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# ***Governance, human rights and infectious disease: theoretical, empirical and practical perspectives***

# 15

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The relationship between the health status of a population and the behavior of the government under which that population lives has been previously explored in war or civil crisis settings, and in the context of chronic health issues such as nutrition, famine, and child mortality (Sen, 1999; Dreze and Sen, 2002). These studies have found that government behavior (sometimes captured by the term “governance”), as measured by indicators such as accountability, stability, rule of law, respect for human rights, and the existence of an independent civil society, plays a significant role in health outcomes – a role independent of, and perhaps even superior to, host genetics, insect vectors, or individual behaviors. Famines stem not solely from bad weather or genetics, but also from the failure of governments to protect their populations from civil strife, or to equitably distribute food aid. Occupational illnesses, such as pneumoconiosis (or “black lung”), can be understood in terms of the risk behaviors and biological susceptibility of mineworkers, but also as a failure of governments to protect individuals in the workplace.

Despite the widespread acceptance of these findings, the influence of governance on infectious disease spread has received far less attention. As the chapters in this volume illustrate, there is an increasing appreciation that factors outside what is traditionally considered the health sphere can contribute to creating or controlling endemic and epidemic infectious disease. Some of these causes are socio-cultural, while others are the result of migrating populations, transportation

infrastructure, and the workforce. There is increasing evidence, from diverse infectious diseases and using diverse research approaches, that suggests that government behavior has an influence on infectious disease spread and control as well.

We begin this chapter by exploring the fundamental obligation of governments to protect health, drawing on both historical state practice and explicit obligations under international human rights law. We note that this obligation extends not only to the provision of health care or to the control of infectious disease outbreaks, but also to the cessation of human rights violations that contribute to poor health or disease risk. We then review recent attempts to quantify the relationship between good (or bad) governance and public health, noting that such quantification is often limited by confounding factors and methodological limitations. By reference to three infectious diseases – HIV and AIDS, Guinea Worm, and SARS – we explore some of the causal mechanisms by which human rights abuses might fuel disease spread and/or constrain the ability of governments to arrest disease. We conclude by reflecting on the importance of developing a coherent framework for understanding the precise relationship between governance, human rights, and infectious disease.

## **The obligation to protect health**

The written records of ancient China, Egypt, India, and Peru document humankind's earliest efforts to provide safe water, sewage, and drainage systems so as to protect public health. In the absence of a clear scientific understanding of infectious diseases, these efforts were largely linked to religious beliefs. City states in ancient Greece created sanitation systems for the entire community, and medical care for the poor. By the thirteenth century, Italian cities had laws modeled after ancient Roman standards to prevent epidemic disease through maintaining clean water supplies, controlling refuse disposal, and monitoring migrants to the city that might be carrying infectious disease (Kiple, 1995). The Elizabethan Poor Laws in Britain in the early seventeenth century strengthened the responsibility of local authorities for health and welfare. The Public Health Act of 1848, passed to improve sanitation in England and Wales, was one of the great milestones in public health history (Fee and Brown, 2005). By the twentieth century, the authority of local, state, and national governments was extended from sanitation and indigent medical care to activities such as chlorinating and fluoridating community water supplies, conducting insect vector control, screening and inoculating against infectious diseases, partner notification and tracking of sexually transmitted diseases, and regulating food, drugs, and the blood supply. Each of these actions acknowledged the widening responsibility of government to maintain and promote public health, especially in the area of infectious disease control.

In more recent years there has been an explicit recognition of the obligation of governments to protect health as a matter of human rights. The Universal Declaration of Human Rights (1948) recognizes that:

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.

The UDHR further recognizes that all people are entitled to “realization ... of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.” Among the social rights recognized in the subsequently ratified International Covenant on Economic, Social and Cultural Rights is the right to “the highest attainable standard of health” (International Covenant on Economic, Social and Cultural Rights, 1966). Under this provision, governments are obligated to respect, protect, and fulfill the “right to health” by taking positive actions that ensure access to high-quality health services, and by refraining from or preventing negative actions that interfere with health, such as denying health care to certain populations or censoring health-related information. The right to the highest attainable standard of health is also intimately linked to the enjoyment of a full range of civil and political rights, such as the right to information, equality, and due process under law. So, for example, a government ban on the reporting of a newly identified infectious disease may violate the right to information under the International Covenant on Civil and Political Rights (1966) and also infringe upon the right to health by preventing individuals from protecting themselves from illness. Violence, discrimination, and arbitrary actions by the state also can have both direct and indirect public health impacts – for example, when police officers arbitrarily detain outreach workers providing life-saving HIV-prevention services, this implicates not only due process rights but also the health of those who benefit from these services (Human Rights Watch, 2006a).

