Health, Human Rights Law, and Applying a Gendered Lens to Addressing Poverty and Emerging Infectious Diseases: Lessons From Ebola in the DRC

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Abstract

The Ebola outbreak in the Democratic Republic of the Congo that began in 2018 demonstrates the complexities of managing a humanitarian response to a global health emergency amidst ongoing conflict in the region. One such challenge is the significant impact of the disease on women, especially those living in poverty. Human rights law provides a framework and foundation for understanding why protections for women have been put in place. When it comes to emerging infectious diseases such as Ebola, gender and poverty are significant factors that must be considered at all levels of the humanitarian response. This article lays out the relevant provisions and protections for health and gender in human rights law, analyzes the role of women in global health, and discusses how global health policymakers and healthcare professionals can more systematically consider the impact of gender on disease by applying a gendered lens to disease outbreak management.

Introduction

The impact of infectious diseases on populations all over the world has long been recognized as an imminent global crisis [1, 2]. The 21st century has seen an increase in outbreaks of emerging infectious diseases (EIDs), which threaten the health and safety of citizens all over the globe [3]. EIDs are diseases that have "recently appeared in a population or have already existed but are rapidly increasing in incidence or geographic range," [4] which explains the widespread fear such disease outbreaks can incite. Despite the many EID outbreaks that have made global news headlines in contemporary history, the international community has struggled to adequately respond, leaving vulnerable populations at risk. For this article, women, especially those living in poverty, are the vulnerable population of interest.

Many factors contribute to the disproportionate impact of EIDs on vulnerable populations, including those stemming from poverty and gender disparities [5]. Socioeconomic status influences health, to the point where "poverty breeds disease and ill health leads to poverty" [6]. Data on gender differences in infectious disease outbreaks also show that disease does not affect everyone equally [7]. Although men and women often suffer from different diseases due to biological differences and social inequalities, women are particularly vulnerable due to the lack of attention and integration of women in global health policies and management strategies of EID outbreaks [8].

One case study that demonstrates the disparate impact on vulnerable populations during EID outbreaks is the current Ebola Virus Disease (EVD) outbreak in the eastern region of the Democratic Republic of the Congo (DRC). This outbreak began in August 2018 and has grown to become the second largest EVD outbreak on record [9]. As observed in the 2014—2016 West African EVD outbreak and other large—scale EID outbreaks such as Zika or SARS [3], the Eastern DRC EVD outbreak beginning in 2018 has had a significant impact on women.

While research has been conducted on so called diseases of poverty and the vulnerability of women during EID outbreaks, the preference to deal with the immediate outbreak instead of addressing more systemic societal concerns forgoes a focus on the individual and their human rights. As a result, little has been done to incorporate the impact of human rights law into the management and response mechanisms of such outbreaks. Human rights law not only brings to the forefront these core issues of inequality, but also introduces supplemental and useful tools for considering how to achieve the most effective response to these emergencies. The first section of this paper provides an important background to the relationship between poverty, women, and EIDs by considering both legal and public health perspectives. The second section analyzes the role of women in global health, particularly in responses to EIDs, by examining how women have been affected in past EID outbreaks and using the 2018 Eastern DRC EVD outbreak as a case study. Finally, this paper concludes with a discussion of

how global health policymakers and healthcare professionals can address this gap by applying a gendered lens to EID outbreak management.

