identifies the state's responsibility to ensure sexual and reproductive health actions and services, especially during pregnancy, childbirth, and the postpartum period. Motherhood and maternal health are afforded special protection under the constitutions of Paraguay and Venezuela. The constitution of Nicaragua provides for special protection to women during pregnancy and also provides for paid maternity leave.

The Ethiopian constitution regulates sexual and reproductive health and rights under its "rights of women" provision. This provision acknowledges the country's historical legacy of inequality and discrimination and provides for affirmative measures to counter it. In this regard, it provides that "to prevent harm arising from pregnancy and childbirth and in order to safeguard their health women have the right of access to family planning, education information and capacity."[34] Nepal's constitution adopts a similar approach that notably states: "Every woman shall have the right relating to safe motherhood and reproductive health."[35] Among one of the most inclusive constitutions, Nepal's law does not limit the right to reproductive health to women of a certain age, reproductive capacity, or marital or citizenship status, as other constitutions have done.

Rights of other vulnerable groups

Multiple constitutions recognize the specific needs of vulnerable groups, including the impoverished, children and youth, the elderly, and workers. Paraguay's constitution requires the government to develop special plans for reproductive health care for people with scarce resources. Eight constitutions refer to children as a key population whose rights should be protected, but only with regards to protection against sexual exploitation, abuse, or violence. The constitutions of Brazil, the Dominican Republic, and Guinea explicitly protect the sexual rights of adolescents and youth, in this case from sexual exploitation or abuse. Ecuador's constitution addresses the right of the elderly to be protected from sexual exploitation. Somalia's constitution refers to the protection of workers, especially women, against sexual abuse, whereas Ecuador's constitution guarantees respect for the reproductive health of all workers and mandates the "elimination of labour risks affecting reproductive health."[36]

It is notable that these provisions address specific vulnerable groups such as women and children, who have historically been viewed as requiring the protection of the law. The right to sexual and reproductive health requires a lifecycle approach that encompasses the needs and vulnerabilities inherent to all life stages, including the youth and older people who were scarcely addressed in the constitutional provisions. Moreover, recognizing children's right to protection of their sexual health is a noble commitment; however, it does not justify failing to address the rights of youth—who assert their sexuality more actively than children—to the respect, protection, and fulfillment of their sexual health. Constitutional framers genuinely seeking to capture the entire spectrum of sexual and reproductive health rights for these and other groups will consider multiple layers of discrimination—not only age and gender but also race, disability, and sexual orientation—and will place equal emphasis on respecting, protecting, and fulfilling these entitlements.

Restricting rights to couples

The constitutions of Brazil and Venezuela afford family planning rights to couples, which is limited to two people in a heterosexual monogamous relationship. The Brazilian constitution only protects the rights of heterosexual couples to reproduction, stating: "couples are free to decide on family planning."[37] "Family" specifically refers to the "stable union between a man and a woman."[38] In the same line, the Venezuelan constitution states that "couples have the right to decide freely and responsibly how many children they wish to conceive."[39] An

exclusive focus on heterosexual monogamous relationships fundamentally clashes with the universality of human rights as it makes exclusions based on marital status and sexual orientation.

These results corroborate the historical challenge and controversy around determining who is entitled to sexual and reproductive health and rights. Debates about who the rights holders are have evolved from the first reference to the "family" in the 1966 Declaration on Population to "all couples and individuals" in the 1974 World Population Plan of Action.[40] General Comment No. 22 clearly signals that all individuals and groups enjoy the right to sexual and reproductive health free from discrimination.[41]

Indivisibility and interdependence with other human rights

Five constitutions (Brazil, Portugal, Ecuador, Paraguay, and Venezuela) refer specifically to the importance of making free and autonomous decisions regarding the exercise of the right to sexual and reproductive health. For example, Ecuador has included the provisions on the right to sexual and reproductive health in Chapter 6 of the constitution that enshrines 'rights to freedom.' This intrinsic relation with the right to freedom refers both to the right to decide on matters of sexuality and sexual life and orientation and to the right to health and reproductive life. Related to these examples are the constitutions of South Africa and Zimbabwe, which enshrine the right to make decisions on matters of reproduction as an element of the right to bodily autonomy.

