



CHAPTER 3

# Global Health, Human Rights, and Ethics

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The recent emergence and reemergence of infectious disease epidemics, the persistent burden of non-communicable disease, the enduring impact of environmental change, and the intractable effects of social disadvantage and inequity have all contributed to the rising prominence of health challenges at a global level. The promise and process of globalization, with its increased interdependence of economic, political, and social domains, accompanied by the integration of goods, services, values, and people, translates into new and interconnected global health threats, worsening health disparities, and heightened global health insecurity.

It is in this context that the human rights and ethics implications of public health challenges and interventions must be pursued and interrogated. Human rights and ethics, encompassing the right to health as well as some degree of the right to non-interference, health equity, and the determinants of health, are central to global health. This centrality is recognized by the World Health Assembly and the World Health Organization (WHO), and is enshrined in international conventions and treaties with relevance to global health, including the Universal Declaration of Human Rights; the International Convention on Social, Cultural and Economic Rights; the Convention on the Eradication of All Forms of Discrimination Against Women; and the most widely ratified of all of these foundational

agreements, the Convention on the Rights of the Child. All of these conventions agree that human rights paradigms and ethics principles are inextricably linked to health and offer a normative framework to understand and address complex health issues experienced at a global level. Analysis of emerging and persistent global health challenges through the human rights and ethics lenses can be a more effective and nuanced approach for framing and responding to global health challenges and allows for focus on both the proximal causes and the social determinants of ill health (Mann, 1997).

## ► Defining Global Health in the Context of Human Rights and Ethics

Though many constructs of global health exist, this field is generally understood to refer to a phenomenon whereby the determinants of health or health outcomes supersede the territorial boundaries of any given state. Global health recognizes that health is determined by conditions, issues, and concerns that typically transcend national boundaries (Stapleton, Schroder-Back, Laser, Meershoek, & Popa, 2014). It highlights issues that may be universally experienced, and accepts that while some burdens and challenges are shared, many

health burdens may be profoundly inequitable and disproportionate. Global issues are often recognized as beyond the capacity of individual countries alone to address through domestic institutions (Stapleton et al., 2014). The world recently witnessed this reality during the 2013–2016 Ebola outbreak in West Africa. The “global” in global health identifies the scope of problem, not the location (Koplan et al., 2009). The U.S. Institute of Medicine (1988) describes public health as “what we, as a society, do collectively to assure the conditions for people to be healthy.” This definition has equal stature in relation to global public health and has particular application to both human rights and ethics.

Human rights instruments more broadly, the right to health specifically, and ethics provide entry points for understanding and outlining underlying systemic and structural social determinants of health that, if addressed, could advance health equity at a global level. Human rights and ethics discourse highlight the conditions necessary for people to be healthy, and the means and considerations necessary to enable these conditions. With human rights paradigms, these conditions also include fundamentals of good or poor governance as well as civil and political liberties, including the right to information and the right to participate in political decision making. The ethics framework insists that issues of equity, autonomy, and benevolence be included as determinants of health programs and paradigms. Underlying the social determinants of health, and considered essential elements necessary to live a healthy life, these sociopolitical and economic forces drive both local and global health inequality and disproportionate burdens of disease and shape the health, legal, institutional, and structural contexts in which they are embedded. They concern the conditions in which individuals are born, grow, live, work, and age and that influence their health status (WHO, 2017).

Just as health threats extend globally, so must the solutions. Increasingly, it has been recognized that there is both a shared global responsibility to realize the right to health and a moral impetus to address health challenges that are universally experienced. Thus, health, ethics, and human rights efforts are, by definition, synergistic. One undertaking cannot be viewed in isolation without a considered reference and integration of the others. While public health endeavors can at times impact on individual human rights and challenge ethical principles and decision making, such as may occur in a global public health crisis, the underlying complementarity of these disciplines has greater prominence than the inherent confrontation between them (Beyrer, 2004).

## ► Setting the Context: Human Rights and Ethical Approaches to Global Health

Both human rights and ethics offer compelling discourses and frameworks to advance global health and ameliorate health disparities and differences that have a global force or reach. At the intersection of global health, human rights, and ethics, a number of consistent themes and challenges emerge. These will be explored throughout the chapter and are briefly outlined here.

First, fundamental human rights and the right to health are interrelated and inseparable. The realization of one right (such as the right to housing) can enable fulfillment and protection of the right to health; conversely, the deprivation of a right (such as the right to participation in civic life) may increase vulnerability to ill health or impair enjoyment of other human rights (Office of the United Nations Commissioner for Human Rights, 2008). Rights abrogation or violation can have measurable impacts on health, such that if an individual or population group experiences discrimination, or a deprivation of their rights, their ability to engage with and benefit from health interventions is diminished (Beyrer, 2004). Although traditionally described as being in conflict, the pursuit of individual human rights and enhanced global health at a population level are increasingly recognized as complementary and interdependent approaches to defining and advancing human well-being. The central premise of securing health for all by targeting marginalized, discriminated-against, and vulnerable populations parallels the sentiment of human rights. Promoting and protecting human rights is inextricably linked with promoting and protecting health.

Ethics, in relation to global health, is both the application of principles and norms for moral guidance and a process for identifying, analyzing, and resolving ethical issues inherent in the practice of public health. Ethics, which has traditionally been considered to exist within the purview of individual behavior and with a bioethical focus, may be recast in the context of public health ethics with broad application to global public health and governance. In turn, global health ethics may be considered a normative project with a common set of principles or values to deal with global health threats (Stapleton et al., 2014).

Second, to stimulate a more considered analysis of health, human rights, and ethics, it is imperative to understand the disproportionate burden imposed by disease and ill health and to appreciate how these

differences influence health outcomes across a range of populations. Health disparities and the social determinants of health are significantly driven by complex structural factors that can contribute to poor health outcomes and adversely affect groups of people who have systematically experienced both a greater burden of ill health and exposure to numerous structural-level social determinants (Jürgens, Csete, Amon, Baral, & Beyrer, 2010; Sollom et al., 2011).

Third (and a related concept), discrimination is often the basis of fundamental structural inequality, such that populations who are marginalized or experience discrimination are more vulnerable to ill health. According to the Office of United Nations High Commission of Human Rights (2008), discrimination refers to any distinction, exclusion, or restriction made on the basis of various grounds that has the effect or purpose of impairing or nullifying the recognition, enjoyment, or exercise of human rights and fundamental freedoms. The implication is that some diseases or health conditions that have a global distribution, such as tuberculosis or leprosy, may singularly affect marginalized populations or be more pronounced in these populations. Marginalization, stigma, and discrimination may be both the cause and the consequence of ill health. In acknowledging the importance of discrimination and marginalization, it must also be noted that some groups—such as women, children, and prisoners, for instance—face an additional risk or vulnerability due to particular circumstance or biological, structural, and social realities (Rubenstein et al., 2016). This vulnerability may be generalized, or it may be specific to certain diseases or interventions.

Fourth, human rights frameworks relate to obligations and duties at the level of the state and, therefore, are dependent on a state-based system of governance. As a signatory to the various human rights covenants, the state has an obligation to respect, protect, and fulfill those covenants in relation to the right to health. Such conventions outline the requirement of states to refrain from interfering in rights, to protect rights from demands of nonstate actors (such as armed groups and private corporations), and to take positive measures to facilitate and enable rights such as provision of immunization, training of health professionals, access to justice, access to sanitation and clean water, and other essential functions within a national health system.

How do ethical principles and human rights obligations and duties apply to states, and are they enforceable? And if the state is the primary custodian in enacting the right to health for populations within its jurisdiction, who should be made responsible and

accountable for global health issues that fall outside state boundaries? Global health issues that transcend the boundary of the state require a coherent and coordinated response through public health activities such as epidemic preparedness, surveillance, health system research, treatment access, and immunization (**EXHIBIT 3-1**). This role and function in relation to global health issues is taken up by a multitude of actors and stakeholders, including nongovernmental organizations, private agencies, and businesses, each of which has its own mandates, motivations, and scope, and each of which also engages in the provision of health at a global level (see also Gostin & Mok, 2009). It should not be assumed that all actors are acting with the similar intent or understand the right to health in the same way. Determining which health challenges should be elevated to a global level of governance is an ongoing debate. Indeed, one of the ongoing challenges to global health is the need to strengthen claims to the right to health and support universality of the right to health (Gable & Meier, 2013).