Background

The human right to health as a foundation for addressing inequality in poverty and gender

As human rights law has developed throughout history, the health has consistently been regarded as a core, fundamental human right in many international legal instruments [10]. The United Nations (UN) Charter (1945), emphasized the need for international cooperation in Chapter IX, and particularly for finding solutions to health problems [11, 12]. In 1946, the World Health Organization (WHO) Constitution declared that the objective of the WHO is the "attainment by all peoples of the highest possible level of health" [13]. In 1948, the Universal Declaration of Human Rights (UDHR) referenced this same objective for health in Article 25(1), highlighting the right to an adequate standard of living through factors such as food, housing, and social services in order to achieve an acceptable standard of health [14]. In 1966, the International Covenant on Economic, Social and Cultural Rights (ICESCR) stated in Article 12 that the States party to the treaty recognize the universal human right to the "highest attainable standard of physical and mental health" [15], achievable through public health prevention, treatment, and control of disease. This provision's drafting history demonstrates that its object and purpose of was to obligate States to address the prevention of disease and malnutrition, two major factors which pose obstacles for achieving health for all [12]. Additionally, the Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14 further explained ICESCR Article 12(2)(c), clarifying that the right to treatment includes cases of accidents, epidemics, disaster relief, and humanitarian assistance, and emphasizing the States' duties to support each other through technology, surveillance data, and other strategies of infectious disease control [8, 16]. With these core international instruments, basic standards of health, treatment, and particularly disease management set the stage for a baseline of States' obligations to respect, protect, and fulfill the right to health.

Currently, the Sustainable Development Goals (SDG) also highlight the right to health. In SDG 3.3, the target to end "the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases" [17] is particularly relevant because neglected tropical diseases (NTDs) are a subset of EIDs and mainly affect the poorest populations in the world [18]. SDG 3.c to "substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries" and 3.d to "strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks" [17] are also important goals for addressing the disproportionate disease burden on States that currently lack the capacity to respond to health crises such as EIDs. These goals, voluntarily assumed by States, continue to build upon the human rights legal foundation of the right to health and further solidify the importance of addressing health with human rights law.

Just as the right to health has been established through international treaties, women's rights have also been protected through Article 12 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), which requires that States party to the treaty eliminate discrimination against women in regards to health care and access to women's health services in connection with pregnancy [19]. Like the CESCR, the CEDAW Committee further explained the importance of protections for women's health through its General Recommendation regarding CEDAW Article 12, stating that States have a duty to ensure access to women's health care services, with an obligation to respect, protect, and fulfill women's rights to health care [19]. Additionally, CESCR General Comment 16 addresses women's health in particular by articulating that States must consistently examine the impact of gender roles on health, and work to remove legal restrictions on women's health issues such as reproductive health [19, 20]. These international treaty provisions demonstrate the importance of protecting the right to health especially as it applies to women.

Poverty as a determining factor of health outcomes in EIDs

Poverty is a main determining factor of EIDs in communities [21] because, especially in developing countries, poverty and poor health are cyclically intertwined [6]. With almost 900 million people living in extreme poverty across the globe, understanding how poverty and disease are related is urgent [22]. Poverty is an important factor which contributes to more opportunities for infectious diseases to affect humans [23]. NTDs are a subset of EIDs which particularly thrive and persist under conditions of poverty [23]. One example is tuberculosis (TB), which is often described as a disease of poverty because of its significant association with factors

such as poor housing and lack of access to health services [24]. NTDs are frequently called infectious diseases of poverty and are the result of the "complex interaction of biological, social, and environmental factors [because they] disproportionately affect poor and disadvantaged populations in which the poverty context reinforces risk and vulnerability" [25]. This is compounded by the fact that disease "control tools such as drugs, vaccines, and diagnostics often do not reach the populations that most need them because of social issues . . . or because they are ill adapted to the cultural, social, and economic realities in which people live" [25].

Another connection between poverty and disease is that since EID outbreaks such as the 2014–2016 West African EVD outbreak, the 2015–2016 Zika outbreak, and the current Eastern DRC EVD outbreak beginning in 2018 can have a very significant impact on a community, they can essentially reach the level of a crisis or disaster. When disasters hit, people living in poverty are much more vulnerable [22]. On top of this, women make up approximately 70% of people living in poverty worldwide, so this indicates that overall, women are more likely to be affected by disasters in poverty—stricken areas [22].

