Drug-resistant tuberculosis and the ethics of tuberculosis control

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Despite the declaration of tuberculosis (TB) as a global health emergency by the World Health Organization in 1994, many in North America were unaware of the rapidly increasing health burden of TB until the highly-publicized Andrew Speaker incident. Speaker, an American lawyer, knowingly left the United States while infected with extremely drug-resistant TB and prompted an international health scare which led to the first federal quarantine order since 1963. This incident highlights the growing concern of emerging drug-resistant strains of tuberculosis, regarding which the WHO issued a global alert in 1996. It also raises many issues meriting ethical examination, including public health measures to control TB, individual obligation to avoid infecting others, and the role of the physician in infectious disease control.

The global health burden of tuberculosis

Historically a leading cause of human mortality, tuberculosis was thought to be on its way to being eradicated in North America as early as the 1950s. This decline was interrupted by a highly publicized resurgence in New York City during the 1980s and 1990s, primarily among homeless and HIV positive individuals. The epidemic was eventually brought under control in the 1990s following enormous health care expenditure and coercive public health measures, including mandatory directly observed therapy (DOT) and detention of patients who were noncompliant with their prescribed treatment regimen. However, TB has remained a significant issue all along in developing nations; with one-third of the global population infected with a latent form, TB is currently the second leading infectious cause of mortality worldwide.

Prior to the Speaker incident, awareness of the increasing global health burden of TB had been largely overshadowed in Western society by media focus on the HIV/AIDS epidemic. The episode also highlighted the threat of emerging drug-resistant strains of tuberculosis. Approximately 20 percent of worldwide TB cases are identified as multi drug-resistant (MDR-TB), and 10 percent of these are extremely drug-resistant (XDR-TB). MDR-TB is defined as TB resistant to at least two of the four first-line medications, namely isoniazid and rifampicin. XDR-TB refers to MDR-TB, in addition to resistance to fluoroquinolones and any one of the second-line anti-TB drugs.

The Speaker incident

Despite acknowledgement from the US Centers for Disease Control (CDC) and the WHO of the emergence and spread of extremely drug-resistant TB (XDR-TB), the issue did not receive extensive attention until Andrew Speaker became a household name in May 2007. Speaker tested positive for tuberculosis in January 2007, following a pulmonary abnormality detected on chest x-ray and CT scan, and a subsequent diagnostic bronchoscopy, for which he was prescribed a standard regimen of first-line medications. He underwent susceptibility testing at the Fulton County TB Clinic in Georgia following the disclosure that he planned to travel overseas for his honeymoon in May 2007. This susceptibility, or sensitivity, testing was done to determine the likelihood that his drug treatment regimen would be effective in eliminating or inhibiting the growth of the infection. The results indicated that Speaker was infected with multi drug-resistant tuberculosis.
Despite being advised by his primary care physician and the Fulton County Health Department that he should not embark on his planned international travel, Speaker flew to Europe without informing any public health official. The discovery through further sample analysis that he had XDR-TB prompted a nationwide border alert, and the Center for Disease Control located Speaker in Rome and instructed him not to travel on a commercial aircraft because of the significant threat he posed to other passengers. Despite this warning, Speaker flew to the Czech Republic and then to Canada, having correctly assumed that there was an order preventing him from boarding any US-bound flight. He reentered the US by automobile and was promptly discovered by the CDC and served the first provisional federal quarantine order since 1963.2

Public health versus individual liberty

One of the main ethical challenges highlighted by the Speaker case is how to balance public health concerns, which encompass the utilitarian aim to promote the greater good, against the libertarian aim of protecting individual rights and liberties. Most would agree that neither public nor individual interest should always be given absolute priority over the other. The challenge, therefore, lies in striking an ethically acceptable balance between these two interests. Speaker’s actions raise questions concerning the ethical obligation of individuals to avoid infecting others, which follows from the accepted ‘duty to do no harm.’8 However, there must be limits to these duties, as it would be excessive and virtually impossible for all potentially infected individuals to take all possible precautions to avoid infecting others. There is no disputing that Speaker behaved in an ethically inappropriate manner in ignoring the health authorities’ traveling advisory. One must also realize, however, that an ethical obligation to avoid infecting others must involve full understanding of the risk of infection. One of the points of controversy in this case involves Speaker’s allegations that he was initially simply cautioned against, and not explicitly prohibited from, traveling.8 Regardless of the truth of this claim, we may learn from it that we, as health care providers, can strengthen this ethical obligation to avoid infecting others by making certain the patient has full knowledge and understanding of the risks involved in undertaking a particular action. Relevant to this case, these include knowledge of the transmission of tuberculosis through airborne spread, the nature of drug-resistant TB, and the dangers of air travel and the risks posed to others.

