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After SARS: Fear and Its Uses

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In the mid-twentieth century, antibiotics and modern medicine seemed to be eliminating the threat of infectious diseases. But since the 1980s and the emergence of HIV/AIDS and the subsequent appearances of Ebola, Hanta Fever, West Nile Virus, Lime Disease, SARS, and Monkey Pox, it is clear that the dangers posed by new infectious diseases or by old ones reappearing in drug-resistant forms (or as weapons of bioterrorism), are fearsome and compelling. Among the recent outbreaks, SARS especially caused hysteria around the world and demonstrated how important public health is to global safety. How much should we be alarmed by each new disease? And how might we use our fears to energize public health agencies and force the public generally to confront the issues of equity and liberty raised by infection?

Despite data showing that endemic diseases such as tuberculosis and malaria kill more people worldwide than the emerging diseases (with the important exception of HIV/AIDS, which has become the number three cause of death in the world), it is the new and unknown illnesses that produce anxiety. Anxiety doesn't grow only from statistical dangers. The sense of personal risk-when disease comes close to our doorstep-seems to be far more important in determining responses than do the numbers and distribution of actual cases. Our worries begin with our lack of knowledge about each new disease, and they grow as a result of media coverage that emphasizes danger and evokes panic even while appealing for calm.

The dangers are real. What the recent disease outbreaks demonstrate is that public health agencies and standards, in the United States and elsewhere too, have fallen prey to their previous successes. In recent years, believing we had conquered infectious disease, we grew complacent and withdrew support from health departments around the country. But now HIV/AIDS, Lyme disease, West Nile Virus, and SARS have shattered our complacency. Actually, it shouldn't have taken new diseases to do that. Consider that, in 1993, faulty water purity surveillance led four hundred thousand people in Milwaukee to succumb to (very old-fashioned) gastrointestinal illness. The protection we get from state agencies, our collective ability to prevent or deal with health crises, is lower today, in many areas, than it was in the past.

We need to worry about this-more, perhaps, than about any particular disease. The decrease in available resources devoted to public health is a serious political problem. Old diseases such as tuberculosis and malaria continue to kill; new diseases-like SARS-are not taking lives at the same level but serve nonetheless to alert us to the fact that we are not safe. If the fear of SARS, or of bioterrorism, can lead us back to more general support for public health, then this is a time to let our worries be our guide.

A little bit of history can provide some perspective on the issues raised by SARS and other emerging diseases. Among the areas left to the states when the Constitution was adopted were public health and welfare. What this meant in practice emerged slowly over time; by the last third of the nineteenth century, most states and big cities had well-developed health departments. These agencies (often working in tandem with departments of public works) took on the mammoth tasks of taming the urban environment: building water and sewage systems, paving streets, and overseeing the food and milk supplies. New York City in the 1840s, for example, engineered the extraordinary task of bringing clean water from the Croton River, forty-five miles north of the city, via a complicated system of viaducts, bridges, and pipes, into city homes and businesses. In an even more amazing engineering feat, beginning in the 1850s, Chicago, situated on muddy flatland, literally reconfigured the geography of the downtown area, lifted city streets and buildings so that sewage could be carried away, and ultimately reversed

the direction of the Chicago River-all this in order to protect the city water supply and the public's health. These are jobs that the private sector could not have undertaken, much less accomplished. Most important for our purposes here, health departments developed increasingly powerful-but also intrusive-ways of controlling infectious diseases.

Rarely in the late nineteenth and early twentieth century did the powers of health departments increase because of endemic diseases such as tuberculosis. Rather, politicians responsible for city budgets responded more readily to the new and frightening diseases that periodically swept through American cities-smallpox, cholera, yellow fever, or plague. Reasoning that because such diseases were not always present, they must be preventable, health officials waged active campaigns to prevent them. In the process, public health departments grew, and their powers and budgets greatly expanded. By the early twentieth century, these departments routinely asserted their authority over individuals who might stand in the way of their activities-softening their interventions, sometimes, with popular education campaigns to teach individuals to change their personal habits and behavior.

The delivery of clean water, safe food, and immunizations has had a remarkable effect on everyday life in the United States. Each of these accomplishments was achieved over time and sustained by a public health infrastructure that required, first, the development of agricultural and industrial sanitary standards and second, the creation of government agencies authorized to enforce these standards. By the twentieth century, these agencies included federal, state, and local departments of health, the Environmental Protection Agency, and the Food and Drug Administration. From nineteenth-century milk stations in cities such as Rochester, New York, and Milwaukee to the twentieth-century Centers for Disease Control and Prevention, multiple levels of protection were created and integrated. Infectious diseases are very local: people are infected and must be isolated one by one, and data must be gathered in each community. But these diseases are also global: SARS hopscotched the world via transcontinental flights. Early warning systems require global data. The work of protection cannot be shouldered by individuals or local governments alone.