Friedman and Gostin (2015) discuss the notion that global health—in this case, referring to public health, universal health coverage, and the social determinants of health—cannot be achieved without concurrent advancement of justice and global health equity. This development would lead to gains in both the aggregate level of health and the distribution of health across populations. The World Health Organization, under the leadership of Tedros Ghebreyesus of Ethiopia, has committed to universal health coverage (UHC) as the primary means of achieving the goal of global equity in healthcare access. However, others propose that improvements in health markers, such as prevalence, mortality, and morbidity, do not necessarily translate directly into improvements in health equity and justice (see, for example, Braveman & Gottlieb, 2014). Some would argue that even though war, crime, hunger, poverty, illiteracy, homelessness, and related human rights abuses interfere with the health of individuals and populations, it does not mean that eliminating these conditions is part of the mission of public health (Rothstein, 2002).

States have a shared responsibility for supporting conditions in which their populations can be healthy, including the implementation of preventive health strategies, health equity, and universal health coverage under a mandate of health for all (see also Friedman & Gostin, 2015). Incorporating the right to health, global health governance provides the institutional, financial, and legal mandates and mechanisms necessary to meet core global health challenges and risks that transcend boundaries in their origin and impact. Global health governance is an appeal to collective

**EXHIBIT 3-1** Ebola, Ethics and Human Rights

The most recent Ebola outbreak, which occurred between 2013 and 2016, exposed in a very specific way the limitations of the global effort—namely, the inequalities in global power structures, the responsiveness of global health governance (see chapter on *Global Health Governance and Diplomacy* for more on strengthening global health governance after the 2013–2016 Ebola outbreak), and the limited epidemiologic information available early on—allowed the virus to flourish uncharted and undetected for up to three months. The sociopolitical realities of containing a highly pathogenic virus were laid bare. The fragility of the region, following years of conflict and instability, was evident in the weakened and dysfunctional public health governance and infrastructure, debilitated and impoverished institutions, and diverted resources, which contributed to a lack of capacity and preparedness. Local cultural practices, which included traditional burial rituals of hand-washing the body, and a highly mobile and interconnected population moving across arbitrary state boundaries allowed unhindered transmission of the virus (Richardson, 2016). It was the perfect milieu fomenting contagion, lethality, stigma, and neglect (Donnelley, 2014; see also Farmer, 2014). That so many health workers, community members, and graveyard workers were nevertheless willing to risk their lives to care for Ebola-infected patients, the many thousands of exposed persons, and those who died of Ebola complications is a tribute to the extraordinary dedication and humanity of these persons. This example reminds us all that the greatest human rights and ethical imperative remains to care for the sick, even when doing so may put us in harm's way.

The effects of the Ebola epidemic on global health structures, public health ethics, and human rights were far-reaching. First, the outbreak raised questions about who has responsibility to protect populations from public health emergencies (see also Calain & Poncin, 2015). The state must fulfill its duties and fundamental obligations to enable its population's enjoyment of the highest attainable standard of health. Revisions made to WHO's International Health Regulations (IHR) in the wake of the severe acute respiratory syndrome (SARS) outbreak required states to institute minimum core public health standards, including public health surveillance, laboratory capacity, and epidemic preparedness. However, the Ebola outbreak exposed the world's vulnerabilities due to the impoverished health systems in a small region of West Africa, decimating and overwhelming these already fragile systems that were unable, despite significant efforts, to meet their populations' most basic health needs (Gostin & Ayala, 2017). The moral impetus to protect and respond must therefore account for the deeply disproportionate impact that an outbreak has on the most marginalized and vulnerable in the event that the national government is incapacitated and unable to ensure health security for its own population.

The Ebola response was also a teaching moment regarding the weakness of global health governance, most compellingly seen in the failure of the World Health Organization to mount an effective response (see, for example, Sands, Mundaca-Shah, & Dzau, 2016). Without the intervention of nongovernmental groups, most notably *Medecins Sans Frontieres*, the loss of life would have been much greater. Eventually, the international community did mobilize resources, but the prominent role assumed by military medicine practitioners, notably from the United States, again exposed the weaknesses in civilian capacity to respond. While military engagement in large-scale disasters and epidemics is often essential, the delegation of humanitarian and public health responses to military and other security forces raises additional human rights and ethical challenges, including concerns from the host countries that public health responses led by military actors can be cover for other—more specifically, military or security—objectives. The U.S. Central Intelligence Agency's use of polio immunization as a cover for investigating the whereabouts of Osama Bin Laden in Pakistan is the most unfortunate example of this kind of abuse: It continues to bedevil polio eradication efforts in Pakistan and Afghanistan, and has led to the targeted killing of many immunization staff, mostly women ("Editorial," 2014).

effort, with engagement of state actors and nonstate actors alike, in pursuit of a collective outcome (see also Dodgson, Lee, & Drager, 2002).

The final point relates to priority setting. Priority setting raises ethical concerns of fairness, justice, and equity. Moreover, when it is applied to particular global health challenges, context-specific concerns inevitably emerge regarding how finite resources may be allocated in a fair and equitable manner. Priority setting will be informed by such considerations as infrastructural capacity, urgency, social value, governance, and financing. Ethics can guide

approaches when a conflict arises between competing values or needs. In the case of a global health crisis, for example, it may be more readily apparent how goods should be prioritized and who should be the primary beneficiary. Resources may be reallocated or reprioritized as a means of containment to protect the affected and the most vulnerable, and this may prevent unaffected populations from maintaining their health needs. In contrast, the best decisions may be less obvious when setting priorities in the provision of non-emergent healthcare strategies, such as obesity or smoking.



## ► Global Health and Human Rights

All human beings are born free and equal in dignity and rights. (Article 1, Universal Declaration of Human Rights [UDHR])

Human rights pertain to the fundamental freedoms, inherent value, and dignity of all human beings. These rights are universal, inalienable, and indivisible. They confer both freedoms and entitlements. The improvement of one right facilitates advancement of others, and similarly the deprivation of one right adversely affects the others. Human rights are independent of nationality, place of residence, gender, religion, race, or any other status (United Nations, 1948).

The founding document of the modern human rights movement, the Universal Declaration of Human Rights (1948), Article 25 (1), provides the minimum standards necessary to ensure adequate health and lays out the duties and obligations of the state for upholding the rights of individuals. The UDHR is not legally binding, but states have bestowed it with great legitimacy through their actions, including its legal and political invocation at the national and international levels. Health is mentioned once in the UDHR, within the context of an overall right to an adequate standard of living:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (United Nations, 1948)

Under international human rights, sovereign states have an obligation to recognize the rights of individuals who reside within their borders.

Subsequent treaties and covenants give further articulation of the rights related to health (**EXHIBIT 3-2**). Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) of 1966, in particular, establishes the right to health. It has a significant focus on what was then called international health and would now be called global health, in the three of its four specific provisions (a, b, and c below):

1. The States Parties to the Present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
  - a. The provision for the reduction of the stillbirth rate and of infant mortality and for the health development of the child
  - b. The improvement of all aspects of environmental and industrial hygiene
  - c. The prevention, treatment, and control of epidemic, endemic, occupational, and other diseases
  - d. The creation of conditions which would assure access to all medical services and medical attention in event of sickness

## ► Interpreting the Right to Health

In 2000, the committee on ICESCR issued a guideline that provides more substantive details on Article 12, the right to health. General Comment 14 on the right to health notes that health is a fundamental human right indispensable for the exercise of other human rights (Office of the High Commissioner for Human Rights, 2000). General Comment 14 proposes

### EXHIBIT 3-2 International Human Rights Instruments Recognizing the Right to Health

- The 1965 International Convention on the Elimination of All Forms of Racial Discrimination: Article 5 (e) (iv)
- The 1966 International Covenant on Economic, Social, and Cultural Rights: Article 12
- The 1979 Convention on the Elimination of All Forms of Discrimination Against Women: Articles 11(1)(f), 12, and 14(2)(b)
- The 1989 Convention on the Rights of the Child: Article 24
- The 1990 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families: Articles 28, 43(e), and 45(c)
- The 2006 Convention on the Rights of Persons with Disabilities: Article 25

that the right to health does not equate to the right to be healthy, but rather is an inherent, inalienable right to the highest attainable right that must be progressively realized through available, accessible, and affordable health care, services, and conditions. Realization of the right to health is more than the absence of disease. Indeed, it implies consideration of the conditions necessary for the realization of the highest attainable standard of health. In addressing these issues, General Comment 14 suggests that achieving this goal must take into account the “individual’s biological and socio-economic preconditions and a state’s available resources” (Office of the High Commissioner for Human Rights, 2000). This provision gives focus to the relationship between the state and the individual by asserting that the state cannot, by itself, guarantee good health, just as it cannot protect against all aspects of ill health (Office of the High Commissioner for Human Rights, 2000).