Access to information and education in relation to sexual and reproductive health were cited in domestic constitutions, reflecting the interrelation between the right to health and the rights to education and to enjoy the benefits of scientific progress and its applications (known as the 'right to science'). While the interdependence between the rights to health and education have received much attention, information and education about health and related technologies also falls within the scope of the lesser-known right to science. The UN Special Rapporteur in the field of cultural rights has underscored that the "rights to science and to culture should both be understood as including a right to have access to and use information and communication and other technologies in self-determined and empowering ways."[42] It is notable that domestic constitutions articulate these interlinkages. For example, the Brazilian constitution mandates the state to provide educational and scientific resources for the exercise of the right to sexual and reproductive health. Paraguay's constitution recognizes the right of persons to receive "education, scientific orientation, and adequate services."[43] The constitutions of Ecuador, Ethiopia, Paraguay, Portugal, and Venezuela recognize that education and information are essential prerequisites for the effective enjoyment of the right to sexual and reproductive health. Notably, the constitution of Ethiopia innovates incorporating capacity building.

Discussion

Our study shows that the right to sexual and reproductive health is not universally respected, protected, and fulfilled in domestic constitutions. Of the 27 constitutions that recognized any aspect of this right, they most often addressed the respect of decisions about one's sexual health and family planning, the protection of sexual health, and the provision of reproductive health care and family planning services (fulfillment). Explicit constitutional references to abortion served to prohibit the service unless a series of narrow exceptions apply. Major shortcomings still exist in most constitutions in relation to the universal recognition and respect of reproductive health rights, the protection of reproductive health, family planning, and abortion services from third party interference, and the fulfilment of all dimensions of sexual health and access to abortion. Few provisions are explicitly universal for all individuals and groups, whereas many provisions protect vulnerable groups or lifecycles such as women, motherhood, and children, and some text even restricts the scope of rights holders. The constitution of Ecuador addresses multiple discrimination only in the context of sexual violence. Various constitutions draw explicit interlinkages between the right to sexual and reproductive health

and the rights to education, science, and to make decisions freely and responsibly in matters of sexuality and reproduction.

Introducing the 'sexual' into the right to sexual and reproductive health

Following the major turning points catalyzed by the Declaration of the World Conference on Human Rights in Vienna and the Declaration on Violence Against Women, General Comment No. 22 gives equal recognition to 'sexual health' and 'reproductive health.'[44] WHO's definition of sexual health—subsequently adopted by General Comment No. 22—requires "a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence."[45] WHO recognizes that sexual health cannot be achieved and maintained without respect for, and protection of, certain human rights, that is, sexual rights. However, our results show that although references to sexual health are frequently found in constitutions, the majority of these references are negative, expressing the right to not be the object of abuse or exploitation, in the corrective sense of combating violations. Importantly, only the constitution of Ecuador moves toward an affirmative concept of sexual rights, such as the right to make decisions freely about one's sexual life and to have access to sexual health care.

Decisional autonomy and freedom from coercion

Only five constitutions refer explicitly to the right to make free and responsible decisions about one's sexual and reproductive health. However, despite substantial international traction for the legal recognition of women's agency over their own sexuality and reproductive function, we identified that the constitutions of China, Vietnam, and Turkey maintain restrictive approaches to issues of reproduction. The constitution of Turkey states that (emphasis added) "the State shall take the necessary measures and establish the necessary organization to [..] *ensure the instruction of family planning and its practice*."[46] These types of provisions subject the recognition of the right to sexual and reproductive health to its exercise in accordance with the government's demographic goal(s) and in a manner that the government considers 'responsible.' This approach instrumentalizes an individual's reproductive capacity to control population growth.[47] In doing so, these provisions contravene the state obligation to respect by interfering with an individual's freedom to control his or her own body and ability to make free, informed, and responsible decisions.[48] Greater emphasis in national constitutions on the individual right to decide on contraception may not only deter state intervention in matters of reproductive autonomy but may help curb discriminatory practices in which, for example, a male partner must give express permission for a woman to obtain contraception.[49]

