Public Health, Human Rights, and the Beneficence of States

Chris Beyrer

Introduction

The first years of the new millennium have been marked by a striking resurgence in epidemic threats to public health, from the SARS epidemic in East Asia and Canada to monkey pox outbreaks in the American Midwest. Humans have manipulated old pathogens like anthrax and, potentially, smallpox, into new biologic agents of terror. And war and its ensuing mass violence, population displacement, and disease outbreaks actively rages in West and Central Africa, the Middle East and Central Asia, and in states as seemingly distant as Burma, Congo, and Colombia, where chronic civil conflicts undermine health and development. These threats to the health of populations have been unwelcome additions to the infectious pandemics which characterized of the end of the last millennium: AIDS, tuberculosis, and disease-resistant malaria, among others—all still largely out of control. Add famine, which has followed the AIDS road deep into southern Africa as inexorably it has followed seemingly pointless wars in the Horn, and all four horsemen of the medieval apocalypse are afoot. Historians of this period of swift globalization and stunning scientific achievement may well view this current period as one of painful recognition of the costs, as well as the benefits, of a truly interconnected world. Public Health, by which we mean the set of disciplines that seek to address threats to populations including epidemic disease outbreaks, has been enormously challenged by these threats. Fundamental tensions over the rights of individuals and the protection of the public good are once again as relevant as they were when Typhoid Mary was quarantined in New York City, and consumptive would-be immigrants were turned away at borders. In many settings, the public has largely generally tolerated these limitations. And this is perhaps especially true when public awareness is high and a disease feared. Asian travel collapsed widely, whether countries were on the WHO travel advisory list for SARS or not.

Individual Rights and the Public Good

Much of the published opinion and debate on the use of centuries old measures like quarantine, isolation, and travel restriction have focused on the nexus of indi-

vidual rights and freedoms versus the public good—on limitations placed on individuals for their protection or for the protection of a wider community. Bayer and Colgrove recently described this resurgent challenge as the need to seek a balance between civil liberties and protection of the public welfare, and there is no question that such a balance is of critical import. In the case of SARS, where the initial infectivity of the suspected pathogen was an unknown, isolation and quarantine turned out to have been essential, and effective, tools in containment. This balance however, is based on a crucial, and little explored underlying assumption, which we might call state beneficence. This is the assumption that a state's actions are based on protecting the health and overall well-being of the governed. Given this assumption, populations may be willing to forfeit some individual rights for reasonable periods. Public health officials posit that with the general welfare at the center of concern, states may legitimately temporarily restrict the rights of citizens, and of travelers and other non-citizens, even if basic human rights (freedom of movement, of association, and others) may be curtailed in the process. And given the premise of beneficence, and of the need to limit some rights for the greater good, international agencies with global health mandates, like the World Health Organization, can expect state cooperation in regional or global restrictions. SARS has shown us that these restrictions can have severe economic impacts. Nevertheless, in an interconnected world, where global travel and exchange are essential to prosperity and development, this kind of cooperation is tantamount to good global citizenship. Leadership and timely and decisive action are called for when anthrax spores are found in congressional mail, or a new respiratory disease begins to kill health care workers. But trust in public agencies is needed too, and citizens have a right to expect transparent and fair actions if they are to temporarily surrender individual or civil liberties.

The Assumption of State Beneficence

But what if state beneficence is partial, limited, or lacking altogether? Sadly, there are all too many states where any rational assessment of social policy leads to the conclusion that state beneficence cannot be taken as a given. The clearest examples of the absence of state beneficence are kleptocratic dictatorships; states run for the benefit of individuals or small elites. In this category we could include the decades-long Mobuto regime in Zaire, Saddam Hussein's Baathist Iraq, the current regime of General Than Shwe of Burma, or that of Charles Taylor's Liberia. In each case, whatever the international community positions have been toward these regimes, it has been abundantly clear to the people forced to live under them that the health and well-being of the citizenry was not of primary concern to the state. General impoverishment and vulnerability to health threats are cardinal characteristics of these states, and it ought to come as no surprise that each shares a record of worsening vital statistics at home and the export of suffering in their respective regions. Indeed, the relationship between these kinds of regimes and infectious

diseases was recently made clear in a lead editorial in the *New York Times* (17 April 2003), entitled "Dictatorships and Disease."