Additionally, General Comment 14 states that the right to health is interpreted as an inclusive right. Specifically, it extends “not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, health occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health” (Office of the High Commissioner for Human Rights, 2000).

## ► The Challenge in Meeting the Right to Health

Under international human rights law, a “right” is put forward as a claim to those social arrangements—norms, institutions, laws, and enabling environment—that can best secure the enjoyment of this right (WHO, 2002). The legal integrity of human rights analysis, as much as its moral appeal, is what gives the human rights movement its authority and force. Under international treaty law, states assume obligations and duties to respect, protect, and fulfill human rights, including the right to health. Violation of this right implies that the obligation and duties have not been met or fulfilled (Cohen, Kass, & Beyrer, 2007).

The rights-based approach to health includes consideration of the underlying determinants to good health such as water, housing, education, and food. Thus, the right to health includes the minimum core services, such as maternal–child health and primary health care, that governments must provide, even in places of scarce resources. While other rights may encapsulate the

essence of a right to health, the challenge remains as to how the right to health may be fulfilled and measured. It is for this reason that some proponents believe a more constrained interpretation of the right to health allows for a more meaningful and representative invocation of this right (Tasioulas & Vayena, 2015).

As part of the application of human rights principles to global public health challenges, public health strategies, such as prevention and treatment programs, must not infringe upon the human rights of those whom they are intended to benefit (**EXHIBIT 3-3**). Similarly, rights-based approaches must ensure that all individuals, and particularly those who experience greater marginalization, stigma, and discrimination, enjoy equal access to services. All too often, however, discrimination and other human rights issues have been both a consequence of global health challenges and a societal cause of vulnerability to these conditions (Mann, 1997).

At least two misconceptions about human rights tend to complicate their application. The first is that often global health challenges are perceived as being part of the realm of “economic, social, and cultural rights” (such as the right to health care) as opposed to “civil and political rights,” such as the right to free expression, association, and due process of law. In fact, many of the violations of human rights that most increase risk—imprisonment without due process, censorship of health information, and violence and discrimination against women as articulated in the International Covenant on Civil and Political Rights (United Nations, 1966) and most national constitutions—have direct public health implications (Beyrer, 2007b). The fact that these rights abuses worsen health outcomes underscores what has been called the “indivisibility” of human rights norms—the notion that civil and political rights and economic, social, and cultural rights are mutually reinforcing and derive from a single principle, the concept of fundamental human dignity.

A second, related misconception is that human rights impose undue constraints on state sovereignty and restrict the legislative branch of government in its efforts to give effect to the “will of the people” (usually the majority) and/or enact effective public health policy. In fact, human rights guarantees are almost always embodied in constitutions or international treaties that have been ratified by national legislatures, and are enforced by judges who are either elected or appointed by elected officials. Moreover, human rights guarantees can come with certain limitations, as long as these limitations can be shown to be necessary and proportionate to a legitimate policy objective. Human rights analysis involves identifying the rights infringement in question (usually by reference to a specific legal guarantee), and then balancing that infringement against

### EXHIBIT 3-3 Zika, Human Rights, and Ethics

The most recent Zika virus outbreak, declared a Public Health Emergency of International Concern in February 2016, and its disproportionate concentration on women of childbearing age, is an example of systemic injustice and inequality in global health. Although many of the clinical manifestations and health sequelae of Zika infection are not all known, the recent outbreak highlights a global health problem with contemporaneous individual-, community-, and country-level dimensions and ineluctable social and ethical impacts.

Acquisition of Zika during the antenatal period has been associated with miscarriage, stillbirth, and neurologic malformations including congenital microcephaly. Infection may occur at any stage of pregnancy, raising a particular challenge for intervention and prevention. Evidence that the Zika virus may also be transmitted sexually has significant implications for women who live in a region with some of the most restrictive sexual and reproductive laws,<sup>1</sup> where approximately 56% of pregnancies are unplanned and gender-based violence is pervasive (Guttmacher Institute, 2017; Roa, 2016).

In the most affected region of Latin America, it is estimated that 23 million women have an unmet need for contraception and account for 75% of unintended pregnancies (Guttmacher Institute, 2017). As many as 95% of pregnancy terminations are performed in unsafe conditions, and a number of countries (including El Salvador, Chile, and Dominican Republic) criminalize abortion under any circumstance. In other countries, abortion may be allowable only in cases of rape or in the event of a significant risk to the mother's life but not in the event of fetal congenital anomalies, including those resulting from Zika infection. In these cases, some women have been legally compelled to carry a pregnancy of a possibly fatal fetal anomaly to full term.

Women living in marginalized and poor communities in Brazil and elsewhere faced the greatest disproportionate burden and deprivation of basic protections and rights and their ability to exercise reproductive autonomy (see also Rasanatham, MacCarthy, Diniz, Torreele, & Gruskin, 2017).<sup>2</sup> Discrimination, economic inequality, and poverty entrench both the risks and impacts of Zika (Phelan & Gostin, 2016).

In response to the outbreak, governments in the region recommended women of childbearing age postpone pregnancy, but few provisions or pathways to avoid an unintended pregnancy were made available, shifting the burden from the domain of the public to the individual. Restrictions on access to contraception, including emergency contraception, safe termination, and post-abortion care, predominated.

Questions have emerged in cases regarding whether the intrusion of the state in the life and decisions of a woman is justifiable and proportional. Is the global public health threat of Zika severe enough to limit sexual and reproductive rights and freedoms? Conversely, is the threat of Zika-associated fetal anomalies sufficient to change existing restrictive laws and policies? There is a moral imperative to create conditions that allow women to decide freely and responsibly on the number, spacing, and timing of their children. Similarly, there is an ethical obligation to ensure equitable access to contraceptive options and safe reproductive services, as well as a duty to minimize harms associated with a Zika-affected pregnancy. However, as the case of Zika succinctly illustrates, to achieve the most optimal outcome, employing ethical principles requires a balancing of interests and context.

1 International human rights documents pertaining to women's reproductive health rights include the International Covenant on Economic, Social, and Cultural Rights [right to health, Article 12; right to nondiscrimination based on sex, Articles 2(2) and 3; right to special protection for mothers and their children, Article 10] and the Convention on the Elimination of All Forms of Discrimination Against Women (women's right to nondiscrimination within law, Articles 2 and 3; right to health, Article 12; and right to reproductive self-determination, Article 16).

2 Laid out by the Committee on Economic, Social, and Cultural Rights, the right to sexual and reproductive health includes both freedoms and entitlements, including the freedom to make free and responsible decision and choices, free of violence, coercion, and discrimination, over matters concerning one's body and sexual and reproductive health (Diniz, 2016).

competing policy objectives. Most importantly, perhaps, human rights aim to give voice to minorities who may be marginalized or disenfranchised by the democratic process (Decker et al., 2015).

## ► Rights-Based Approach to Global Health

Social justice and the protection of human rights do not ensure good health—free people

can make poor choices, and affluence carries its own burdens of morbidity and mortality. But social justice and limitations on basic rights and freedoms, on human dignity itself, can have direct and indirect effects on the health of individuals, communities, and populations. (Beyrer, 2007a)

Jonathan Mann, a public health physician, was an early proponent of the integration of medicine, public health, ethics, and human rights (Gostin, 2001). He believed that health and human rights were indistinguishable.