Coherence between robust constitutional text and domestic policy

The constitution of Ecuador offers a robust example of how the respect-protect-fulfill framework can be fully integrated into constitutional commitments. First, the constitution of Ecuador adopts a holistic, lifecycle approach that addresses sexual and reproductive health and captures the health needs of all people at all life stages and regardless of whether they have borne children.[50] It extends beyond the limits of 'women' and 'mothers' as rights holders or the narrow entitlement to maternal health.[51] Second, Ecuador's constitution recognizes sexual and reproductive rights both from a negative perspective (protection against sexual violence and guaranteeing sexual safety) and a positive view (right to freely make informed, voluntary, and responsible decisions on one's sexuality, one's sexual life and orientation, health and reproductive life, and to decide how many children to have). It is the only constitution to protect confidentiality about one's sexual life. Notably, the constitution obliges the government to fulfill these rights by promoting access to safe conditions in which decisions about sexuality can be made free from coercion. Third, provisions concerning sexual and reproductive health care

consider the human rights elements of availability ('permanent, timely'), accessibility ('non-exclusive,' 'universality'), acceptability ('interculturalism,' 'with a gender and generational approach'), and quality ('quality,' 'effectiveness,' 'bioethics').[52] Fourth, most of these provisions are universal and some are tailored to vulnerable groups including the elderly and students. The constitution recognizes the need for prioritized care to people who are 'doubly vulnerable' in situations of sexual violence.

However, caution must be exercised to ensure the effective translation of and coherence between constitutional law to domestic policy. The case of Ecuador makes for a good example of this phenomenon where, despite the robust constitutional protection of the right to sexual and reproductive rights, the enjoyment of these rights is hampered by contradictory (secondary) domestic law and inadequate health services. A chronic lack of access to modern contraceptive methods and age-appropriate information and education contributes to high rates of pregnancy among adolescents and drives the demand to terminate unwanted pregnancies.[53] Against this backdrop, domestic law criminalizes abortion—with very few exceptions—resulting in devastating health consequences for women: 18% of maternal deaths between 1995–2000 were due to unsafe abortion.[54] Therefore, further work is needed to translate the constitutional provisions and the international obligations into lived reality for the residents of Ecuador.

Tension between the constitutional rights to life and to sexual and reproductive health

Curiously, the 2011 amendment to the constitution of Ecuador introduced robust provisions on sexual and reproductive health while maintaining a provision adopted in the 1980s that recognizes and guarantees life from the time of conception.[55] The tension between the protection of life from conception and the right to sexual and reproductive health has been addressed by General Comment No. 22—and many other UN bodies. The General Comment explicitly recognized the obligation of the state to provide safe abortion, guarantee the availability of these services, and remove all barriers to access, including repeal of all laws that criminalize or restrict access to abortion.[56] Moreover, a new General Comment on the Right to Life is being drafted and the available version follows the same line as General Comment No. 22, stating that even though states parties may choose to limit access to abortion, this cannot result in violation of other rights under the ICCPR, including the right to life of pregnant mothers and the prohibition on exposing them to cruel, inhuman, and degrading treatment or punishment.[57] Therefore, in accordance to the international obligation of the state, such constitutional provisions shall be repealed and cannot ground a total ban on abortion. These regulations shall maintain legal exceptions for therapeutic abortions necessary for protecting the life of mothers, *inter alia* by not exposing them to serious health risks, and for situations in which carrying a pregnancy to term would cause the mother severe mental anguish.[58]

Limitations

One potential limitation of our study concerns the search scope. We intentionally chose terms from the right to sexual and reproductive health that are clearly articulated in international law. It is possible that our search did not detect constitutions that implicitly govern or 'catch' the right to sexual and reproductive health in provisions for other, related rights. For example, constitutions enshrining a right to health could include reproductive health in their scope; however, our study did not include any related rights that are not expressly framed around sexual and reproductive health, nor did it include indirect drivers or factors that influence the right to sexual and reproductive health, such as provisions on child marriage/age of consent or violence against women. This is because the scope of our study was to understand how domestic constitutions address these concepts elucidated under international law and recently affirmed by the Committee in General Comment No. 22.

An additional limitation inherent in our study is that terminology in domestic constitutional law

may undergo divergent interpretation and application than the standards agreed in international law. This phenomenon inevitably limits the potential impact of the constitutional provisions identified in our study.