Gender as a determining factor of health outcomes in EIDs

Another key determinant of health is gender [26]. Gender refers to societal and cultural factors that differ between traditional male and female roles [27]. Studies on the relationships between sex and gender to infectious diseases have been conducted across a variety of disciplines, which has acted as a barrier to application of this research in outbreak settings as each discipline tends to work in isolation [27]. Thus, to fill this gap, it is important to integrate a gendered lens into outbreak response and management.

Disease does not affect men and women equally [7]. Women are a particularly vulnerable group because they "disproportionately bear the burden of poverty and disease" [28]. Thus, vulnerability is deeply gendered [29]. Not only do over 80% of women in the world live in low—or middle—income countries, putting them at higher risk for EIDs, women also live longer [29]. Over a lifetime, the "social context of women's lives place exceptional burdens on the quality of life lived" [29]. Understanding the pre—existing biological and socio—cultural conditions in which women live is an important foundation for understanding their vulnerability in crises and disasters. Risks related to health concerns from cooking fumes in the home and complications with pregnancy "overlap with developing countries and are exacerbated in the contexts of poverty combined with conflict . . . [and] such risks are further aggravated in situations of humanitarian crisis" [29].

State and international core obligations to protect health for all

Although there are international legal instruments protecting health, given the vulnerabilities of those living in poverty, especially women, it is not surprising that many States lack the capacity to "progressively realize and ensure that a minimum core of a properly functioning health system and infrastructure . . . exists for people to gain access to health services" [30]. While States are required to prevent disease through all appropriate measures, given varying levels of access to resources, the States that experience the most NTDs "are least able to counter the existing imbalance in disease prevention research and development" [30]. This lack of capacity in many States in the Global South has been attributed to "historical vulnerability from slavery, colonialism, neocolonialism, bad governance, and neoliberal reform policies like structural adjustment" [31]. In addition to individual obligations, States also have an obligation to cooperate internationally [12]. If a State lacks capacity, the international community is called upon to act via a 'collective responsibility' [30]. The ICESCR addressed collective responsibility, stating that States should realize the rights in the Covenant "individually and through international assistance and co—operation, especially economic and technical" [30].

Case study on the DRC EVD outbreak beginning in 2018

The most recent EVD outbreak began in August 2018 in the eastern region of the DRC, originally concentrated in North Kivu and Ituri provinces [32]. It has since grown to be the second largest EVD outbreak on record [9]. Although this is the tenth EVD outbreak to take place in the DRC, there are many factors which differentiate this outbreak from those in the past [33].

Past outbreaks in the DRC were not concentrated in the eastern region of the DRC, a decades old conflict zone where violence continues today [34]. Compared to the 2014–2016 West African EVD outbreak, the population in North Kivu province is more dense than that of Guinea, Liberia, and Sierra Leone combined [35]. Additionally, North Kivu shares borders with four provinces and two countries [35, 36]. The historical insecurity of this subregion is accompanied by the presence of over one hundred active, non—state, armed groups. These groups are remnants of former conflicts such as the DRC independence, the 1994 Rwandan genocide, and the civil

war that established the regime of former President Joseph Kabila [37, 38].

In the broader context, the history of the DRC has not provided a backdrop conducive to effective management of deadly EIDs. Centuries of colonialism led to decades of armed conflict, which continues today and has spread deep—rooted mistrust of the government across the country, especially in the Eastern DRC [39]. The DRC is also one of the three poorest countries in the world, despite its rich natural resources, so while colonialization may no longer be an issue, exploitation has an ongoing presence in country [39]. These elements contribute to the context in which the current Eastern DRC EVD outbreak has taken place. It is important to understand this context in order to analyze the impact of EIDs on women in poverty.