While not always defined in the language of human rights obligations, epidemiologists, national governments, and international agencies have increasingly recognized that since health is shaped by the broadest spectrum of social, cultural, and political factors, the analysis of health status and programs designed to respond to poor health must take all of these factors into account. Areas of public health, such as health promotion, that traditionally emphasized individual lifestyle choices and personal responsibility are now being reframed to recognize broader influences on individual behaviors and broader responsibility of government for promoting healthy social environments. A milestone of this shift was the 1986 World Health Organization’s Ottawa Charter, which set out five key areas of action for influencing healthy behaviors: building healthy public policy, creating supportive environments, strengthening community action, developing personal

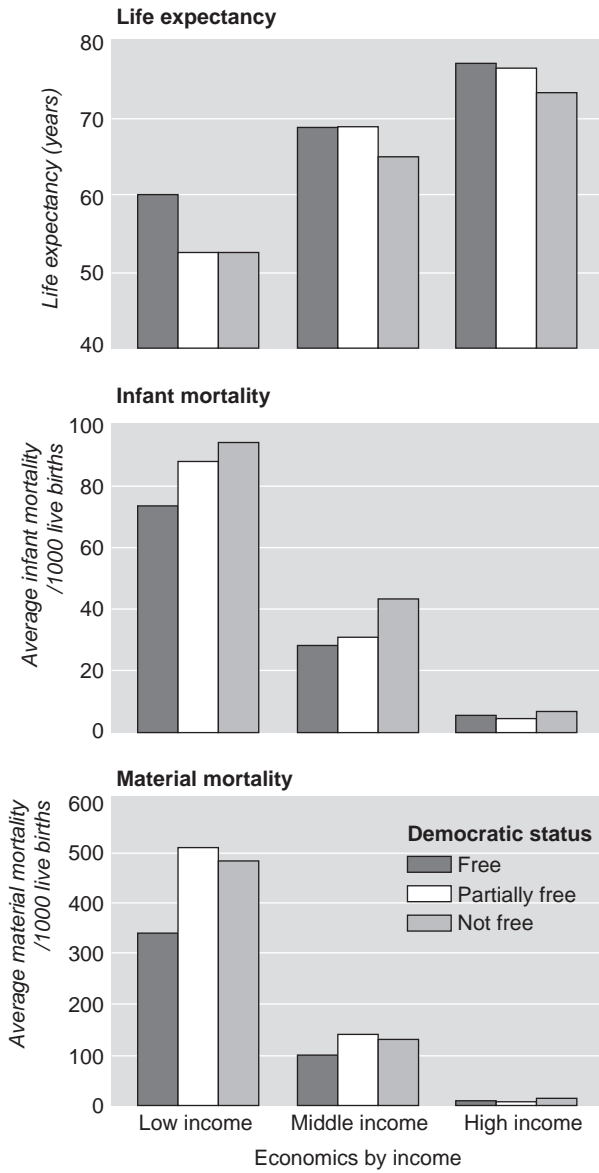
skills, and reorienting health services (WHO, 1986; Breslow, 1999). Critics of “black box” epidemiology, who advocated for more contextualized and structural analyses to be incorporated into epidemiological studies, mirrored this movement (Susser and Susser, 1996a, 1996b). The field of social epidemiology, which looks at social factors that shape disease vulnerability, also recognizes the important role of political context and human rights violations in fueling infectious disease spread.

## **Linking measures of governance to general health indicators**

Both governance and health can be measured in many different ways, and one factor complicating efforts to measure the association between the two is the difficulty finding accurate, sensitive, and specific enough indicators for either variable. Broad measures of population health – such as life expectancy, and infant and maternal mortality – have been chosen by a number of authors, in part because these indicators capture (and average the effects of) multiple specific diseases and are broadly distributed across the population. To measure governance, two approaches have been used. Some authors have chosen the rankings of the organization Freedom House, which scores countries based upon political rights and civil liberties, electoral process, political pluralism and participation, functioning of government (including transparency and corruption), freedom of expression and belief; association; organizational rights, rule of law and personal autonomy; and individual rights (Freedom House, 2006). Other authors have used a set of governance indicators collected by the World Bank that includes measures of voice and accountability, political stability, government effectiveness, regulatory quality, rule of law, and corruption (Kaufmann *et al.*, 2003).