Future steps

Although the global community has endorsed the right to sexual and reproductive health in the ICPD and Beijing Plan of Action, the global development agenda has until now skirted around the issue of reproductive health and rights. Yamin and Boulanger emphasize that if sustainable progress is to be made in women's health then initiatives inclusive of sexuality and reproduction are needed to address the core issue of women's empowerment.[59] Now, considerable attention is given to reframing women's health around sexual and reproductive rights that consider a life-cycle approach independent of reproductive capacity. In a broader development perspective, realizing the right to sexual and reproductive health are also among the key objectives of the Sustainable Development Goals (SDGs) and direct references to the human rights treaties encompassing the right to sexual and reproductive health are found in the targets themselves.[60] In July 2017, the High Level Political Forum conducted a thematic review of SDGs 3 and 5 that showed only modest progress since 2015. The achievement of these goals demands much further work requiring—among other things—that states ensure equity; fulfill, protect, and promote human rights and gender equality; and secure adequate and sustained financing and investment in scientific research and innovation.[61] The Global Strategy for Women's, Children's, and Adolescents' Health (2016–2030) has as a key objective to "expand enabling environment" where the right to health and well-being can be achieved, specifically by removing barriers to the enjoyment of rights and by promoting gender equality.[62] Our results can also serve as a baseline measure to track any legal reform achieved in national constitutions in the pursuit of the SDGs related to the right to sexual and reproductive health.

Future research should examine the translation of domestic constitutional law to domestic policy. One important component of implementing law and policy in practice is sufficient and sustainable financing. Enshrining a state responsibility to invest in reproductive health may prove an encouraging strategy to give effect to these rights, which has been a notorious challenge especially in times of austerity. For example, funding shortfalls are a key factor explaining why most developing countries were unable to meet the health-related Millennium Development Goals (MDGs) by 2015.[63] Also, the monitoring tools developed by the Centre for Reproductive Rights consider that the allocation of adequate budgetary resources is an essential element to assess state compliance with their commitments.[64] Moreover, the right to sexual and reproductive health is the first to be adversely affected by state budget cuts in response to austerity measures.[65] Shalev cites the example of Croatia in which contraceptives were the first type of medication to lose state funding and abortion was the first medical act to be removed from the free health care services.[66] Future research can be directed to whether and how the legal recognition of the right to sexual and reproductive health and specific provisions regarding budget allocation can not only support the realization of these rights but also their ability to withstand changes in government administrations or economic or social strife.

Key recommendations for domestic law

Constitutional law, as all domestic law, should conform to a human rights approach to protect and promote the right to sexual and reproductive health. Specifically, committed governments should expressly respect, protect, and fulfill these rights for all individuals without discrimination.

First, barriers to the full enjoyment of the right to sexual and reproductive health and rights should be removed from constitutional law. In line with General Comment No. 22, governments should end the codification of coercive practices in family planning and restrictive approach to abortion in constitutional law. Second, the right to sexual and reproductive health should be framed in a manner that is sensitive to the different needs of

men and women, intersex and transgender people, and to their needs at different stages in their life cycles. Both sexual health and reproductive health deserve equal protection and promotion under constitutional law. This includes the right to make informed decisions free from coercion about one's sexuality and one's reproduction, and the right to access health care for sexual and reproductive needs, including contraception, access to comprehensive sexuality education, and safe abortion services. Furthermore, it is crucial to incorporate the paradigm of rights enshrining sexual and reproductive rights. Third, it is important to reaffirm the indivisibility and interdependence of the right to sexual and reproductive health with other human rights. Our article provides examples of existing constitutional text that may be considered by future constitutional framers and governments truly committed to realizing the right to sexual and reproductive health.

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LETTER TO THE EDITOR

The Rule of Law as a Social Determinant of Health

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This letter to the editor is based on the author's address to the World Justice Forum in The Hague, July 10-13, 2017. The author spoke in his capacity as co-chair of the African Think Tank on HIV, Health, and Social Justice and president of the Africa Judges Forum on HIV, Human Rights, and the Law.

The rule of law is increasingly understood as a foundational determinant of health; one which underlies other socioeconomic, political, and cultural factors associated with health outcomes.[1] Strengthened rule of law and related human resource capacity are critical for achieving the health outcomes of the 2030 Agenda, Agenda 2063, the African Health Strategy, and other global and regional development frameworks in Africa.[2] The law and justice sector plays a critical, though often unacknowledged, role in every health challenge. Universal health coverage (UHC) systems can only be established, financed, and monitored through processes and structures established by law. Good health systems governance also requires civil society participation, and government transparency and accountability.