Women play an integral role in global health and applying a gendered lens to all levels of EID responses provides better protections for women and more effective management strategies of EID outbreaks

The role of women in global health

1. *Informal caregivers*

The 2014–2016 West African EVD outbreak began in December 2013, and in just eight months, women made up "55—60% of all Ebola fatalities in Guinea, Liberia, and Sierra Leone" [40]. News headlines asking "Why Are So Many Women Dying from Ebola?" revealed that "women in Ebola—hit countries do not enjoy the promise of equality called for under human rights law" [7]. Since increased risk in transmitting EVD comes from basic day—to—day interactions, traditional gender roles put women in especially vulnerable positions [40].

One role that women fulfill in many societies is the caregiver in the home. This societal expectation that women must care for the family greatly contributes to the disproportionate impact that EIDs such as EVD and HIV have on women [7]. For especially fatal diseases such as EVD, women are not only caring for more individuals, but the work is also more dangerous because the disease is spread through direct contact with bodily fluids [7]. This is particularly challenging because the intensity of care given at home is often equal to that given in a health care facility, but not all women are formally trained health care professionals [41]. There is a gap in education for women who are informal caregivers, which further perpetuates the disparate impact of EIDs on women.

Due to traditional gender dynamics and their roles as caregivers, women are also often heavily involved in mourning and burial rituals. When their loved ones die, women are the "ones to perform funeral rites such as washing bodies and preparing them for burial" [40]. During the 2014–2016 West African EVD outbreak, Sierra Leone reported that as many as 365 deaths were connected to one funeral, and when the outbreak first began in Guinea, approximately 60% of all EVD cases were connected to traditional burial practices [7]. Since EVD is still transmissible after death and women have such prominent roles in these rituals, their gendered functions as caregivers and mourners puts them at a disproportionately higher risk of infection [26].

Additionally, women in many societies are seen as the primary caregivers in the household, and when they fall ill the gendered caregiving roles are not reversed. Instead of the men taking care of the women, other women in the community are responsible for caring for each other [7]. This is partially due to socio—cultural aspects of what are appropriate roles for men and women, and also contributes to women being more vulnerable to EIDs. Nevertheless, while the role of women as caregivers is clear, during past EVD outbreaks "men dominated informational meetings on the disease" [42], leaving out the key voice of women and putting them in a vulnerable place without adequate information or agency to voice their concerns during these discussions.

2. *Health workers*

The healthcare workforce is also an at—risk population during EID outbreaks due to the ways in which these diseases are spread. For example, since EVD is spread through contact with bodily fluids, the close level of contact that healthcare workers have with infected patients puts them higher risk of transmission. Healthcare workers are between 21 and 32 times more likely to be infected with EVD than the general adult population during an outbreak [43]. Especially in countries where the healthcare workforce is already scarce (i.e. West African countries during the 2014–2016 West African EVD outbreak), losing healthcare workers to EVD is particularly challenging for effective management of the outbreak [43].

While men often perform higher—level healthcare positions such as doctors due to gendered differences in education levels, women also play important roles in the healthcare workforce. In almost all countries, the nursing staff is predominately female, and nurses make up a considerable proportion of the healthcare workforce [27]. For example, during the 2014—2016 EVD outbreak in Sierra Leone, 70% of healthcare workers were nurses and midwives [7]. The work conducted by nurses differs from doctors. Nurses are often the healthcare workers in direct

contact with the most patients, leaving them more vulnerable to contracting disease [27]. The WHO reports that "nurses and nurse aids account for more than half of all health worker infections" [7]. As a result, since nurses are overwhelmingly female and the duties of nurses put them at higher risk of contracting disease, "the occupational exposure of nurses can be considered a gender related exposure" [27].

Another consideration related to the high infection rates of healthcare workers is that decreases in the healthcare workforce result in decreases in the availability of health care services for women [7]. This is especially significant in States that already lack adequate health infrastructure and resources. EID outbreaks further exacerbate the many health inequalities that women already experience [26]. Given the specific provisions under international law to protect women's health, the lack of available health care services for women due to a decrease in healthcare workers is a serious concern.

