

PUBLIC HEALTH AND HUMAN RIGHTS IN AN ERA OF EPIDEMICS

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Abstract

This article explores the tension between individual human rights and the need to protect the public health. It focuses on the role of social workers, who have a moral and ethical responsibility to protect the human rights of the individuals with whom they work and to ensure that the public health of their communities is promoted. Drawing on examples from epidemics including Ebola, HIV/AIDS, and tuberculosis, the article suggests ways in which social workers can proactively engage individuals and communities in supporting public health while also ensuring that individual human rights are promoted.

If one were to ask a random sampling of social workers if they considered health care to be a basic human right, they would almost certainly answer “yes.” Ask them if they consider public health to be a priority, and they would likely also say “yes.” In a sense, the individual’s human right to well-being and the more general maintenance of public health appear as the same *right to health*.

The language of individual rights is clear. In 1946, the Covenant of the World Health Organization declared that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition” (World Health Organization 1946). Since then, several other United Nations covenants have relied on the same “highest attainable standard of health” or similar language in articulating further facets of the right to health (Leary 1994, 28-29). Article 25(1) of the *Universal Declaration of Human Rights* states that “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including [...] medical care” (United Nations 1948). Clearly, advocates for human rights have recognized the right to health, at least in principle, for decades.

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But while the health and well-being of individuals suggests the need for adequate medical personnel, diagnostics, and treatment, public health refers to disease prevention and health promotion at the level of the collective: defined as group, community, organizational, geographical, national, or international levels. Maintaining health at these collective levels sometimes requires eliminating any one individual's rights to freedom of movement and association, as when the mandates of public health require measures like quarantine in the interest of the greater population. Many human rights documents acknowledge this need for extreme measures, but prioritize public health only as a method of last resort (Leary 1994, 39).

Social workers can be positioned between the needs of clients as individuals and the needs of the larger community in which they work. In the case of an individual's right to health and the demands of a public health regime, a social worker must strive to find a balance between these two competing domains. An analysis of how this tension has manifested in the course of various health crises and epidemics will help to show how supranational organizations, governments, non-governmental organizations (NGOs), and individual social workers can all influence the implementation of public health strategies with conscious attention to human rights. This paper thus examines the spread of and response to Ebola, HIV/AIDS, and tuberculosis and how individual rights have been protected and promoted—or not—throughout these epidemics. It thus strives to show the common trends and begins to craft a path forward to ensure that human rights are protected even in contexts that necessitate adherence to the demands of public health.

As an illustration of one tension between individual rights and the claims of public health, recall the recent case of Kaci Hickox, a Doctors Without Borders nurse who upon her return from working with infected individuals in Sierra Leone was quarantined first by officials in New Jersey and then by the government of her home state of Maine (Fitzsimmons 2014; Flegenheimer, Shear, and Barbaro 2014). Hickox later defied the quarantine, arguing that such an order violated her human rights (Weiser and Goodman 2014). She eventually won a court order that permitted her to self-monitor for symptoms through the end of the virus' potential incubation period (Reuters 2014). Hickox's case led to some health care workers deciding not to travel to affected areas, or to routing their travel through areas where they were less likely to face a quarantine (Hartocollis 2014). In Ebola-affected areas, "fearful patients have avoided hospitals, thus spreading Ebola infection in the community with individuals left untreated for myriad other health hazards, ranging from malaria and chronic disease to childbirth" (Gostin 2014, e49). Fear can drive away

some people living with the disease or at risk of infection, and can keep them from medical care and prevention education (Eba 2014; Staley, Johnson, and Krellenstein 2014). It is precisely because widespread quarantine or isolation orders could promote an environment of fear and mistrust that public health officials have sought to limit the use of such orders to cases of imminent threat of harm to the community with no other practical way of mitigating that threat.