Human rights violations lead to adverse health events and, therefore, have measurable impacts on physical and mental well-being (Gostin, 2001). Similarly, framing health disparities as a violation of human rights facilitates a more useful interpretation and implementation of the human rights instruments. The progressive realization of the right to health at a global level gives emphasis to the shared responsibility and obligations of the global community.

Mann's legacy has grown and expanded since his tragic early death in 1998. The field of health and human rights, and of public health or global health and rights, has made critical contributions to our understanding of health inequalities, disparities, and the social and structural determinants of health that have proved so challenging to address through technological or biomedical advances alone.

## ► Global Health and Public Health Ethics

Public health ethics uses ethics principles and norms to identify, analyze, and resolve moral challenges in public health. As described earlier, when public health ethics focuses its lens on global public health challenges, it might be examining issues that extend beyond the boundaries of the state, such as pandemics, or global issues that recur within territories' or countries' own borders.

Public health ethics has largely concentrated its attention around two main areas: (1) balancing individual liberties with the ethical duty to improve the welfare of the public and the needs of many and (2) the moral duty to improve social justice as a means of improving the public's health. As such, public health ethics is concerned with the pursuit of equity in health, which then guides the approach taken to remedy the inherently unjust health inequalities. Further, public health ethics seeks to determine how to best balance the needs of a population as a whole and the liberties and rights of the individuals who make up those populations. An oft-cited example is the case in which the state executes its agency through a public health intervention to restrict individual choice, privacy, or freedom of movement in an effort to prevent or contain disease as a means to protect others in the community or to limit suffering.

The greater the burden imposed by a public health intervention or program (e.g., limitations on individual liberties), the stronger the evidence must be to demonstrate that it will achieve its goals (Kass, 2001). Hence, a restriction of liberty must be justified

and proportionate to the perceived or known threat. Public health goals of producing benefits, preventing harms, and generating utility may outweigh or override moral considerations of individual liberty and justice when certain justificatory conditions of effectiveness, necessity, least infringement, and proportionality are met (Childress, Faden, Gaare, & Gostin, 2002). In instances when the benefits and burden are uneven, the expected benefit must be even greater (Kass, 2001).

Public health ethics is somewhat distinct from medical ethics. The latter has notably deeper historical roots. Medical ethics provides a set of principles to help guide physicians through moral challenges in the practice of medicine, including those that may arise between physician and patient. Tom Beauchamp and James Childress (2013) have outlined four ethical principles to guide medicine:

1. *Principle of respect for autonomy*—that is, values and loyalties are determined freely and voluntarily without coercion (e.g., informed consent).
2. *Principle of nonmaleficence*, which implies minimization of harm or injury.
3. *Principle of beneficence*, which refers to doing good by acting with the best interest of the other in mind. It implies a duty to balance benefits and harms and ensuring that benefits outweigh harms.
4. *Principle of justice*, which concerns fairness and distribution of common goods fairly. Thus, when goods or resources are limited, a means for fair distribution must be determined such that “those persons who are equal should qualify for equal treatment.”

These principles are intended as nonhierarchical, such that no one principle is superior to another and each principle is considered *prima facie*.

While many frameworks for medical ethics have been put forward, frameworks for the ethics of *public health* work are a more recent contribution. While the foundations of both public health and medical ethics are similar, they also differ in some critical ways. Most notably, while both require the provision of benefit and the minimization of harm, public health targets this requirement to communities as a whole, and measures benefit the entire society. Medical ethics, by contrast, is more likely to focus exclusively on the well-being of individuals. Furthermore, public health is afforded legal authority in many environments to ensure that the *public's* health is improved and/or not threatened and, at times, can use invasive measures, as needed,



ranging from medical isolation and quarantine to mandatory hospitalization, as seen in multiresistant tuberculosis and extensively drug-resistant tuberculosis (XDR-TB), to secure that goal. Public health ethics, then, provides a framework for balancing the important and core value of public or societal benefit with restraint to ensure that individual rights and values are neither ignored nor compromised whenever possible. Public health ethics also puts emphasis on justice and equity, both as predictors of good public health outcomes and as a moral good for their own sake.

Public health ethics shares many core values with human rights but, again, is different in some critical ways. Public health ethics, at its core, is concerned with ensuring that public health interventions provide benefits and minimize harms; that they respect individuals' dignity and rights to the greatest extent possible; and that they are implemented fairly and, to a great degree, serve to increase equity. These values are completely consistent with those of human rights covenants and paradigms. Unlike human rights, however, ethics is not founded in law. While ethical norms may contribute the rationale for many laws, ethics itself has no legal standing, and "moral rightness" is not legally enforceable.

Appealing to ethics in crafting and implementing public health interventions nonetheless is critical for three reasons. First, engaging in morally right action is important in and of itself. That interactions, including interactions related to public health, ought to be implemented consistent with the highest ethical standards is itself an important end. Civil societies, by definition, are bounded by shared moral norms and practices (as well as by more formal laws and regulations), and those who are in leadership positions should uphold them.

Second, professional ethics requires a commitment to engaging *in one's work* in ways that are consistent with high ethical standards. Most of the established health professions, including medicine and nursing, have longstanding codes of professional ethics; public health more recently adopted its own code of ethics for public health professionals. Such professional codes help to self-regulate a profession (**EXHIBIT 3-4**). Acting in accordance with moral norms and codes is important to the integrity and trustworthiness of the professionals who practice public health and doing so also serves to instill trust in the profession on the part of the public.

### EXHIBIT 3-4 Global Health, Ethics, and Research

Health research in low- and middle-income countries (LMICs), in pursuit of global health outcomes, raises complex ethical challenges. Research in such countries is vital to advancing knowledge on preventable disease, infectious disease epidemics, and treatments that have a global reach. However, ethical guidelines and regulations may be vastly inconsistent across different country settings due to limitations of capacity and infrastructure. Maintaining sound ethical guidelines in these settings is considered critical to safeguard against potential exploitation of research participants.

Amon et al. (2012) highlight the challenges that arise when investigating human rights violations as determinants of, or structural barriers to, health, and in particular when engaging with marginalized, stigmatized, and criminalized populations, especially when they face a disproportionate burden of ill health as a result of their social status. Amon et al. relate the experience of agency in health-based research in more repressive countries where a research ethics committee functions as an agent of the state, protecting state interests rather than legitimately representing, or protecting, the interests of vulnerable groups and research participants. This kind of environment can prevent health researchers from investigating health outcomes associated with state actors, government laws and policies, and social and cultural norms.

Other issues relate to consent in emergency settings and access to data, interventions, and treatments for the target population when research is complete. An example of the latter arose during HIV perinatal trials in the late 1990s when more inferior interventions, compared to the standard best available treatment, were employed (Ijsselmuiden, Kass, Sewankambo, & Lavery, 2010). In this case, debate arose over whether use of an inferior regimen, considered more logistically or economically feasible to distribute and contributing to overall public health gains in a resource-constrained setting, should have precedence over the gold-standard intervention even though it would reach fewer people (Ijsselmuiden et al., 2010).

Further examination of this trend was undertaken in a report by the Commission on Health Research for Development, which describes the vast differential between global health needs and global health research. In what is referred to as the 10/90 gap, less than 10% of global resources targeting global health research are allocated to health in low-income countries, which account for more than 90% of the global burden of preventable deaths, included neglected diseases such as Chagas disease, leishmaniasis, and human African trypanosomiasis. Conflict and political or social instability can also have profound effects on health interventions and epidemiologic surveillance efforts through disruption of health data collection and information systems, compromising the quality and sampling of core data.

(continues)

**EXHIBIT 3-4** Global Health, Ethics, and Research*(continued)*

The Nuremberg Code formalized the ethical standards and principles for the conduct of medical ethics, particularly in research involving human participants. Formulated in 1947 in Nuremberg, Germany, following revelation of the murderous and tortuous conduct of Nazi doctors in World War II concentration camps, it serves as a blueprint for the rights of subjects in medical research (Shuster, 1997). The Nuremberg Code delineates core principles critical to clinical research, which are also broadly applicable to nonresearch contexts. These principles include informed voluntary consent given freely, without coercion, duress, or force, as well as the right for withdrawal, thereby extending the ethic to “first, do no harm” and protecting the rights of the individual. Article 7 of the International Covenant on Civil and Political Rights (United Nations, 1966) articulates this requirement by stating: “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected with his free consent to medical or scientific experimentation.”