In a 2004 article in the *British Medical Journal*, Alvaro Franco and his colleagues plotted life expectancy and maternal and infant mortality in 170 countries against the “freedom index” produced by Freedom House (Figure 15.1). Controlling for determinants of health that include socio-economic and political measures such as wealth, equality, and the size of the public sector, the authors found a statistically significant relationship ( $r = .XX$ ,  $P < .0X$ ) between freedom ratings and health indicators at all income levels. In their conclusion, they speculate that democracies produce better health outcomes because they “allow more space for social capital,” like social networks and pressure groups, opportunities for empowerment, better access to information, and better recognition by government of people’s needs (Franco *et al.*, 2004).

In a similar study, again using life expectancy, infant and maternal mortality as health indicators, Alvarez-Dardet and Franco-Giraldo (2006) analyzed data from 23 post-Communist countries during the last decade of the twentieth century. Again there was a significant correlation between the level of democratization



**Figure 15.1** Health indicators in 170 countries by classification of economies (World Bank) and democracy (Freedom House), 1998. Source: Franco *et al.* (2004).

and health ( $r = 0.XX$ ,  $P < 0.0X$ ), taking into account both wealth and the level of inequality.

In a third study, using governance indicators collated by the World Bank, Reidpath and Allotey (2006) plotted a composite governance indicator against infant mortality and healthy life expectancy (disability adjusted life expectancy) in 176 countries, and found significant correlation ( $r = -0.68$  and  $r = 0.72$ , respectively,  $P < 0.001$  for both). To control for *per capita* wealth the authors performed regression analyses, which identified both governance and wealth (measured as *per capita* gross domestic product (GDP)) as independently, and significantly, associated with life expectancy and with each other. The authors noted that these multiple correlations, as well as the correlation with another variable studied, the adequate supply of water, made it difficult to fully describe causality.

## **Linking measures of governance to infectious disease indicators**

The attempt to demonstrate quantitatively a link between governance factors and a more narrow measure of infectious disease risk in particular has been more challenging, in part because infectious disease risk is not spread evenly across populations, and comparisons between countries of the prevalence of a specific disease miss the over-burdening of some communities or subgroups within a country. In addition, governance influences different infectious disease risks in different ways, and presents distinct challenges to governments – compelling different types of government policies and approaches. For example, the risks posed by mosquito-borne diseases such as malaria or dengue fever present different possibilities for spread and control than, for example, hepatitis B or C, which are transmitted through sex or blood contact.

Nonetheless, the belief that there is a link between governance and specific infectious disease spread stems from an understanding that how governments handle infectious disease is determined not just by epidemiologic characteristics, but also by the overall political and social climate of the nation. Experience shows, for example, that the response to infectious disease epidemics will be strongly influenced to the detriment of the public health by the level of social opprobrium against the populations affected, by social discomfort with the means of transmission implicated (such as drug use or sex), and by fear and ignorance surrounding the disease or its means of transmission. These factors may make it important for governments to address infectious disease spread through working respectfully with at-risk populations, rather than adopting top-down approaches (such as criminalizing disease transmission, instituting mandatory testing, and quarantining people living with infectious diseases) that risk driving these populations even further to the margins of society where they cannot be reached with prevention services.

The theoretical basis for this observation is built upon the pioneering work of Jonathan Mann and Paul Farmer, who were among the first to describe the impact of human rights violations on health. Mann argued that pervasive human rights abuses perpetrated against socially marginalized groups (e.g. sexual violence, discrimination, police abuse) increased their risk of acquiring HIV, and that coercive public health responses such as quarantining and forced testing served to drive these groups further into hiding and fuel the epidemic (Mann, 1999). Informed by years of delivering HIV care in Haiti, Paul Farmer used the term “structural violence” to describe conditions of poverty, sexism, racism, and political violence that constrain individuals’ ability to make informed and autonomous choices about their health (Farmer, 1999; Farmer, 2004).