Enabling legal environments are essential to reduce the burden of communicable and non-communicable diseases, as well as injuries, and to provide care, treatment, and support to people affected. States need legal powers and the human resource capacity to regulate production, marketing, and sales of tobacco and other unhealthy products, and to resist spurious legal challenges in national and international courts and tribunals.

A functioning criminal justice sector is essential to stem the flood of falsified and substandard medicines across Africa. It is also critical that the legal sector understands the international legal obligations to protect intellectual property, in order to ensure access to affordable medicines. Legal capacity to understand trade and investment treaties is vital for national regulation of the importation of unhealthy foods and beverages.

Public health law capacity—broadly understood—is critical to achieving 21st century health goals.[3] The scope and depth of public health law capacity needed to achieve these goals is still poorly understood. Few law school graduates have the multidisciplinary perspective and capacity to support government action to achieve these goals.

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Expanded legal education and partnerships between faculties of law, medicine, economics, and other sectors are urgently needed to support resilient systems for sustainable health. Civil society networks, including advocates for civil and political rights, must be engaged to ensure robust public debates on the allocation of resources for health. Long-term capacity building plans are needed, as well as urgent short-term assistance. Enabling legal environments and public health law capacity must be acknowledged as building blocks of African health systems.

Access to justice, whether to courts, alternative dispute resolution mechanisms, or traditional justice systems can improve access to health services for girls and women and other vulnerable and marginalized populations.[4] Court action can challenge overly broad legislation on constitutional grounds, such as inappropriate public health measures to address infectious diseases. Court action may also advance group health rights, such as for HIV-positive pregnant women who need medication to prevent HIV transmission to their infants at birth. Conversely, competent and affordable legal advice and representation may help vulnerable groups fight discrimination. Key populations most at risk of HIV infection are one such group.[5]

As court action often goes hand in hand with social mobilization, respect for civil rights is imperative. The global revolution in drug pricing and access to generic medication began in 2000 in South Africa, and was defended by civil society organizations of patients, communities, and legal activists. When global pharmaceutical corporations challenged the government policy, the court permitted civil society organizations to join the action in support of the government policy. Mass social mobilization resulted in intense global media coverage, and the pharmaceutical corporations dropped the case. As a result, millions of people across Africa and around the world now have access to more affordable essential medicines for HIV and other diseases.

Effective laws and an enabling legal environment are as critical to a healthy society as clean water. Every public health challenge—from infectious and non-communicable diseases to injuries, from mental illness to universal health coverage—has a legal component. Despite this, in many countries, legislation, policies, and practices are antiquated, contrary to human rights obligations, and hostile to public health goals, threatening the achievements of SDG health targets in those countries and regions.

What are the social determinants of health?

According to the World Health Organization (WHO), the social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels. Social determinants arguably play the largest role in determining the public's health. Our public health is determined by the policies and practices in place in our homes, schools, workplaces, and communities. Many of these determinants are difficult, if not altogether impossible, to control, such as economic standing, genetic predispositions or proclivities, and the customs, traditions, norms, and attitudes of the community in which we are raised. By developing policies that have a wide-reaching impact and improve both social and economic aspects of communities, social determinants of the public's health can have a positive impact, as well.

There is a great deal of research on the social determinants of health. Most of it points to three overarching factors:

Income inequality. Once a country has reached the point of development where most deaths come not from infectious diseases (tuberculosis, dysentery, cholera, malaria, flu, pneumonia, etc.), but from chronic diseases (heart disease, diabetes, cancer), the economic and social equality within the society is a greater determinant of death rates and average lifespan than the country's position with regard to others. The United States, for instance, lags behind Japan, Sweden, Canada, and many other less affluent countries in the life expectancy of its citizens. The difference seems to be the size of the gap between the most and least affluent segments of the society.

Social connectedness. Many studies indicate that "belonging"—whether to a large extended family, a network of friends, a social or volunteer organization, or a faith community—is related to longer life and better health, as well as to community participation.

Sense of personal or collective efficacy. This refers to people's sense of control over their lives. People with a higher sense or stronger history of efficacy tend to live longer, maintain better health, and participate more vigorously in civic life.

Although few international laws have been adopted specifically to promote human health, many international laws have possible indirect effects on health as they may impact the social determinants of health (that is, the external conditions in which people live that may affect their health). Examples of social determinants of health include armed conflict, employment, empowerment, environment, finance, human rights, poverty, sanitation, social policies, trade, and water supply.