Perhaps the most dramatic example of integrated health agencies working to protect the public from epidemic threat came in New York City in 1947. A traveler brought smallpox from Mexico to the city, walking the streets and shopping with his wife, exposing others to the disease, before his illness was so advanced that he entered Bellevue Hospital for treatment. Physicians had not seen a case of smallpox in decades, and did not recognize it until the man had died and exposed still more people. Alerted to the danger, the city health department, with help from state and federal agencies, vaccinated more than six million New Yorkers in a month, the largest and most successful smallpox immunization campaign in American history. Swift action and the effective use of community organizations and all levels of government protected New Yorkers from a potential health disaster.

Today we expect to be free of infectious disease; we take our health for granted. Infectious, respiratory, and gastrointestinal illnesses are relatively few and far between. When we are afflicted with such illnesses, we expect to recover quickly and fully. We do not worry too much about exposure among strangers; when we visit other people's buildings we drink the water and enjoy the air conditioning. We have come to assume that we are safe in our everyday environment.

But our safety has come at a cost to our civil liberty. Early in the twentieth century, New York's medical health officer, Hermann Biggs, realized that the powers vested in health departments were "extraordinary and even arbitrary." When individuals stood in the way of health department good works, especially in times of epidemics, they were pushed aside. Such powers, although wielded lightly in many cases by reformers who believed they were making the world safer for everyone, became the focus of significant resistance. As we contemplate the re-expansion of health powers today, examples from early twentieth-century Milwaukee, San

Francisco, and New York can provide cautionary lessons on how best to proceed.

In Milwaukee, during a smallpox outbreak in 1894, a month of public rioting resulted from health department attempts forcibly to remove sick children from their families to take them to the isolation hospital. The health commissioner, determined to save lives from this horrible disease, vowed to "break heads" to enforce the law. He failed to notice that the methods he used, because of the resistance they provoked, rendered his efforts at smallpox control ineffective. The "broken heads" were disproportionately those of poor immigrants, who were especially wary of governmental authority. Because of the perceived discrimination, the complete lack of sensitivity to cultural difference, and the highly coercive tactics used by the health department, Polish and German immigrants took to the streets and ultimately managed to prevent the commissioner's enforcement of the health measures.

In San Francisco, the "arbitrary" powers of the health department fell disproportionately on Chinatown when the plague hit in 1900. The first case of plague was diagnosed in a Chinese man named Wong Chut King, and before daybreak the next day, the Chinese section of the city was quarantined and traffic in and out curtailed. Nonetheless, the white residents of the section were permitted to come and go. Court action ultimately brought a semblance of justice to the situation, and the quarantine fell, but not before the health department's racism had been revealed.

In New York City, the famous case of an Irish immigrant woman named Mary Mallon demonstrated the risks to individual freedom of public health activity taken in the name of the many. Found to be a healthy carrier of typhoid fever, "Typhoid Mary" was quarantined on an island in the East River for twenty-six years, her civil liberties radically restricted, because her cooking endangered anyone who ate her food. Even while thousands of other carriers walked the city's streets, Mallon remained on the island, a striking example of how far the health department could go in order to preserve the public's health.

What are the obligations of sick and well individuals to help and protect each other? And what role should government play in enforcing those obligations and protecting Americans from the risk of infectious disease? In the cases of the Milwaukee smallpox riots, Wong Chut King, and Mary Mallon, it is relatively easy to see how discrimination and coercion worked against successful public health efforts. They made everything more difficult by alienating the very people whose trust was needed in order to bring them into the health care system.

Two things are clear, and from these we must build our medical and political responses to the threat of epidemic. First, the public health risk is real and immediate: worldwide an estimated six million people will die in the coming year from tuberculosis, malaria, and AIDS combined. If we can use lesser killers such as SARS, West Nile Virus, Monkey Pox, and other emerging diseases to hammer the point home, we can strengthen health standards, rebuild public infrastructures, and demonstrate how government can work in the general interest. Second, public health activity itself carries risks. So we must also work to ensure that government agencies do not overstep the bounds of fairness and equity as they wield their big stick.

The argument for fairness needs to address three dangers: the labeling of whole categories of people as threats to the public's health; the isolation of individuals and neighborhoods; and possible scapegoating in the allocation of responsibility for the spread of disease. Let us consider each of these in turn.

Labels. As we learned from our early experience with HIV, just to be identified as a new disease sufferer or carrier can itself be threatening. Calling Mary Mallon "Typhoid Mary," designating some SARS carriers "super spreaders," or describing an individual as "patient zero," attaches a stigma to the named people. Labeling an individual or a group of individuals dangerous to the public is not a benign act that leads automatically to medical understanding and cooperation.