A second foundational document concerning ethics is the Declaration of Helsinki. Introduced in 1964 and revised in 1975 by the World Medical Association, it outlines standards and protocols of research, including the requirement that the proposed research be reviewed by an independent research ethics committee. In 1979, the U.S. Department of Health and Human Services’ Belmont Report provided further moral guidance by reiterating principles of respect for persons, beneficence, and justice as part of conduct of research using human subjects. These significant contributions continue to govern approaches to medical ethics and health research in humans. Research ethics committees are considered a widely accepted and fundamental component of conducting health-based research involving systematic collection of data and analysis of data on humans.

Third, as a means to an end, good ethics makes good public health sense. Ethics asks public health to ensure programs will be beneficial before imposing them on the public. It requires that individuals and communities be treated with dignity, and it requires that *all* communities receive appropriate public health interventions, not just those with more privilege or influence. Upholding these moral norms is relevant not just for their own sake: They make obvious sense for public health. Such principles help to ensure that more people get health benefit and that the “targets” of public health programs will better trust that such programs are initiated to further their own interests rather than to further some arbitrary goal on behalf of the state’s leaders. Promotion of health equity has been shown through countless studies to improve the public’s health. And where public health actions *do* need to infringe on civil liberties, such as in enforcing immunization requirements for public schools, it is critically important that targeted populations perceive that these programs are fair, that they are based in sound science, and that the privileged (by resources or power) are not exempted from the programs (Beyrer, 2004).

Several approaches to considering ethics in public health proposals have been put forward. One six-step approach is offered here (Kass, 2001).

*Step 1. What are the public health goals for the proposed intervention, policy, or program?* These goals generally should be expressed in terms of public health improvement, such as the degree to which the program will reduce morbidity or mortality. For example, a human immunodeficiency virus (HIV) screening program should have as its ultimate goal that fewer

incident cases of HIV will occur, rather than that a certain proportion of individuals will agree to be tested.

Also relevant when considering public health goals and benefits is to whom the benefit will accrue. Public health interventions often are targeted to one set of individuals so as to protect *other* citizens’ health. For example, partner notification programs and directly observed therapy for tuberculosis are designed, primarily, to protect citizens from the health threats posed by others. Restricting someone’s liberty to protect that person—generally framed as paternalism—poses different ethical burdens than restricting liberty to protect the interests of others.

*Step 2. How effective is the intervention or proposed program at achieving its stated goals?* Proposed interventions or programs are based on certain assumptions that lead us to believe the programs will achieve their stated goals. Step 2 asks us whether actual *data* exist to support these assumptions. In general, the greater the burdens posed by a program—for example, in terms of cost, constraints on liberty, or targeting particular, already vulnerable segments of the population—the stronger the evidence must be to demonstrate program effectiveness. Indeed, because many public health programs are imposed on people by governments and not sought out by those targeted by the programs, the burden of proof lies with governments or public health practitioners to prove that a program will achieve its goals. If there are no good data to demonstrate program effectiveness, the analysis can stop right here, and, ethically, the program should not be implemented. Conversely, the presence of good data alone does not justify the program; it

simply allows public health practitioners to move to the next stage of the analysis.

*Step 3. What are the known or potential burdens of the program?* If data suggest that a program is reasonably likely to achieve its stated goals, the potential burdens or harms that could result from the public health work must be identified. The majority of such harms will fall into four broad categories: (1) risks to privacy and confidentiality, especially in data collection activities; (2) risks to liberty and self-determination, given the power accorded public health to enact almost any measure necessary to contain disease; (3) risks to health, if public health interventions carry some risk to the individuals affected; and (4) risks to justice, if public health practitioners propose targeting public health interventions only to certain groups. Data collection may not simply be viewed as a violation of personal privacy to individuals; breach of confidentiality of such data—deliberate or incidental—can lead to significant and tangible harms. Personal health information, such as that related to HIV status or sexual orientation and/or gender identity, can be dangerous in certain settings, if obtained by authorities and/or social acquaintances; even seemingly benign data such as vital statistics can reveal patterns about ethnic groups or neighborhoods that could lead to stigma, discrimination, violence, and/or forced relocation of identifiable groups.

Health education generally is thought of as the ideal public health intervention because it is completely voluntary and seeks to empower individuals to make their own decisions regarding their health. Unfortunately, education may not be effective in all settings. When it fails to meet the state's expectations, policy makers may feel the need to resort to more restrictive measures.

Regulations and legislation, strictly speaking, are coercive, since they impose penalties for non-compliance. As such, they pose risks to liberty and self-governance. While many such measures (e.g., mandatory immunizations) have demonstrated efficacy, they nonetheless are the most intrusive approach to public health. Certain mandated interventions, such as immunization or mass deworming campaigns, are implemented only when the population benefit is considerably larger than the risk to individuals, yet ethics tensions remain when even very small risks are created for healthy individuals because of public health campaigns. Further, the law can impose threats to justice if regulations pose an undue burden on particular segments of society, and the law can be designed in ways to reduce inequalities as well.

*Step 4. How can burdens be minimized? Is the least burdensome approach being implemented?* Once burdens have been identified, ethics requires programs to be modified in ways that minimize burdens

without greatly reducing efficacy. If disease surveillance is equally effective with unique identifiers as with names, if voluntary programs yield almost identical cooperation and effectiveness as mandatory ones, or if individuals can be informed in advance about why interventions are being introduced, then these “burden-reducing” approaches should be taken.

*Step 5. Is the program implemented fairly?* Consistent with the principle of distributive justice, there must be a fair distribution of benefits and burdens in public health programs. Public health benefits such as clean water cannot be limited to one community alone, and equitable treatment is similarly required when restrictive measures are proposed. Injustice is wrong not just for its own sake, but for the material harms that can follow. This does not mean that programs or resources must be allocated equally or identically to all communities; rather, allocations must be *fair*. That is, differences cannot be proposed arbitrarily or based on historical assumptions about who might be at risk or who is more responsible. Instead, targeting of programs to one community and not another must be justified with strong attention to data. Moreover, the social consequences must be considered when targeting of programs occurs, and balanced against the benefits to that community or others. Also central is the role that public health can play in righting existing injustices, especially given the strong link between social inequities and poor health outcomes (Starfield, 2005). Several conceptions of justice allow and even require unequal allocation of benefits to remedy existing inequities (Daniels, 1985; Rawls, 1971).

*Step 6. How can the public health benefits and the accompanying burdens be balanced?* Even to the extent that public health professionals aim to follow the previously described requirements, disagreements invariably will emerge over interpretation—which types of freedoms must prevail, which types of burdens are acceptable, and which types of targeting are unjustified? Procedural justice, then, requires fair procedures to determine which public health interventions, in the end, should go forward. This process will require communities to discuss what is gained from good public health, and why such benefits often must be organized collectively. Dissent around proposed programs or interventions deserves special attention if raised by an identified subgroup, such as an ethnic minority, particular age group, or residents of a particular region. In general, the greater the burden imposed by a program, the greater must be the expected public health benefit. Likewise, the more uneven the benefits and burdens—that is, when one group is burdened to protect the health of others—the former must be both the scientific justification and the expected benefit.

## ► Case Studies in Global Health, Human Rights, and Ethics

### Obesity and Taxation on Sugar-Sweetened Beverages

Obesity and its associated conditions represent an epidemic of global proportions that does not discriminate by gender or socioeconomic status. While the rate of obesity is increasing globally, the absolute rates of its occurrence are higher with low income and low education. Most of the world's population now lives in countries where there are more deaths attributable to being overweight than underweight (Basu, McKee, Galea, & Stuckler, 2013; see also Development Initiatives, 2017).