Since 2001, the HIV/AIDS and Human Rights Program at Human Rights Watch has gathered thousands of testimonies from persons living with and at high risk of HIV, documenting the link between human rights abuses against them and their risk of HIV. These abuses have included rape, domestic violence, sex discrimination, and other abuses against women and girls; arbitrary arrest, beatings, torture, and the over-incarceration of injecting drug users, gay and bisexual men, sex workers, and other vulnerable groups; arbitrary detention of AIDS activists and outreach workers; and censorship of science-based HIV/AIDS information (Human Rights Watch, 2006b).

One of the first attempts to explain quantitatively the link between a specific infectious disease and governance factors was the study conducted by Menon-Johansson (2005) using World Bank governance indicators to examine HIV prevalence in 149 countries (see Table 15.1). The study found a significant negative correlation between HIV prevalence and all six governance dimensions ( $r$  ranged from 0.12 to 0.20, and  $P$  ranged from 0.03 to 0.001). The study, though statisti-

**Table 15.1 HIV prevalence correlations for each governance dimension and mean governance**

Governance dimension	Correlation coefficient ( $n = 149$ )	$P$ value
Voice and accountability	-0.123	0.032
Political stability and absence of violence	-0.164	0.004
Government effectiveness	-0.204	0.000
Regulatory quality	-0.157	0.006
Rule of law	-0.194	0.001
Corruption	-0.184	0.001
Mean governance	-0.170	0.003

Source: Menon-Johansson *et al.* (2005); original publisher, Biomed Central.



cally significant, suggested that governance accounted for only a small percentage of the variance in HIV prevalence from one country to the next.

To address the relatively weak correlation found by Menon-Johansson (2005), Reidpath and Allotey (2006) re-analyzed the data using a single composite indicator from the six governance dimensions provided by the World Bank. The authors found a similar result ( $r = 0.2$ ,  $P < 0.05$ ), and concluded that analyzing structural measures such as governance versus single diseases was bound to show a weaker correlation than broader measures unless the diseases were ubiquitous. However, the authors say little about the limitations inherent in comparing across countries an infectious disease such as HIV that is manifested in different communities (because of different frequencies of dominant risk behaviors) and was introduced at different times into different communities and countries. As HIV is still a relatively newly introduced infection in many countries, measurements assessing current HIV prevalence versus governance may as yet be inappropriate. The dynamics of the global HIV epidemic are still fluid and, particularly in Eastern Europe and Asia, future prevalence is uncertain, making an analysis using current prevalence an uneven comparison.

## **Case studies**

A clearer way to illustrate the relationship between governance and infectious disease is through case studies. This section highlights three diverse examples of infectious diseases, and explains how governance influenced their spread. In the first example, of Guinea worm disease, we will discuss how the neglect of rural and often ethnically marginalized populations led to a disease with a simple life-cycle and relatively easy means of eradication being undercounted and largely ignored despite significant personal, community level, and national economic and health impacts. In the second example, HIV/AIDS, we will discuss how a disease of socially marginalized populations (for example, injection drug users and, in sub Saharan Africa, women) was both initially ignored and subsequently poorly controlled by governments with poor records on human rights and governance. In the third example, we will discuss how the lack of political freedoms in China led to poor recognition and handling of a newly identified infectious disease, severe acute respiratory syndrome (SARS).

### **Guinea worm**

Guinea worm disease, also known as dracunculiasis, is caused by an infection with the nematode *Dracunculus medinensis*, which lives in the subcutaneous and connective tissues – generally of the legs. Guinea worm disease is characterized by a small, intensely painful blister that is formed by the adult female worm

(which, over the course of roughly 12 months' incubation, can grow to a meter in length) as it emerges to release its larvae. Larvae released into stagnant fresh water are ingested by tiny copepods (*Cyclops* spp.), which after two weeks of development are infective when swallowed.

Guinea worm is primarily a rural disease and, despite an enormous economic impact on rural communities, where it is endemic (and an enormous cumulative national economic impact), the disease was little noticed because its burden was primarily felt among the rural poor. Many health ministries in countries where it was endemic – a broad band across sub Saharan Africa, Yemen, Afghanistan, and Pakistan – had little awareness of the disease (Needham and Canning, 2003) and were doing virtually nothing about it.