The Hickox case brings to light issues of power and privilege, inequality and injustice, and systemic abuses affecting individuals, communities, and populations. While Hickox claimed that her rights were being impacted by the quarantine order, it was impossible not to focus equal attention on individuals living in Liberia and Sierra Leone, where the disease was running rampant (Gostin 2014, e49). The response in those less-developed countries has been hampered by the lack of public infrastructure and resources. But the severity of the outbreak also correlates with what the United States Department of State (2014a; 2014b) has described as “severe” and “major” human rights abuses in the countries hardest hit by the epidemic. As Farmer (1999) notes, groups experiencing oppression also have higher risks of poor health care access and worse health outcomes.

This correlation of oppression and poorer outcomes can be seen in the disparate responses to health crises based on populations affected. For instance, in the early 1980s, there were separate but simultaneous outbreaks of AIDS and Legionnaires' disease in the United States. Each outbreak received widespread media coverage. The spread of both diseases required a speedy public health response from the federal government. However, AIDS was perceived as only affecting marginalized and stigmatized populations—gay men and injection drug users—while the victims of the outbreak of Legionnaires' disease were almost exclusively middle-class, white, presumptively heterosexual men. Between June 1981 and May 1982, the Centers for Disease Control and Prevention spent less than \$1 million on HIV/AIDS research and prevention, while spending \$9 million on Legionnaires' programs, even though 1,000 of the 2,000 AIDS cases at the time had proved fatal, while fewer than 50 people had died of Legionnaires' (Bronski 2003). This disproportionate distribution of resources was due in large part to the stigma applied to gay men and drug users at the time. AIDS failed to receive more equitable funding until it began to be seen as a threat to the so-called “general public” several years later, and could no longer be ignored.

Looking beyond HIV or Ebola, we can see more interaction between human rights and public health in the context of the tuberculosis epidemic. *Mycobacterium tuberculosis* infections have been present in

humans since antiquity; the disease is curable and preventable, but is often fatal, especially in developing parts of the world (World Health Organization 2014). Treatment of active—i.e., symptomatic—tuberculosis requires a combination of antibiotics, taken over at least six months, if it is a “simple” wild-type *M. tuberculosis* infection (Lawn and Zumla 2011). However, Multiple Drug-Resistant Tuberculosis (MDR-TB) is becoming increasingly prevalent worldwide (World Health Organization 2014). MDR-TB is often caused by poor patient adherence to medication, which can occur for many reasons, but in the developing world, often occurs because of poor or inconsistent access to health care services. Once resistance has developed in the tuberculosis patient, the “first-line” medications are no longer effective, and more costly second- or third-line treatment protocols must be implemented. Because of the virus’ ease of airborne transmission, the long latency period for many infections, and the inability of many in poorer countries to access effective screening or prevention methods, tuberculosis continues to ravage developing nations.

After HIV, tuberculosis is the second-leading cause of death worldwide, and is spreading quickly in many of the same countries that have poor human rights records (Farmer 1999; World Health Organization 2014). People living with HIV are significantly more susceptible to tuberculosis infection and have reduced health outcomes once infected. There is also evidence that they are more infectious and likely to pass on tuberculosis to others (World Health Organization 2014). The same human rights violations that put people at additional risk for HIV infection—lack of access to education, human trafficking, and poor access to health care—also increase their risk of acquiring tuberculosis.

In the late twentieth century, Farmer (1999) noted that in Russian prisons, which were rife with human rights abuses—including overcrowding, extended detention without charge, and physical abuse—tuberculosis was common because prisoners could not avoid being exposed to MDR-TB. “Increased TB risks should be seen as a violation of rights; TB, as a form of punishment” (Farmer 1999, 1487).

In discussing the HIV epidemic, Farmer (1999) notes that “there is considerable overlap between the groups at risk: if you are likely to be tortured or otherwise abused, you are also likely to be in the AIDS risk group composed of the poor and the defenseless” (1490). The same appears to be true of other epidemics as well. If social workers, policymakers, and direct service providers can recognize this correlation and begin to proactively target services towards individuals at risk of other human rights violations, current and future epidemics may be controlled more quickly.