The etiology of obesity is complex, with this condition resulting from an interplay of genetic, biological, environmental, sociopolitical, and behavioral factors (Malik, Pan, Willet, & Hu, 2013). Yet the rapid change in obesity rates globally suggests that the primary factors are environmental and behavioral rather than due to genetics, as the human genome could not have changed so rapidly. Traditional obesity prevention strategies, which have targeted individual behavior change, have yielded limited success. In more recent years, there has been growing interest in taking more of a public health approach to obesity, by intervening in the food environments in which people make their food consumption choices. Interventions related to the food environment can include changes in the production, availability, regulation, cost, and marketing of food and beverages.

One component of diet significantly implicated in the overweight and obesity epidemic globally is the high intake of dietary free sugars and, more specifically, the consumption of sugar-sweetened beverages (SSBs) (Brownell et al., 2009; Colagiuri, 2017). In the United States, for example, SSBs are the single largest contributor to adults' and children's daily caloric intake (Bleich, Wang, Wang, & Gortmaker, 2009), and increased consumption of SSBs has been associated with increased prevalence of obesity, cardiovascular disease, and diabetes (Brownell et al., 2009; Malik et al., 2013; Schulze et al., 2004; Te Morenga, Mallard, & Mann, 2013). In the United States, consumption of energy-dense foods in the form of sugary beverages accounts for almost half of the total daily intake of added sugar (Malik et al., 2013; see also Colagiuri, 2017). It has been estimated that 8.5 million disability-adjusted life years (DALYs) are related to SSB intake. The proportional mortality due

to SSBs is highest among younger adults, with this factor contributing to more than 1 in 10 of all diabetes- and obesity-related deaths in nearly every region of the world; in Mexico, 30% of deaths in those younger than age 45 years are attributed to SSB consumption (Singh et al., 2015). Restriction or elimination of sugary beverages has been associated with positive changes in body weight. Sugar-sweetened beverages are less satiating, have a high-caloric load, and are nutritionally deplete.

There is also compelling recent evidence that the food industry colluded with scientists in the 1960s and 1970s, when evidence began to appear on the harmful effects of sugar consumption, to focus on the purported harmful effects of dietary fat, rather than sugar (O'Connor, 2016). In a situation strikingly reminiscent of the tobacco industry's tactics, the sugar, corn-producing, and soft drink industries sought to avoid regulation of their products even as evidence of their harms emerged (Kearns, Schmidt, & Glantz, 2016). For example, industry-supported scientists at Harvard University, in a 1965 paper in the *New England Journal of Medicine*, deliberately underplayed the role of sugar in coronary artery disease, instead focusing their attention on the harms associated with fat and cholesterol (Kearns et al., 2016).

Public health efforts targeting obesity have traditionally relied on health education about good nutrition (including, for example, requirements for food labeling and public awareness of the “food pyramid” or “food plate”); individual-oriented strategies are underscored by the fact that the diet industry is a \$60 billion business in the United States (Kass, Hecht, Paul, & Birnbach, 2014). In proposing public policy related to the food environment—whether related to marketing, pricing, taxation, or other influences—one must consider the ethical ramifications of alternative approaches and then choose the strategy that will yield the desired results while simultaneously posing the fewest threats to other ethically important values (Kass et al., 2014).

An ethics analysis of alternative policy options must first start by determining what the public health goal of a proposed policy is—for example, to decrease population obesity, rather than to reduce SSB consumption, which might simply lead to substitution with an equally harmful beverage. Second, one must determine how much evidence there is that the proposed policy will actually result in the intended public health benefit. Third, public health programs should constrain liberties as little as possible, and minimize the risk of other important harms or burdens. The fourth requirement is a justice consideration, requiring



interventions to avoid disproportionately burdening a particular population without important justification and to aim to, at least in part, reduce disparities in the population. Fifth, the introduction of a policy must follow fair procedures and should be accompanied by accountability measures. Finally, the symbolic relevance of public institutions must be preserved.

One public health intervention that has garnered particular attention as a response to the burgeoning obesity epidemic is taxation of SSBs—an approach that has been implemented in several cities in the United States and also in Mexico. Taxation is a form of public policy that allows governments to exert mild influence over products or practices they wish to encourage or discourage. For example, some jurisdictions have chosen to allow cigarettes and alcohol to remain completely legal, but have imposed higher levels of tax than the typical sales tax to provide a disincentive for their purchase (Kass et al., 2014).

One of the main ethical critiques of the SSB tax has been a liberty-based one: This view states that taxation is government overreach, and that individuals should be able to consume what they want and make their own choices. A second critique is a justice-based one, rightly citing that sales taxes are regressive, meaning that the impact on lower-income individuals is proportionally higher if they choose to buy SSBs than it is on wealthier individuals.

An ethics analysis would go deeper than these arguments, asking whether progressive taxation is required for products where there is not a government (public health) interest in ensuring access, and then asking which types of liberties governments are required to preserve. Most central to the answer would be the fundamental human rights—rights to freedom of religion, press, whom to love, and speech are most essential for governments to preserve. Claiming that there is a “liberty interest” in being able to buy and consume unhealthy products is not entirely irrelevant—the ability to pursue pleasurable activities is certainly important—but when the liberty is so deeply distant from the fundamental rights and liberties that must be preserved, more room for compromise is absolutely allowable. Indeed, the ability to still allow free access to SSBs while simply providing a financial disincentive for their purchase, similar to that instituted in many regions for cigarettes, is increasingly being viewed as both an ethically acceptable strategy and one with public policy acceptability.

While these critiques are important, an ethics analysis must go beyond claiming that there is a liberty infringement in taxing SSBs. Although a central responsibility of government is to protect foundational

liberties from unwarranted intervention, it does not necessarily follow that fundamental liberties are threatened when public policy discourages consumption of unhealthy products or prohibits government spending on them (Kass et al., 2014). Also, and less often discussed in the context of liberty and taxation, too little state intervention in improving population health can violate individuals’ right, just as too much can (Wilson, 2016). Limitations on health can threaten individuals’ ability to pursue their life course and independent priorities. While SSBs remain widely available on the market, the intent of a tax is to act as a disincentive, rather than to prohibit their use outright. The personal pleasure to be derived from consumption of SSBs is absolutely worthy of consideration, yet such pleasure does not rise to the level of a fundamental freedom (Kass et al., 2014).

Invoking the right to health, and the concomitant obligations laid out in human rights frameworks, brings the protective function of the state and its role in obesity prevention through taxation of SSBs into sharp focus. Under the human rights provisions, states must take steps to enable full realization of the right to achieve the highest attainable standard of health. The state violates individuals’ rights if it fails to take cost-effective and proportionate measures to remove health threats from the environment. For example, the right to adequate food implies enabling food security through access to nutritionally dense foods, responsible food labeling and appropriate food regulation, and a particular emphasis on advertising and marketing of foods and beverages to children and to schools. High intake of SSBs among the food-insecure and low-income populations is an important consideration, especially given that nutrient-dense foods are often more difficult to access or cost prohibitive for these populations.

## HIV/AIDS

The HIV/AIDS pandemic remains one of the greatest challenges to human health, with more than 70 million being infected with the virus, and more than 35 million deaths due to AIDS-related causes having occurred by the end of 2016 (Joint United Nations Programme on HIV/AIDS, 2017). Since its inception, the HIV pandemic has been different from the pandemics of influenza, smallpox, or polio; all of those diseases were greatly feared, yet none generated the kinds of social opprobrium against the infected individuals that the HIV pandemic has so regularly created (Cohen et al., 2007). The scale of the HIV pandemic—and the stigma, discrimination, and violence that surrounded

its sudden emergence—catalyzed a public health response that expanded human rights in principle and practice and ignited ethical debates.

While the prospect of a cure and a preventive vaccine remain elusive, comprehensive and combination treatment/preventive programs have proved to be critical interventions to mitigate the impact of HIV infection and reduce HIV incidence in many settings and populations. Despite these advances, a large majority of individuals living with HIV or at risk of HIV still do not have access to prevention, treatment, and care and are unaware of their HIV status (Joint United Nations Programme on HIV/AIDS, 2017; WHO, 2014). The vast majority of people unable to access treatment reside in low- or middle-income countries and communities. In key affected populations,<sup>3</sup> identified as people who have both higher likelihood of HIV infection and greater risk of being excluded from essential HIV services, HIV incidence continues to rise, even as incidence stabilizes or declines in the general population (WHO, 2014). Outside of sub-Saharan Africa, 80% of all new HIV infections among adults occur among people from key populations and their immediate sexual partners (Joint United Nations Programme on HIV/AIDS, 2017).