Social determinants of health can also be understood as the circumstances in which people are born, grow, live, learn, work, and age, which are shaped by a set of forces beyond the control of the individual. These are the intermediate determinants of health, downstream from the structural determinants. They include material circumstances, and psychosocial and behavioral characteristics. They include the living and working conditions of people, such as their pay, access to housing, or medical care.

Structural determinants

Structural determinants are the root causes of health inequities, because they shape the quality of the social determinants of health that people experience in their neighborhoods and communities. Structural determinants include the governing process, economic and social policies that affect pay, working conditions, housing, and education. The structural determinants affect whether the resources necessary for health are distributed equally in society, or whether they are unjustly distributed according to race, gender, social class, geography, sexual identity, or another socially defined group of people.

Good governance and health

While many public policies contribute to health and health equity, improving population health is not the sole purpose of societies and their governments. A lack of policy coherence across government can result in one part of government supporting the implementation of national strategies on malnutrition or non-communicable diseases, or international treaties such as the WHO Framework Convention on Tobacco Control, while other parts of the government promote trade, industrial development, and initiatives that can be harmful to health and well-being. One reason that these inconsistencies arise is a lack of understanding across sectors about the linkages between health and quality of life, and the broader health determinants such as economic growth. They also arise because policies that appear to be unrelated may have unintended impacts that go unmeasured and unaddressed. These linkages are particularly important in understanding how these health inequities arise between population groups.

To contribute to policy coherence across government in order to address the social determinants of health equity, the health sector needs to understand the imperatives of other sectors and form common understanding of health, its determinants, and broader societal well-being or quality of life. This requires political will, as well as innovative solutions and structures that build channels for dialogue and decision-making across traditional government policy siloes.

In practice, this means engaging in several actions, including:

- coordinating support to a network of trainers implementing the WHO training manual on health in all policies in countries, regions, and WHO programs;
- supporting and implementing workshops for improving the skills of government policy-makers, program leaders, and health provider groups

to ensure coherence across sectors in policies, services, and programs responding to disadvantaged groups' needs; and

- supporting dissemination of information on intersectoral governance for determinants of health equity and exchange of evaluated case studies through the Intersectoral Action Case Study Database for Health Equity (ISACS).

The rule of law as a social determinant of health

Whether embodied in constitutions, statutes, regulations, executive orders, administrative agency decisions, or court decisions, the law plays a profound role in shaping life circumstances and, in turn, health. The ways in which this occurs can be broken down into four categories.

The law can be used to design and perpetuate social conditions that can have terrible physical, mental, and emotional effects on individuals and populations. One obvious example in this category is the "separate but equal" constitutional doctrine that allowed racial segregation in housing, health care, education, employment, transportation, and more.

The law can be a mechanism through which behaviors and prejudices are transformed into distributions of well-being among populations. Health care discrimination and bias can take many forms: it can be based on race, ethnicity, disability, age, gender, or class (or socioeconomic status). Class-related health care discrimination alone can take multiple forms.

Laws can be determinative of health through their under-enforcement. For example, a perfectly good set of housing regulations aimed at keeping housing units safe, clean, and quiet are of little value to individual and group health if there is neither the will nor the resources to enforce them. Substandard housing conditions, including the presence of rodents, mold, peeling lead paint, exposed wires, and insufficient heat—all of which are common among low-income housing units—can cause or exacerbate asthma, skin rashes, lead poisoning, fires, and common illnesses, yet a clinical encounter cannot "cure" these housing problems. While their consequences can be treated medically, the causes require robust enforcement of existing laws.

Finally, the law can be used to structure direct responses to health-harming social needs that result from factors like impoverishment, illness, market failure, and individual behavior that harms others.

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LETTER TO THE EDITOR

Refusal to Treat Patients Does Not Work in Any Country—Even If Misleadingly Labeled "Conscientious Objection"

CHRISTIAN FIALA AND JOYCE H. ARTHUR

We would like to point out some serious problems and contradictions in the study "Regulation of Conscientious Objection to Abortion: An International Comparative Multiple-Case Study," by Wendy Chavkin, Laurel Swerdlow, and Jocelyn Fifield (*Health and Human Rights Journal*, vol. 19, no. 1, 2017).