Social workers operating at both the macro- and micro-level can use their awareness of intersecting systems of power and privilege in order to recognize individuals and communities that may be at a higher risk for health crises. Working to ensure they have access to health care, education, and preventive services will involve a coordinated response across disciplines—including medical, behavioral health, legal, and social services—as no one group of advocates and service providers will be able to solve the problem (Clay 2014). Recognizing that health care and other human rights are interdependent requires that social workers in the areas of human rights and NGOs—as well as health care providers and policymakers—begin to treat them as such, and advocate for the protection and promotion of all human rights concurrently.

When at-risk populations advocate for themselves during epidemics, social workers may feel conflicted about their identification with individuals in need and their work to protect and improve entire communities. Farmer (1999) describes “the rejection by the poor of separate standards of care,” and notes that “the destitute sick are increasingly clear on one point: promoting social and economic rights is the key goal for health and human rights in the 21st century” (1487). Marginalized populations will be frustrated by the violations of their individual rights, and social workers have a natural orientation toward fighting against these violations. However, social workers also see the broader implications of public health activities, and the potential impact of those activities on health at a community level. Social workers are thus in the position of ensuring that individual rights are only impinged upon to the absolute minimum degree required to protect the public health and of advocating for all other options before restricting human rights. On an organizational and government level, social workers can proactively work to advance human rights in the context of public health by proposing and promoting contingency planning to address potential epidemics. Regions and NGOs that have clear plans for addressing contagious outbreaks are considerably less likely to react from a place of panic and fear when these outbreaks inevitably occur.

Advances in medical technology over the last few decades have also rendered quarantines and their associated restrictions on human and civil rights much less necessary than in the past. For instance, Siddhartha Mukherjee at Columbia University has proposed that polymerase chain reaction (PCR) testing be implemented on individuals who have been potentially exposed to Ebola. This rapid test, which is relatively inexpensive and requires only a small blood sample, takes only a few hours to run. Instead of the current 21-day quarantine period, PCR testing could determine if someone is infected in the time it takes to fly

from West Africa to the United States (Mukherjee 2014). A passenger could have a blood sample taken prior to boarding and the results would be available prior to deplaning. Passengers who tested positive could be isolated and treated, and other passengers could be screened for exposure. Similar advances in HIV testing have allowed diagnoses to be made as soon as a few days after exposure—a major leap from the six-month “window period” required by early tests. This has reduced testing-related stress and also improved the ability of public health officials to respond quickly to newly-infected individuals, helping them reduce their risk of transmitting the virus to others. The fact that similar testing is available for detecting Ebola infection, but has not been made widely available, is disappointing. During the current 21-day quarantine implemented in several areas, individuals who may have been exposed to Ebola are kept away from family, friends, and loved ones, and have almost complete restrictions placed upon the human rights of freedom of movement and freedom of association (Fitzsimmons 2014; Weiser and Goodman 2014). While there are logistical, financial, and technical issues to overcome in widely implementing this type of testing, if it is possible to allow exposed individuals to retain their dignity, autonomy, and basic freedoms while still protecting public health, social workers have an ethical obligation to advocate for this approach.

Social workers have the ability and the training to bridge the divide between population-level efforts to promote public health and the need to preserve individual human rights. Whether we work in direct service, NGOs, or government agencies, we can approach our work with a recognition of the impact of public health initiatives on individual freedoms. We can ensure that we balance the need to slow the spread of epidemics with the obligation to protect individual dignity and liberty. Even when there is a need to make significant rapid decisions against a backdrop of fear and uncertainty, social workers can ensure that their colleagues and organizations take the time to consider all available options before implementing efforts that may unnecessarily deprive individuals of their human rights. We can recognize violations of human rights when they occur and work to address them with governments and advocacy organizations. We can also take proactive steps to ensure that the communities where we work have access to the health care services that will prevent outbreaks of infection, and that systems are prepared for a quick and effective response to epidemics when they first occur.

Ultimately, though, the interrelatedness and tension between all the various human rights, including the right to health care and the right to public health, emphasize the assertion that “all human rights are universal, indivisible and interdependent and interrelated” (United Nations General

Assembly 1993). Without access to health care, achieving and maintaining public health is virtually impossible. If public health is not a priority, then health care resources become overtaxed. One cannot exist without the other, even though they can at times place different demands on decision makers and communities.

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