In reaction to this neglect, in 1991 the Forty-Fourth World Health Assembly (WHA) laid out a strategy for Guinea worm eradication that includes three key governmental steps based on transparency and accountability (Hopkins and Ruiz-Tiben, 1991; WHO, 1991). The widespread availability of information on both epidemic and endemic infectious disease burdens helps to shape the process of the prioritization of response to public health threats. In democratic countries, this information can be used to facilitate the participation of civil society in setting the agenda and goals of public health campaigns and, through civil society involvement, of ensuring their effectiveness.

The first step in the proposed campaign for global Guinea worm eradication was to create a national plan based on a national survey to identify all endemic villages and assess the annual number of cases. In most of the countries affected, prior national surveys had greatly undercounted the number of people infected, and thereby understated the burden of disease. For example, prior to the national eradication program in Nigeria, less than 5000 cases were counted annually. After conducting a true national survey under the newly created Guinea worm program, between 640,000 and 650,000 cases were uncovered (Hopkins and Ruiz-Tiben, 1991).

The second step set out by the WHA strategy was to create safe water supplies using health education messages, “reinforced by religious and traditional/political leaders in the village, schoolteachers, agricultural and other extension workers, community organizations, and by the mass media (radio, posters, etc.) in the local languages” (Hopkins and Ruiz-Tiben, 1991). This kind of effort includes and fosters community participation, but perhaps more importantly encourages and re-emphasizes transparency and openness about infectious disease rather than suppression of information.

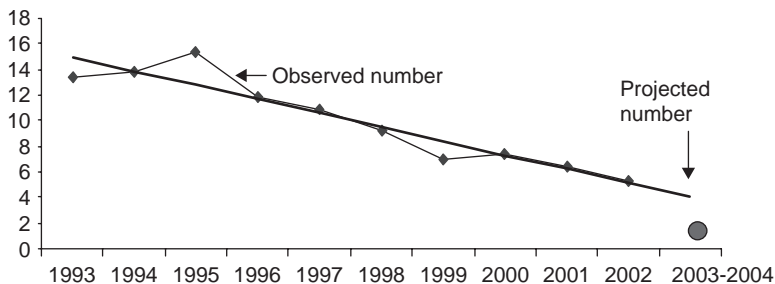
The third step, case containment, includes free treatment, which serves to encourage individuals to come forward for Guinea worm screening and health education. The total strategy for Guinea worm eradication illustrates a strategic balancing of concern for human rights and public health. It is an open and participatory approach. Governments demonstrate accountability to individual and community needs, and target the intervention in ways that are inclusive and

non-coercive. Based on this strategy, 11 of the 20 nations most impacted by Guinea worm have been successful in eliminating the disease from their countries, and the overall number of people infected has been reduced from an estimated 3.5 million in 1986 to 10,674 in 2005 (Carter Center, 2006).

## HIV and AIDS

When it was first recognized in the early 1980s, AIDS was labeled “gay-related immune deficiency” (GRID). Soon afterwards, it was discovered that HIV was easily transmissible through the sharing of syringes among injecting drug users. The association of a new and poorly understood disease with stigmatizing and criminal behaviors (as well as the widespread blame of “foreigners” for the introduction of the disease) led, quite predictably, to a wide range of ineffective, discriminatory, and stigmatizing public health control strategies. Throughout the history of the HIV epidemic, governments have variously attempted to criminalize HIV transmission, quarantine people living with HIV, and censor factual information about safer sex and drug use. Political leaders have pandered to the stigma surrounding HIV by denying the extent of epidemics in their countries, and, in some cases, suggesting that AIDS is a punishment for perverse and sinful behavior. Such policies and attitudes, largely discredited by experience and research, have pushed already vulnerable groups further to the margins of society and ultimately undermined both HIV prevention and human rights.