Global health security requires a gendered lens to adequately address the disparate impact of EIDs on women

The field of global health security emerged in the 21st century. It expands upon the definition of public health security and includes "the health consequences of human behavior, weather—related events and infectious diseases, and natural catastrophes and man—made disasters" [44, 45]. Additionally, public health emergency preparedness brings in proactive and reactive legal components to best prepare and respond to such emergencies [45].

Since women play such integral roles in global health and are greatly and differentially impacted by EIDs, it is important to consider these issues with a gendered lens. The CESCR recognized this by recommending that States "integrate a gender perspective in their health—related policies, planning, programmes and research in order to promote better health for both women and men [because] a gender—based approach recognizes that biological and sociocultural factors play a significant role in influencing the health of men and women" [8]. Thus, women are a key voice that should be "included at all levels of planning and operations to ensure the effectiveness and appropriateness of a response" [26].

Although these recommendations have been made by many international actors, little has been done to integrate women into global health security responses. During the 2014–2016 West African EVD outbreak, women were invisible at every point during the international response [26]. It is clear that women are closely intertwined in EID responses, "yet they are invisible in global health strategy, policy or practice . . . [and] only made visible through motherhood" [26]. When it comes to addressing gender during a disaster such as an EVD outbreak, the tendency is to focus on Ebola first and gender later, as if gender concerns are an optional add—on that others can address after the outbreak has ended [7, 46].

Besides playing important roles in global health security, particularly in societies like the DRC's North Kivu province, women are often leaders and heads of households. They are not only responsible for caring for their families, but their positions give them social power as well, and it is with this power that they care for entire communities [47]. This is especially important for EIDs like EVD because community fear and distrust of governmental and international actors during recent outbreaks have greatly complicated the EVD management response. Just seven months after the Eastern DRC outbreak began in 2018, studies reported "low levels of trust in government institutions and widespread belief in misinformation about EVD" [48]. This distrust has led to "reduced adherence to EVD preventative behaviors" such as vaccination [48]. To combat these challenges, it is vital to "[engage] locally trusted leaders and service providers . . . [in order] to build trust with Ebola responders who are not from these communities" [48].

One example of how the WHO has tapped into the power of women to address this is through a partnership with Mama Mwatatu, a female radio show host so well known in her community in North Kivu she earned the nickname Mother Counsellor of Beni [49, 50]. Her listeners are mostly female, so in a short time she has managed make a significant impact on EVD management efforts in Beni [50]. She uses her broadcast to emphasize the reality of the disease and answer her listeners' questions about EVD. If she is unable to answer a question, she passes the question on to WHO experts to gather accurate information, forming an invaluable partnership between the WHO and the local female community [50]. Julienne Anoko, a social anthropologist for the WHO, has also proven the power of women. She collaborated with the Collectif des Associations Feminines to educate 132 women leaders about EVD and send them back to their local communities to conduct information campaigns explaining EVD vaccines, treatment, contract tracing, and the vulnerability of women and children to EVD. Ultimately, the campaigns reached over 600,000 people who would not have otherwise been reached due to fear and stigma [50]. These are just a few examples of how women can contribute to the management of an EID outbreak. Women are a key connection to the local population, and at a time when trust

in authority figures is low and misinformation is high, it is vital to reach all corners of affected communities.

Conclusion

While gender may not be the first consideration of most global health policymakers and healthcare professionals responding to an EID outbreak, it should be. Applying a gendered lens to EID outbreaks reveals the disproportionate impact of EIDs on women, due to their higher rate of living in poverty and susceptibility to disease as a result of gendered roles in many societies. Women's rights to health are codified in many provisions of international and human rights law, but the connection between gender and EID response has not yet been developed. Due to women's heightened susceptibility and integral role in EID management, empowering women to do global health work in their communities and supporting them is an extremely effective way to combat not only the current EVD outbreak, but to strengthen global health security as a whole.

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