The study purports to show that it is possible to accommodate health care providers' "conscientious objection" (CO) to legal abortion while assuring that women with an unwanted pregnancy have access to health care services. The researchers examined four countries—England, Italy, Portugal, and Norway—all Western democracies with laws that allow CO for abortion. They conclude that England, Norway, and Portugal are able to permit CO by law and still provide and fund abortion care. Italy is the major exception, where access to legal abortion is seriously compromised due to a very high number of objectors.

However, significant information is omitted from the study, the choice of countries and interviewed stakeholders are selective and unrepresentative, and the findings are interpreted in a biased way. The study does not lend weight to the acceptance of CO for abortion in any country, including the four studied. Instead, the results confirm that refusing to provide basic health care cannot and should not be "accommodated" with patient needs—not even if the treatment refusal is misleadingly called "conscientious objection."

In the introduction, the authors explain that CO was introduced into law "out of political compromise or pragmatic necessity," but they omit the obvious reasons for this unprecedented intrusion of personal beliefs into medical regulation. Individuals are allowed to boycott a democratically decided law because of society's deference to religious beliefs and traditional views that assign women to a childbearing role. This points to an inappropriate and unethical basis for CO in reproductive health care—one that has little in common with the military CO it is dishonestly named after. Indeed, many people have argued against the exercise of CO in health care, but the authors never mention this opposing view.[1]

The study's selection of four countries that allow CO is biased and rather puzzling. At least 22 countries allow CO through regulation, so why did the authors exclude most of them? They cite the four countries' ratification of various international human rights agreements as one apparent reason. However, ratified agreements are no guarantee of compliance and have limited relevance to the utility of CO regulation. They also state that the four countries meeting their requirements are those with CO clauses in statute, legal abortion, and funded health care, and are "all high-income Western European countries with liberal

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abortion regimes." However, CO regulations vary widely and are not directly comparable across the four selected countries.

Italy does not have a liberal abortion regime and has no legal limits on the exercise of CO. The 1978 Italian law that legalized abortion grudgingly allows it while trying to limit it as much as possible.[2] Nothing in the law requires doctors to provide abortions—it requires them only to *consider* whether to do so in each case, and gives them wide discretion to refuse. CO is now widespread in Italy, exercised among 82% to 91% of all gynecologists, according to the authors—even though gynecologists are the only health care professionals who can legally provide abortion care. Italian women cannot escape to private clinics as they can in England, because the Italian law limits abortion to public facilities—which are not obligated to provide the service. While some private clinics and "conscientious objectors" do provide abortions for profit in Italy, many women resort to illegal abortion or travel to other countries.[3] In Switzerland, 23% of all abortions in the border region of Tessin are done for women from Italy.[4]

Why did the authors not select one of the three countries (Sweden, Finland, and Iceland) that disallow any refusal to treat, including for abortion?[5] Without such an example, any comparison of the utility of "regulation of CO" will be incomplete and misleading. The authors briefly mention such countries but understate the situation by claiming that the absence of CO regulation has "been interpreted to mean that providers lack a legal right to object." In fact, CO is actively disallowed by policy in Sweden, Finland, and Iceland, as well as by court jurisprudence in Sweden.[6] The prohibition of CO has positive consequences—women have good access to abortion, and providers are held accountable for their professional obligations to patients.

The selective aspect of the four countries is also apparent with the inclusion of England. It cannot have escaped the authors' notice that England is not a country on its own and therefore not directly comparable to the other three. Did the authors select this part of the United Kingdom because CO is less of a problem in England compared to other parts of the country, such as Northern Ireland?

A major flaw is that the authors rely only on what the laws state and what their invited stakeholders said. The latter were arbitrarily selected for convenience, based on the researchers' ability to find them and conduct interviews. They included lawmakers, legal experts, health system officials, medical association representatives, reproductive health advocates, academics, bioethicists, anti-abortion advocates, and religious freedom advocates. Few of these people would have any knowledge of what is happening on the ground. CO regulations are poorly enforced in almost every country, and the study interviewees highlighted the "scant or spotty regional and national data on the prevalence and characteristics of objection" in their countries. Therefore, it is not possible to conclude that CO works well in some countries just by examining their laws and interviewing people who are not directly concerned and not even on the frontlines. They cannot know the extent to which CO laws are ignored or disobeyed by objectors, or how often women are denied services and treated unjustly.[7]

It is also difficult to understand why the authors would select stakeholders who are against abortion or who have only religious qualifications, while excluding the only persons affected by CO—pregnant women. Leaving out the real-life experience of women in a subject that affects them alone recalls the dark era of the paternalistic past and goes against all modern human rights values.