One of the most dramatic recent examples of this occurred in Thailand in 2003, when the Thai Government declared a “war on drugs.” Prior to this, the Thai Government had received praise for its successful non-punitive approach to AIDS, exemplified by its efforts to promote condom use among sex workers and military conscripts in the 1990s. By contrast, the “war on drugs” was a harsh “zero tolerance” policy that flew in the face of proven HIV prevention strategies, such as provision of sterile syringes or oral methadone to people who inject drugs. Purportedly in response to a rise in methamphetamine use in the country, in January 2003 the then Prime Minister Thaksin Shinawatra called for “ruthless” drug enforcement based on “an eye for an eye” (Human Rights Watch, 2004). There followed a period of mass arrest and incarceration of drug users for even low-level crimes such as possession of narcotics and syringes for personal use. Thaksin instructed local officials to create “blacklists” of suspected drug offenders, and in August 2003 instituted a shoot-to-kill policy against alleged drug traffickers smuggling methamphetamines from neighboring Burma. By the end of the “first phase” of the drug war, an estimated 2275 people had been shot dead in apparent extrajudicial executions (CNN, 2003; AFP, 2003). Thaksin blamed these killings on internecine violence among drug traders, yet at this writing a full investigation of the killings still has not taken place, despite some indication that investigations might occur in the wake of Thaksin’s having been overthrown



Source: Unpublished Data, Sarkar S, UNAIDS SEAPICT

**Figure 15.2** Estimated and observed number of methadone maintenance therapy patients in Thailand, 1992–2004. Source: Sarker, S., Joint United Nations Programme on HIV/AIDS Southeast Asia and Pacific Intercountry Team (unpublished data, 2004).

in late 2006. Throughout the drug war, senior government officials encouraged violence against drug suspects. At one point Thaksin said: “There is nothing under the sun which the Thai police cannot do ... If there are deaths among traders, it’s normal” (Human Rights Watch, 2004).

In addition to the assault on individual rights, Thailand’s “war on drugs” proved to have a negative impact on public health. While pronouncing that drug users were “patients” in need of treatment, Thai police in fact subjected drug users to mass urine testing and detention in military-style boot camps. Many drug users were incarcerated in prisons where syringe-sharing was common and access to HIV prevention information and services was minimal to non-existent. Instead of seeking drug treatment and HIV prevention services, many drug users escaped into hiding (Human Rights Watch, 2004). One study revealed that 37 percent of drug users who had formerly attended drug treatment centers in Chiang Mai were staying away, and that there was an increase in sharing syringes because sterile syringes were more difficult to obtain (Bhatiasevi, 2003). The HIV rate among Thailand’s injecting drug users has remained at approximately 40 percent since the 1990s, even as it has declined among sex workers and the general population (see Figure 15.2).

The plight of women in sub Saharan Africa also illustrates the link between human rights abuse, poor governance, and HIV/AIDS. A case in point is the Kingdom of Swaziland – the last remaining absolute monarchy in Africa, and home to the highest estimated rate of HIV infection in the world. As of 2005, an estimated 38 percent of the country’s adult population was HIV-positive (Joint United Nations Programme on HIV/AIDS, 2005). Most of those infected are women and girls, due to their increased biological risk of acquiring HIV through

unprotected heterosexual sex and also because of the country's pervasive violence, discrimination, and economic marginalization of women. These social forces inhibit the ability of girls and women to make informed decisions about their health in general, and specifically with regard to protecting themselves from HIV (Human Rights Watch, 2003). The country's monarch, King Mswati III, reigns over a system of both absolute monarchy and extreme patriarchy. While a recently ratified constitution contains guarantees of both a balance of powers and gender equality, the mechanisms to enforce these guarantees – independent courts, a robust civil society, and a political opposition – do not exist. The country has been under an official “state of emergency” since 1973, with the King retaining effective control over all branches of government.

In addition to the pervasive authoritarianism and disrespect for the rule of law, the underlying social context of the AIDS epidemic includes the widespread subordination of women to men. Seventy-five percent of all land is considered “Crown land,” which is governed by highly patriarchal and gender-biased customary law (Scholz and Gomez, 2004) that prevents women from owning, inheriting, or disposing of property. A Swazi woman enjoys the right to use her father's property, but is expected to marry and depend on the property of her husband. Married women are treated as the legal equivalent of minors, unable to sign contracts or represent themselves in court. If a woman is widowed or separated from her husband, her property typically reverts to (or is grabbed by) her husband's family. Because of these conditions, it is perilous for Swazi women to leave even violent marriages, to refuse sex, to object to polygyny, or to insist on condom use. This helps to explain why in Swaziland, as in numerous African countries, a significant percentage of HIV infections among women occur in marriage. Married women may be unable to seek health care or information because of a lack of resources or dependence on their husband or male relatives. They are also less likely than men to have attended school, where they might have gained access to information about HIV prevention or the skills to become economically independent.