Rather, stigmatization can make disease control more difficult. The phrase "Typhoid Mary" might have initially been a simple description, but Mary Mallon never saw it so simply. She understood that it took away her individuality, her self, her life, and this led Mallon vigorously to resist all public health efforts to "deal" with her. "Stigma and discrimination are the enemies of public health," wrote Jonathan Mann, former Director of the International AIDS Center. When people who are infected are treated as if they were polluted, they are unlikely to cooperate in the treatment. In order to stem epidemic threats, we need to educate without stigmatizing, to work toward building trust rather than resistance.

Isolation. In thinking about how far the government might go to control infectious diseases, we must consider that isolation is one of the most useful and one of the most frightening possibilities. Some states considered isolating all individuals infected with HIV; others isolate only "uncooperative" infected individuals. Cuba provides an example of how the delicate balance between personal liberty and public health protection can be subverted. In 1986, it began a national program to contain AIDS, which included systematic screening, isolation of all HIV positive individuals, and the requirement that all HIV positive pregnant women abort. The plan was not voluntary. The government forced citizens to leave their work and their communities and move to settlements of the infected, separated from the larger society by barbed wire. Such extreme measures resulted in much individual suffering without completely containing the virus. This experience should help guide our thinking about the uses and abuses of isolation.

Nonetheless, isolation of the sick has to be part of twenty-first-century public health administration. For infectious diseases such as SARS, which maintain their infectivity for days after the initial symptoms appear, and for which there is (as yet) no treatment that stops or reduces infectivity, isolation of the victims is the only known method of preventing the spread of the disease. Isolation can be onerous for people who are ill; it is especially so for people who may be infectious but are not very ill, and egregiously so for those who are healthy but carriers. The Cuban example shows us the suffering of individuals caused by an authoritarian approach to isolation. But the story of the spread of SARS in south China shows us the suffering and death that occurs when carriers are not isolated. Effective and fair public health responses lie somewhere between these two extremes.

A health policy that emphasizes a custodial over a health-keeping function makes it easier to expel individuals from society. No doubt, there will always be men and women who have to be forcibly separated from their fellows in order to keep them from willfully transmitting disease. But in more ordinary cases, we need a policy more effective than coercion, one that recognizes that people who are potentially dangerous to others must be made aware of their infectivity and taught how to minimize or prevent it. If there is public confidence in a benevolent and nondiscriminatory health care system, people would be more likely to cooperate even with (temporary) isolation, and coercion would be less necessary.

Scapegoats. Unfortunately, health policies in the United States have often been discriminatory and unfair. We have scapegoated certain groups or individuals for spreading disease and used the threat of disease to divide people along already familiar fault lines of race and class. Mary Mallon perceived that her status as an immigrant, single, working-class woman led to her unfair treatment at the hands of health officials. In San Francisco in 1900, health officials blamed all the city's Chinese inhabitants for causing plague, rather than tracing the contacts of the sick. In the 1930s, the U.S. Public Health Service began an experiment in Macon County, Alabama, to trace the "natural" development of syphilis in African American males, and in the process denied the participants the benefits of effective therapy. The Tuskegee syphilis study, now notorious, lasted forty years. In our nation's history, immigrants, the poor, and African Americans have frequently been despised and feared, and then labeled and isolated, as harbingers of disease and death.

Fairness in health policy is not just a matter of consistent application of the laws. If so, the

Cuban example would be a model. We need to develop substantive policies that consider both civil liberty and public health protection as equally valued national priorities. In 1922, A.J. Chesley of the Minnesota Board of Health described the public health dilemma we still face today-in terms appropriate to his age, when the business of America was business, and still to ours. He argued that officials aiming to reduce the threat from diseases first had to convince the public that it was good business and good public policy to provide funds for health work. People had to understand that loss of productivity caused by preventable diseases was too costly to be tolerated. Second, he urged that those individuals who might endanger the public health had to be economically and socially supported so that they would be willing to endure hardships (such as isolation). Chesley understood that the public was right to demand protection against communicable diseases, but he insisted that the people who carried those diseases were also right to demand protection. Only by understanding the perspectives both of those at risk of catching a disease and of those who might be carrying it could realistic public health programs develop.

Historically, epidemics have not been controlled by the actions of individuals or the private sector. A well-maintained infrastructure, broad public coalition building, and community education and organizing have been essential to successful public health campaigns. The new invasions of infectious disease demonstrate again that protecting public health requires building institutions and procedures that are adequately funded and that operate fairly. Our recent experience with SARS isolation requires us to look especially carefully (at a time when indefinite detention seems possible again) at the methods in place for dealing with the next plague. Effective epidemic control, justly administered, with the smallest restriction of individual freedom compatible with public health, can give government what it doesn't have now-a good name.

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