In the authors' case summaries of the four countries, it becomes clear why the negative consequences of CO appear to be reduced in Norway, England, and Portugal. First, all three countries "reserve certain positions for non-objectors." In other words, refusal to treat under CO is allowed only to a certain extent. Second, all hospitals in Norway and Portugal are obligated to provide abortions and are responsible for employing enough personnel to do so. Third, while doctors in England can object in the public system, the National Health Service contracts out most abortion care to private organizations like the British Pregnancy Advisory Service and Marie Stopes, who of course hire only non-ob-

jectors. This shows that CO can be minimized by imposing firm restrictions, because it results in fewer objectors. England and Norway both have low numbers of objectors, which may also relate to low levels of religiosity in both countries. Therefore, the authors are wrong in asserting that CO regulation can accommodate objectors—in fact, the most successful CO regulations reduce the numbers of objectors to very low levels, to the point that it should become feasible to prohibit CO entirely.

Portugal is deemed successful by the authors on the basis that it is small, so women can travel to find an abortion provider and even receive funds to do so. Also, all public hospitals are obligated to provide abortions. But little is known about the number of objectors in Portugal, whether hospitals and objectors are obeying the law, and what actually happens to women. As the authors admit, "Rigorous data on the prevalence of objection are not available." Also, few objectors are even aware of their legal duties to inform the national Order of Doctors and their patients about their objection. This reporting aspect of the CO law is not being followed because, apparently, "informal adjustments suffice."

The authors' study concedes that allowing CO makes access more difficult for women and increases the burden on health care systems to provide abortion, which they often fail to do. There are "varying degrees of implementation" of the laws, which generally require health care institutions to expend their own resources by hiring extra providers while paying objecting doctors to not do their job, or to contract out abortion care to private clinics. Further, health care personnel often have insufficient knowledge of the law, and Italy has a significant amount of "convenient objection" unrelated to conscience, as well as excessive workloads for abortion providers. None of that stops objectors in Italy and Portugal from complaining that attempts to hire non-objectors are discriminatory, even though hospitals must provide abortions by law.

Indeed, the authors note that "[a]ll interviewees opposed to abortion expressed discontent with any constraints on CO." This confirms that CO regulations are fatally flawed because of the assumption that objectors will follow them. The authors admit that all four countries have had clinicians who "illegally invoked CO to the provision of emergency contraception, intrauterine devices, and post-abortion care," as well as "uneven and incomplete monitoring of compliance." As we know, many anti-abortion doctors refuse to obey a requirement to refer, and some will even let a woman die rather than perform a life-saving abortion required by law.[8]

The study actually shows that CO regulations give a false sense of security to those who wish to "simultaneously" protect doctors' refusal to treat and patients' right to health. The conflict between these two objectives brings to mind the Enlightenment of the 18th century, when societies recognized the need to limit the power of religious beliefs and switch to evidence-based decision making. Why, in the 21st century, are we still debating whether this secular principle should apply to women with an unwanted pregnancy?

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LETTER TO THE EDITOR RESPONSE

Much to Debate about Conscientious Objection

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Because Christian Fiala and Joyce Arthur absolutely oppose conscientious objection (CO) to abortion, they reject our very research question.[1] We were not debating the desirability of CO but, rather, evaluating the efficacy of laws and policies that regulate the practice of CO in countries in which CO to abortion is permitted by law. Regardless of Fiala and Arthur's opposition, CO is lodged in the abortion laws of the four countries we chose, as well as in 15 of the 22 we had found in an earlier search.[2] We explained our rationale for country selection in the methods section, which was based on normative research concerns regarding study design, data availability, and feasibility.

We concur that there is much to debate about the political desirability of CO to health care and would add that there is also much to debate about which tactics strategically improve women's access to care, and engage and support willing clinicians and health sectors. As it is a reality that CO is legally permitted in many countries, this study was intended to assess whether access to care could be maintained in those cases where CO is currently enshrined in law, to extract pragmatic lessons for other such jurisdictions and to provide evidence to inform political and strategic deliberations.

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