## **SARS**

*This section stems from discussion with Jennifer Prah Ruger, and draws upon her 2005 article “Democracy and health” in the Quarterly Journal of Medicine, 98, 299–304.*

The case of Severe Acute Respiratory Syndrome (SARS) in China illustrates how a lack of democratic freedoms can render a country unable to respond promptly to a new health crisis. In 2003, when SARS first emerged in the southern Chinese province of Guangdong, the Chinese Government's immediate response was to cover up, rather than reveal, both the scope and severity of the

disease. The government's censorship of news about the spread of SARS ultimately accelerated the spread of the disease (*The Economist*, 2003a; Rosenthal, 2003) by limiting the information available both to citizens (who needed information on precautions and care) and to national and international government health authorities (who needed information to inform decision-making and improve their understanding of a poorly understood disease). Further hindering an effective response, the government threatened citizens with execution and lengthy imprisonment should they become infected with or knowingly spread SARS (Eckholm, 2003).

As news of SARS in China spread through unofficial channels imperfectly monitored and controlled by the Chinese Government, the Chinese Government reversed direction and pledged honest reporting of infections and accountability of public officials (for example, they fired both the Mayor of Beijing and China's Health Minister). While these steps at first brought hope for more effective public health strategies and wider political reform (*The Economist*, 2003b), subsequent efforts fell short of that goal. Far from acting as an independent and free agent, the Communist Party's newspaper, *People's Daily*, instead served as a Party instrument by publicly praising government leadership and strategies and misreporting public opinion. For example, it noted that "the people have become more trusting and supportive of the party and government" (Eckholm, 2003).

China's failure to contain and effectively address SARS ultimately increased pressure on global institutions such as the World Health Organization (WHO) to become more actively involved in "governance" at an international level, resulting in reforms intended to allow it to "fight future international threats" more powerfully (Stein, 2003).

## **Limitations**

In addition to the methodological limitations to illustrating quantitatively the relationship between governance and infectious disease control, there are several examples that can be cited to suggest that more authoritarian responses lead to more effective disease control, or that governance has little ultimate impact on infectious disease rates. Certainly it is true that, despite the best (or worst) intentions of individuals and governments, infectious pathogens can be stubbornly indifferent or even contrary to theories of health and human rights. HIV transmission can be limited in civil war settings, for example, even when human rights abuses are widespread and governments have collapsed. In Angola, a protracted civil war which reduced cross-border travel and trade is thought to have left the country somewhat protected from the early introduction and spread of disease compared to many of its neighbors; however, the war also impeded the ability of the government to conduct surveillance and education around the disease, and destroyed the health services needed to respond to AIDS. The war also

curtailed the formation of a vibrant civil society, such as the development of NGOs and AIDS service organizations, which have been highly effective in both prevention and care elsewhere.

Post-conflict countries often see a sharp increase in HIV prevalence, presumably as measures of governance are improving, indicating that the relationship between HIV and governance may involve a similar time-lag to the relationship between widespread transmission of HIV and the onset and recognition of AIDS. In Mozambique, for example, the HIV rate soared shortly after the cessation of civil conflict in 1992. Another example of the difficulty with the temporal relationship between governance and HIV prevalence comes from the Kingdom of Swaziland, referred to above. The rapid rise in HIV prevalence, from 4 percent in 1992 to 26 percent in 1996, did not occur with a simultaneous deterioration of governance; rather, the precondition and weaknesses in Swaziland allowed for the rapid spread of HIV once it was fully introduced into the country. Conversely, the apparent improvement in the HIV epidemic in Zimbabwe, with HIV prevalence decreasing from 25 percent to 20 percent between 2001 and 2005 despite a worsening human rights and governance environment, may be reflective of earlier actions by the government and, importantly, by international donors, while the impact of current government actions will only be reflected in the years to come (Human Rights Watch, 2006a). Vaccine-preventable diseases may similarly reflect a time-lag between the breakdown of governance (and hence vaccination campaigns) and the accumulation of a large enough susceptible cohort of individuals to sustain disease transmission.

Affluent societies with representative governments are also not immune to leadership failure. For example, during the early years of the AIDS epidemic there was cover-up and scandal over the failure of regulators in Canada, Japan, Ireland, France, and elsewhere to stop promptly the use of tainted blood products that were infecting hemophiliacs with HIV. While broad measures of governance may relate generally to the willingness of governments to adopt effective disease control policies, government policies to control diseases that affect specific (favored or non-favored) populations, or are related to culturally sensitive transmission modalities, may be poorly correlated with overall measures of governance.