Key populations, collectively at the global level, are disproportionately affected as a result of the additional social and structural factors that increase their vulnerability. Stigma is recognized as a powerful social determinant of health and a key driver of health disparities in vulnerable groups (Poteat et al., 2015). In many instances, this vulnerability increases when individuals are unable to realize their rights and face stigma, exclusion, harassment, and violence as a result of both their HIV status and their membership in a key population. When stigma and discrimination in healthcare settings are both overt and hidden, they may lead to delayed HIV testing, concealment of positive serostatus, and poor uptake of HIV services (Fay et al., 2011).

In 2017, 78 countries had repressive laws criminalizing homosexuality or propaganda of homosexuality; in 13 of these countries (e.g., Sudan, Iran, Nigeria, Somalia), homosexual acts are punishable by death (Carroll, 2016). In an overwhelming number of countries that criminalize homosexuality, HIV prevalence is at the highest levels, although the absence of such laws in other countries does not necessarily mean they have lower rates of HIV. Criminalization sanctions and reinforces existing prejudices and legitimizes violence; in practical

terms, it translates into increased barriers to equitable access to essential services and treatment. Enforcement of antidiscrimination and protection laws invokes core human rights standards and is a key component toward advancing the health of the most vulnerable. Protecting the human rights of the most vulnerable populations necessarily includes efforts to decriminalize sexual behaviors, recognize diverse gender expression and identity, and provide inclusive and sensitized services.

Against this background, this section will explore in detail the human rights and ethical dimensions of the global health challenge that is HIV. The focus will be on two public health approaches that have defined the response: (1) HIV prevention and (2) equity of and access to HIV treatment. The use of human rights and ethics tools applied to the HIV context highlights the integrative and complementary nature of these perspectives, as well as important differences between them.

## Prevention

From early on in the pandemic, tension between individual human rights and the role of the state as duty bearer drove the response. Prominence was given to individual human rights, with a focus on risk, behavior change, and agency through campaigns on access to care, information, HIV testing and counseling, and use of condoms. However, population-based policies, such as universal access to condoms and needle syringe programs, that prioritized access to prevention tools were often selectively implemented in different countries, leaving large networks within many populations at significant risk and lacking the basics of HIV prevention services.

The emergence of newer preventive paradigms, including treatment as prevention, has reframed prevention efforts to have an increased focus on the integration of individual rights into collective public health policies. Strategies such as preventing mother-to-child transmission, harm reduction, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), prevention of violence and decriminalization, and provision of opiate substitution medication for people who inject opiates have had a profound impact by stemming the acquisition and transmission of HIV. To further explore HIV prevention and the application of human rights and ethics frameworks, the section that follows highlights two examples: Harm reduction and treatment as prevention.

3 Key affected populations are defined as people who have been identified as belonging to population groups most at risk of HIV. They include men who have sex with men (MSM), transgender people, people who inject drugs, and sex workers. Vulnerability extends to groups of people who have an increased susceptibility to HIV infection as a result of their specific circumstance or context—for example, adolescents, people in closed settings, orphans, street children, and migrant and mobile workers.

People who inject drugs are at risk of HIV and other blood-borne viral infections, including hepatitis B and C, through sharing of contaminated, non-sterile syringes and injecting equipment. Globally, 123 countries—that is, 78% of the total 158 countries that report data on injecting drug use—attribute cases of HIV to injecting drug use (WHO, 2014). In 2012, it was estimated that approximately 12.7 million (range: 8.9–22.4 million) people on a worldwide basis had recently injected drugs; of those, 1.7 million people (13.1%) were living with HIV. Data from 49 countries show that the risk of HIV infection was, on average, 22 times greater among people who inject drugs than among the general population (WHO, 2014).

Injecting-drug users endure institutionalized vulnerabilities as a result of arbitrary deprivation of rights in the form of mandatory testing, inadequately targeted services, social marginalization, and punitive measures to contain drug dependence through arrest and imprisonment. Indeed, the most elemental concerns of the human rights agenda are also the determinants of the health outcomes for injecting-drug users, who face the prospects of incarceration, violence, stigmatization, isolation, and discrimination (Wolfe & Cohen, 2010). As Wolfe and Cohen (2010) note, core principles of human rights—including liberty and security of the person, autonomy, privacy, and freedom from cruel, inhuman, or degrading treatment—are vital components of effective health programs for this population group.

In the few countries that do not criminalize drug use, political and legal barriers prevent access to prevention without discrimination, and to justice such as freedom from arbitrary arrest and detention (WHO, 2014; Wolfe & Cohen, 2010). Examples can be cited of compulsory treatment centers, ostensibly used to rehabilitate or detoxify, that hold people without charge, right of appeal, or evaluation by a health professional, addiction specialist, or psychiatric specialist. In other cases, individual liberty has been usurped by law enforcement as a means of containment, further impeding universal access and public health efforts. Interned in prisons, injecting-drug users may be exposed to infectious diseases, violence, overcrowding, and high-risk behaviors. Access to key treatments, such as antiretroviral therapy, may also be limited due to ingrained stigma and perceptions of instability that may jeopardize adherence. A more recent and pressing example is the “war on drugs” in the Philippines, which highlights the difficulty of globalizing ethical, moral, and evidence-based public health interventions in highly criminalized settings where extrajudicial killings are being actively encouraged and enjoy

broad popularity in the populace. This generates a broader discussion of how human rights and ethics may be applied in these settings.

## Treatment as Prevention

Results of a landmark clinical trial in 2011 demonstrated that early treatment of the HIV-infected partner in sero-discordant couples with antiretroviral therapy provides durable and reliable protection against sexual transmission to the uninfected partner. This intervention was found to 96% effective in decreasing the risk of HIV acquisition (Cohen et al., 2011). This trial, named HIV Prevention Trials Network (HPTN) 052, supported the use of medical therapy as a public health prevention strategy, thereby changing the landscape for HIV prevention.

These findings have been further supported by the landmark “Opposites Attract” study of HIV sero-discordant male same-sex couples, led by Andrew Grulich and colleagues, which showed that men living with HIV and virally suppressed had no documented HIV transmission to uninfected partners despite low use of condoms (Bavinton et al., 2014). The study findings suggest that when treatment as prevention is at its most optimal, an HIV-positive individual with an undetectable viral load has a negligible risk of transmission.

This situation changes issues of disclosure and raises questions about whether there remains a moral requirement to disclose HIV status if all reasonable attempts to reduce risk are taken. Similarly, if the viral load levels are undetectable to the extent that the risk of transmission is practically negligible, is there an obligation to disclose (Haire & Kaldor, 2015)? Indeed, the question may be whether the obligation to prevent viral transmission lies solely with the individual who is infected, or whether all parties have a collective responsibility to protect and prevent this disease (Sugarman, 2013). Is it morally wrong to situate the health of an infected person as secondary to the public health benefits of a suppressed viral load, particularly when the treatment may carry side effects or toxicities (Haire & Kaldor, 2015)?

Additional issues arise for key population groups. Despite the evidence, in a number of instances, trials and rollouts of this strategy are being hampered in countries where repressive laws exist and criminalization of homosexuality is pervasive and, in some cases, where there has been an expansion of the HIV epidemic in many MSM populations (Beyrer et al., 2016). Treatment as prevention has been demonstrated to have limited utility in other key population groups,

such as people who inject drugs, particularly in circumstances where other interventions such as oral substitution therapy are unavailable.

### Treatment: Equity and Access

The emergence of treatment options was a critical turning point in the HIV response, with dramatic reductions in morbidity and mortality following in their wake. The potential benefits of earlier initiation of therapy far outweigh the potential risks of increased exposure to drug toxicity and emergence of viral resistance in the setting of suboptimal adherence.