How have these relationships operated? Charles Taylor has used his Liberian national forces as a private army in the diamond trade, exporting war to Sierra Leone, and more recently, to Cote d'Ivoire, in an expanding circle of violence, social chaos, and slaughter. Mobuto left Central Africa a dark legacy, one that includes sporadic Ebola outbreaks and ongoing HIV spread, in addition to a war involving at various levels, nine other African states, a war that stains the regimes of Uganda, Rwanda, and post-Apartheid South Africa, to name only a few. And Burma under Than Shwe continues to generate new refugees for Thailand and India, and to export heroin and methamphetamines in staggering quantities to China, India, Thailand, Laos, and beyond (Beyrer et al, 2000). In addition to grossly under-funding public health and mishandling its own HIV epidemic, Burma also serves as the incubator for malaria drug resistance in southeast Asia, and to continue seeding the mountains of the Thai-Burma border with landmines (Human Rights Watch, 2002). The U.S. Department of State recently confirmed reports of systematic rape of ethnic minority (Shan) women and girls by Than Shwe's forces as a tool of the junta's ethnic cleansing policy in minority areas (HRW, 2003).

States like these rule by force. They have to, their unpopularity means they can only stay in power through coercion, intimidation, and suppression of dissent. Looked at from the perspective of a citizen of one of these states, the balance of individual rights and the public good must seem utterly perverse. When neither the protection of individual rights nor the public good motivate state actions, public health suffers. When trust in the state and its agents is lacking, what reason should individuals have to assume that anything the state is reporting is true? Or that temporary restrictions on civil liberties will indeed be temporary? One of the dangers of such fundamental abrogation of trust is that when such states do try to respond to a disease outbreak or other health threat, they have little credibility. Hence when such states do try to "do the right thing" their motives are suspect and the information put out through state organs distrusted. In a situation like AIDS, where donors funds are increasingly available, the lack of public trust in many states can inhibit condom uptake, or lead people to refuse HIV testing even when it is made available. Health information becomes suspect when it appears in what the public knows to be state censored media.

Blatantly coercive states where beneficence is lacking are thankfully, a minority. Much more common, arguably, are states where the assumption of beneficence holds, but to a partial or limited extent. The People's Republic of China is an example. The ideology of the ruling party is based on a premise of beneficence, on an effort to strengthen and modernize China, albeit with a strong emphasis on the public good over individual rights. There is a clear limit, however, defined as essentially anything that threatens the primacy of the party. Freedom to trade is tolerated; freedom to dissent in political or religious spheres is not. Hence China's initial response to SARS, and the party's almost reflexive desire to repress information

about the epidemic, which led, as such suppression often does with infectious diseases, to a much wider epidemic (Parry, 2003). For those working on HIV/AIDS in China, the initial SARS response was painfully familiar. Because provincial officials and their associates in Beijing have been implicated in China's iatrogenic epidemic of HIV among poor rural blood donors, transparency is still limited, and the party continues to place restrictions on medical and epidemiologic investigations of this outbreak. It may be the most severe iatrogenic epidemic of HIV to have occurred since the start of the pandemic (Beyrer, 2003). It is encouraging that China's leaders appear to have realized that continuing to deny SARS was causing more damage to the regime than transparency could have, and that they changed course.

Beneficence may be limited by a range of other factors; incompetence, corruption, adherence to bureaucracy over the public good, sheer poverty. The last of these, simply lacking the resources to respond, is paradoxically one of the simplest to address. There are a wide and growing range of donors active in public health, and even the poorest states, if they can demonstrate genuine concern for health and development, can increasingly find partners and make impressive gains. Incompetence and bureaucratic rigidity on the other hand, are much more difficult challenges for public health. Not least because inefficient and ineffective systems generally lead to slow responses, and in a global epidemic environment, timeliness is essential. The approval process for collaborative health efforts in Ethiopia is a case in point. This desperately poor country has a wide range of public health problems, and an estimated 10% of all people with HIV in Africa are Ethiopians. Yet approvals can take two to four *years* to move through the multiple layers of Ethiopia's bureaucracy. Ethiopia's catastrophic famines of the 1980s are now largely understood to have been caused as much by state inertia and incompetence as by drought. The famine underway now across the country has been attributed, at least in part, to the disastrous border war with Eritrea—many donors, including the IMF and the World Bank, suspended aid when it became clear that it was being diverted to the war effort, and not to poverty alleviation.