## **Assessing governance**

The diverse chapters in this volume illustrate that factors such as human behavior and socio-economic conditions can have as great or a greater impact on the risk of infectious disease as does the microbiology of disease pathogens. If this is true, it is equally important to examine the factors that structure these socio-ecological factors in the first place. We have argued that government conduct plays an important role in shaping the social context in which individuals live,

behave, and make decisions about their health. Not only do governments help to shape the risk environment for infectious disease, but they also determine the manner in which diseases are contained and controlled.

Quantitative analysis of the link between governance and public health provides an interesting starting point for this discussion; however, it has not yet been able to capture the complexity of how governments balance human rights and public health in the context of specific disease threats, and the consequences of the choices and trade-offs made. There are several ways in which the relationship between governance, human rights, and infectious disease may be understood. The degree to which governments are respectful of human rights, and are responsive and accountable to their citizens, will influence the effectiveness with which they respond to disease threats and openly communicate about epidemics. This applies to both epidemic diseases, which governments may conceal in an attempt to maintain social order, as well as to endemic diseases among the poor, which governments may ignore out of political expediency. Individual violations of civil and political rights by governments or non-state actors can constrain the ability of individuals – especially socially marginalized groups – to make informed decisions about their health, thus increasing their vulnerability to infectious disease. These human rights violations may have less to do with health policy *per se*, and more to do with government actions (and inactions) lying outside the health sphere. A government's commitment to human rights will determine the level of coerciveness with which it responds to infectious disease threats and, in turn, how effectively a disease is contained and controlled. Even governments that choose proactively to address infectious diseases may do so in a manner that sacrifices individual rights to a perceived social benefit. A rational and proportionate balancing of individual rights against larger policy objectives may be more likely to reap benefits for public health than ignoring or downplaying human rights.

What is certain is that governance matters to health – that the way in which people are governed, whether their human rights are respected, and the institutions of democracy and civil society can have tangible health consequences at both the individual and population level. Despite the range of work in this area, there have been few attempts to describe the actual mechanisms by which rights and democracy can impact health, and attempts to measure these relationships in quantitative terms have been limited and largely unsuccessful. Even more rare have been efforts to design programmatic interventions that would enact political reforms in countries hard-hit by infectious disease, and evaluate the health impact of these reforms. Operational work in the area of health and human rights has largely been confined to documentation and advocacy work by non-governmental organizations, and has gained little acceptance by the global health community.

If governments are to effectively address the political factors that shape infectious disease epidemics, greater collaboration between health experts, human rights advocates, and legal professionals is likely to be necessary. Human rights



law suggests a full range of concrete and justifiable remedies for abuses that fuel infectious disease and impede civil society's response to it (Mann, 1996). Mechanisms of human rights accountability, such as courts, national human rights institutions, United Nations, and other multilateral procedures, and traditional "naming and shaming" techniques by non-governmental organizations have the ability to further human rights goals and thus have an impact on public health. Greater academic research into the precise links between democracy, human rights, and health can further assist policy-makers in implementing rights-based approaches with rigor and integrity. Tools such as the *International Guidelines on HIV/AIDS and Human Rights*, the *Human Rights Impact Assessment* (co-authored by Mann and Gostin), and extensive human rights documentation and advocacy by non-governmental organizations can further operationalize this approach by providing recommendations and policy guidance to governments (Gostin and Mann, 1994; Human Rights Watch, 2006a; Office of the High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, 2006).

Public support for grassroots health activists and community-based organizations, legal protection against political violence, detention, and other human rights abuses, and promotion of a robust and independent civil society should all be recognized as underpinnings for preventing and controlling future infectious epidemic diseases and improving overall health (Navarro, 1978; Committee on Economic, Social and Cultural Rights, 2000; Roth, 2004).

Ultimately, different infectious disease risks present different challenges in balancing human rights and public health goals in the response to epidemics. This balance should be determined by the epidemiologic characteristics of the disease and the methods available and practical for its control, and not by the level of social opprobrium against populations affected, societal discomfort with transmission through illicit or intimate behavior, or fear and ignorance.

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