Universal access to medicine has the promise to deliver much-needed treatment to those most at need and to extend life expectancy. Nevertheless, identifying those who are infected shortly after acquisition and initiating treatment remain a challenge to the arresting the epidemic. Treatment is reliant on individuals knowing their status and having access to non-coercive testing.

In 2016, WHO released consolidated guidelines recommending that all people living with HIV be provided with antiretroviral therapy, removing limitations on eligibility for HIV-positive individuals. Expanded access to treatment resonates with the 90-90-90 targets—that 90% of people living with HIV have knowledge of their HIV status, 90% of people who know their status have access to and receive ART, and 90% of people who receive ART have suppressed viral loads. Despite this concordance, even the most ambitious targets for expanding access to antiretroviral therapy recognize that many people in need of treatment will not receive it. Utilitarian arguments as applied to access to medicines promote an ethics of resignation and the observance that resource scarcity is accepted as inevitable, and the pressure to identify and address inequality is diminished by the dissemination of those scarce resources within a population (Smith, 2016). Populations and groups who have been systematically excluded and disenfranchised from treatment programs, such as migrants and ethnic minorities, and stigmatized groups including sex workers, injection-drug users, prisoners, and sexual and gender minorities, continue to face difficulty in obtaining treatment access. The issue of equity in treatment access is complicated by the fact that in some countries, the overwhelming majority of people in need of treatment come from politically marginalized or vulnerable groups. Perhaps the clearest example of this is injection-drug users, who are consistently under-represented in national treatment programs despite accounting for the overwhelming majority of people in need of treatment in many countries.

The reason for such under-representation in treatment access may be an underlying pattern of human rights abuse that renders certain populations less able to obtain basic health care.

Under human rights law, the guiding principle for equitable access to antiretroviral treatment is that of nondiscrimination and equality under the law. This principle accepts that governments have difficult choices to make and that not every “social good” can be made universally available. Undertaking a commitment to do the greatest good for the greatest number of people may be at odds with treatment paradigms. Expanding access to medicines that are known to be less efficacious or carry a greater toxicity profile, but that are inexpensive and, therefore, can reach a greater number of people, including those who may otherwise not have access to treatment, may be more beneficial or preferable than provision of the gold-standard treatment in all settings, with the understanding that this resource may be finite and available to fewer people (Persad & Emanuel, 2016). The former option challenges the idea that refusal to offer treatment, if deemed substandard or potentially more harmful, overemphasizes nonmaleficence to the extent that it is a dereliction of duty (Persad & Emanuel, 2016). The latter position reinforces the notion that equal access to the best available treatment for all people should be the primary goal (Smith, 2016).

In international covenants, governments are generally prohibited from intentionally or unintentionally denying social benefits to individuals on the basis of, among other things, race, sex, national or ethnic origin, religion, and political viewpoint. Sometimes such denial will be justified, as when pregnant women are given preference for treatment to prevent HIV transmission from parent to child. Nevertheless, such decisions should never be based on unfounded or stereotypical assumptions about marginalized groups—such as the assumption that injection-drug users should not qualify for treatment programs because they are “noncompliant” or incapable of adhering to a treatment regimen. In the case of antiretroviral treatment, their eligibility should be based on clinically relevant criteria and, beyond that, on criteria that are justified in the circumstances and that do not offend human dignity (**EXHIBIT 3-5**).

The procedures by which these criteria for treatment access are set should likewise be subject to both human rights and ethics standards. International human rights law recognizes the “right to participate,” which should include a positive obligation on governments to solicit the views of affected populations in formulating public policy (International Covenant on Civil and Political Rights, 1966). More urgently,



### EXHIBIT 3-5 Test and Treat

While it has been estimated that 53% of all people diagnosed with HIV are on antiretroviral therapy (Joint United Nations Programme on HIV/AIDS, 2017), approximately 30% of people living with HIV at a global level remain undiagnosed and unaware of their seropositive status (WHO, 2017). In resource-poor settings, roughly half (19.5 million) of those individuals eligible for treatment are receiving treatment (Joint United Nations Programme on HIV/AIDS, 2017). The evidence consistently shows that stigma and discrimination in healthcare settings are both overt and hidden, leading to delayed HIV testing, concealment of positive serostatus, and poor uptake of HIV services.

“Test and treat” is a strategy that universalizes voluntary counseling and testing and offers immediate treatment to individuals who test positive, irrespective of clinical stage or CD4 count. It is premised on the notion that if individuals are made aware of their status, they will access treatment and alter high-risk behaviors.

Test and treat is a proven intervention in settings where the HIV epidemic is not widespread or generalized. Even so, some challenges remain. Despite this strategy’s potential to recruit newly diagnosed persons into treatment, to preserve autonomy, and to normalize and destigmatize HIV, barriers remain in regard to linkage to care once the diagnosis is known as well as persistent issues related to viral resistance and adherence.

authoritarian governments that place restrictions on civil society, including crackdowns on AIDS activism and censorship of the press, risk adopting HIV/AIDS policies that do not reflect the needs of their population. These “first generation” human rights guarantees (freedom of speech, freedom of the press, freedom of association) are essential to treatment rollouts to the extent that they foster the political participation of the widest range of stakeholders possible. Procedural justice, as mandated by ethics in creating significant public health policy, has such rights as its cornerstone.

## ► Conclusions

Public health, human rights, and ethics have universal and deeply shared values. It is the mission of public health to improve health, reduce morbidity, and reduce mortality wherever it does its work. Human rights and ethics, too, have basic sets of principles and rules in common that are intended to guide and/or dictate behavior in a variety of situations so as to ensure that human rights and ethics norms are not compromised in the pursuit of good public health outcomes.

While the principles and values of human rights and public health ethics generally are shared, a significant difference between them remains in terms of targets and redress. Ethicists generally have little legal power to challenge what may be viewed as unethical practices or programs, even where the targets of such ethical critiques or advocacy are governments or publicly sanctioned policies. Human rights activists, in contrast, explicitly target governments or the policies they endorse; international tribunals, war crimes trials, and the like are among the most potent tools wielded by human rights advocates.

Thus, whereas human rights organizations explicitly try to challenge rights violations through existing legal systems, ethical frameworks try to shape shared societal norms for morally appropriate behavior—norms that, in turn, may be reflected in the law. In addition, human rights proponents often channel their arguments through media or advocacy, whereas in ethics this is less likely to be the primary means of communicating.

In certain contexts, the goals of public health, ethics, and human rights can be very well aligned. Public health, as a branch of government, has extraordinary power to further the public’s health in ways that are beneficial, careful, and fair. But because such significant power, wherever it is given, can so easily be abused, both ethics and human rights have created their own sets of checks and balances. Ethics and human rights provide the moral and legal “brakes” to redirect public health to more constructive tactics, and to highlight to public health professionals, through advocacy, argumentation, and accountability, what are and are not justifiable uses of state power and intervention in the name of furthering public health. Ethics and human rights also advocate proactively for just structures for public health—for creating the conditions under which individuals and communities can thrive.

It has been the thesis of this chapter that the human rights context in which public health work is conducted has an extraordinary impact on which public health tools ultimately must be selected to have ethically sound public health responses. The relationship of citizens to their governments has a tremendous impact on public health status in different locales; indeed, the degree to which governments believe that they have a responsibility to care for the health of their public varies strikingly from country

to country. Similarly, when public health seeks to intervene, the human rights or political context into which it enters will influence to a great degree both the potential public health benefits of a given intervention and the ways in which a given intervention is deemed ethically acceptable, ethically unacceptable, or ethically required.

## Discussion Questions

1. How might the sale of high-sugar soft drinks in public schools be framed as a human rights issue?
2. What role do states have in regulating foods known to be damaging to health but popular with citizens?

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3. In country X, HIV rates are disproportionately high among sexual- and gender-minority adolescents and adults. Same-sex behavior between consenting adults is criminalized. How might decriminalization of these behaviors affect HIV programs? How might this be addressed from a human rights perspective?
4. Adults have a right to purchase and consume the foods and beverages they like and want. Yet aggressive marketing of unhealthy foods can disproportionately affect the health and well-being of the poor, the marginalized, and those with less access to quality health care. How does a public health ethics framework help address the balance of freedom and responsibility? Choice and exploitation?
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