Trust in government requires some level of transparency. Secretive regimes, those that engage in censorship, or attempt to limit public access to information, the Internet, or opposition voices, are particularly problematic for this new era of global epidemic disease threats. At the most basic level, science has become a truly international undertaking, and restrictions on scientists limit a state's ability to participate as threats unfold. Internet access in Burma is restricted by security edicts of the junta, but also by government fees. Individuals can apply for Internet access or modems, but if approved, must pay 5,000 USD as a license fee, well beyond the reach of nearly all Burmese citizens (Personal communication to the author, 2002). The secretive North Korean dictatorship has had health officials concerned for over a decade that food security has led to large-scale malnutrition among North Koreans. While we have some data and some testimony from refugees, no population level assessments have been allowed. What are the implications of the lack of transparency for disease outbreaks? Most obviously, epidemics can begin and spread

before the global public health community is made aware they are happening. In the case of the initial SARS outbreak Guangdong, it was more than five months before Chinese officials allowed international investigators to interview the first index cases, only to uncover that nearly all of them worked in the same exotic animal market (Chou, 2003). This is a classic example of why transparency matters—indeed, with a swifter and more transparent investigation at the start, Asia's SARS outbreak, its costs now counted in the many billions of dollars and over a thousand lives, might have taken an altogether more benign course.

How Can a Human Rights Approach Improve Public Health Responses?

Public health cannot alter the fact that many regimes do not have the interests of their constituents at heart. But there may be approaches to an explicit political and human rights focused approach, which can help practitioners and agencies better cope with public health threats in an interconnected world.

First, state beneficence cannot be taken as a given. Critical thinking about the human rights and political contexts in troubled states may allow for deeper analysis of emerging threats and clearer assessments of state responses or non-responses. Evidence-based assessments of the role repressive laws, bad governance, censorship, corruption, and malfeasance play in state policies can lead to understandings of health threats more grounded in reality, greater awareness of our own roles and actions, and insights into structural impediments to improving public health.

Second, the tools of public health can be used to investigate and assess the impact of poor governance and human rights violations on populations, epidemics, and wider public health threats. This is of crucial import, as much of mainstream human rights and civil society work is too often analytically limited to legal approaches—to investigation and reportage on the right violations of individuals. Globally, human rights workers need public health tools, and public health research needs political analysis.

Third, a rights-based framework can allow public health to serve and to partner with those forces for social change which are the long term hope for people living under oppression. These forces include women's organizations, health advocates and activists, ethnic minority leaders, people and institutions working toward democracy, open societies, empowerment, and basic rights. Working with such persons is not only ethically right, it has often been the only way to reach scientific understanding in the face of official censorship and denial. The price of intellectual freedom and scientific integrity in repressive states is high, and those of us who enjoy it at little cost have a responsibility to our peers. And because uncensored inquiry is fundamental to the scientific endeavor, we risk the loss of scientific validity if we accept censored versions of events.

Fourth, a human rights framework for public health practice can help us design interventions that take the harms and realities of lacking or limited state beneficence into account. This can help us answer a fundamental question raised by

Madeleine Albright as Secretary of State: "How do we help people living under despots without helping the despots themselves?" There is a growing body of innovative methods and approaches to public health problems which attempt to do just this. Using novel and uncensored media, cross-border interventions, and working with non-governmental agencies have been used in diverse settings to help people living under despots. Linking health aid and other forms of assistance to civil society milestones is another approach.

Conclusions

The HIV/AIDS pandemic, now well into its third decade and spreading in states as diverse as Belarus, Ukraine, Indonesia, and Papua New Guinea, has shown us that we truly are sharing an interconnected world. As we struggle to deal with both ongoing and emerging threats to public health, and to reach just balances of the rights of individuals and communities, it is critically important not to lose sight of the many states where neither the rights of citizens nor the well-being of the community drive policy. Secretive, rights-violating regimes make poor global citizens in a world where new threats can emerge from obscure corners of the world (like occupational exposures in the butchering of masked palm civets or chimpanzees) and spread fast and far. The mishandling of public health threats in such states may be due to incompetence, malfeasance, official denial, censorship of science, bureaucratic inertia, or the desire not to lose face on the global stage. This is true for state failure in an array of other arenas, including economics and development. But public health failures are likely to have effects beyond state borders, and to affect us all. And this may be reason for some hope: outbreaks like SARS cast a bright light on ineffective responses, and may be one more reason for the citizens of the world who live in free societies to be concerned over the fate of those who do not.

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