It might also be possible that Speaker was not adequately reassured that he would receive acceptable care in Italy, or be returned to the US in a timely manner for treatment. While he might have been aware of the risk he posed to his fellow travelers in returning to Canada, his sense of ethical obligation might have been distorted through a lens of fear following a frightening diagnosis of extremely drug-resistant TB. Although it is also entirely possible that his actions were driven by selfishness and self-interest rather than fear, the health authorities could have endeavored to alleviate this fear by assuring him of the quality of TB-related care in Italy and providing him with a plan and timeline for returning him to the US.

Another ethical challenge regarding TB control, along with other infectious diseases, follows from the concept that an individual is both a victim of disease and a vector by which the disease may be transmitted to the greater population.9 How may we determine to what extent isolation measures, namely the coercive restriction of movement, are justified for the purpose of TB prevention, and who should be confined? Factors to consider in making these decisions include whether or not the patient is infectious and the risk the free movement of the patient poses to the general population. There is an obvious difference between confining someone with active illness and refuses to take their medication from someone with latent illness or a very low risk of contagion. One of the ethical failings in the control of the New York City TB epidemic involved the confinement of noninfectious patients who, although labeled as ‘recalcitrant’ for failing to take their medications properly and to report for scheduled medical appointments, posed no immediate infectious
danger to others. One of the interesting aspects of the Speaker case is that, although he was infected with an XDR-TB strain, his level of contagion was actually quite low, yet he was still placed and kept under federal quarantine for several months. It would not be unreasonable to infer that the isolation measures were therefore influenced by his noncompliant behavior and the threatening nature of his diagnosis, as opposed to strictly his level of infectious risk. As physicians, we should advocate for appropriate diagnostic tests to assess the patient’s level of infectivity and for evidenced-based isolation measures that are appropriate to the risk posed by the patient.

Fear-Driven Public Health Measures

Smith, Battin et al. discuss the ethics of public health decision-making regarding infectious diseases in context of their overwhelming ability to provoke fear and panic in populations. They argue that this fear can lead to emotionally-driven decision making that challenges basic medical ethics principles such as autonomy and social justice. In certain instances, the results of these decisions may be positive. For example, during the New York TB outbreak, the decision to institute mandatory directly observed therapy was motivated by the recognition of drug-resistant strains of the disease that were more difficult to eradicate, and this eventually helped to stem the outbreak. However, in other instances, fear-driven public health procedures may come into conflict with bioethical principles or even basic human rights. South Africa’s current policy involves enforced quarantine of patients with drug-resistant TB in prison-like hospitals with high fences patrolled by guards to prevent escape. Although the country is battling the highest global TB prevalence with a concurrent HIV/AIDS epidemic, some patients are required to spend several years in hospital, long past the point of infectiousness. Several recent studies have ascertained that these hospitals can, in fact, serve as breeding grounds for drug-resistant TB, such that patients with MDR-TB are contracting XDR-TB strains at an alarming rate. Thus, not only is this enforced quarantine a challenge to patient autonomy and human rights, but it is posing additional risk to the patients and is a huge financial burden on an already weak health care infrastructure.

The enormity of the media attention the Speaker case received, as well as the issue of the first federal quarantine in over 40 years, highlights the panic and fear that the emergence of drug-resistant tuberculosis has engendered in Western society. Given that his actual contagion was low, one must wonder whether the nature of his diagnosis with XDR-TB and the fearful response provoked by his actions influenced the health authorities’ decision to take extended isolation measures. This highlights our role as physicians in an era of mass media coverage to put infectious diseases and epidemics into context for the general public, and to assuage community hysteria when it is disproportionate. We have an ethical obligation to help our patients understand the severity of a situation, such as the danger posed by travel with infectious disease, but must also help public health authorities to minimize fear-driven decision making that is non-evidence-based or ethically suspect.

Social Justice in Tuberculosis Control

Another interesting aspect of the Speaker incident involves the fact that the case of one infected individual traveling through the developed world could generate so much media attention and bring the issue of drug-resistant TB to the global stage, when it has been a serious problem all along in developing nations. Speaker does not resemble the typical TB patient in that he is a wealthy, white, educated male from a developed country. Infectious diseases affect primarily the poor and developing world due to lack of sanitation and weak healthcare infrastructure, among other factors. When making public health decisions that may pose ethical challenges and infringe upon individual rights and freedoms, it is important to consider the nature of the population these decisions will affect. As developing nations are oppressed by virtue of their economic position, and will shoulder the burden of public health measures for the control of tuberculosis, it is important to give consideration to individual rights where possible, as the “blame, stigma, and ostracism associated with isolation and quarantine
are especially real for diseases linked to the poor… or the disenfranchised.”

Conclusions

Though by no means exhaustive, the ethical issues highlighted with respect to the Speaker incident illustrate the need for ethical reflection in developing public health policies for tuberculosis control. Drug-resistant tuberculosis, which has now become a global threat, is largely propagated in poor countries where poverty and a weak health care infrastructure often preclude finishing a full course of TB treatment. Improved health care provision in endemic areas would therefore reduce the frequency by which we would have to make public health decisions that challenge individual rights and freedoms. The role of the physician must involve providing the patient and the public with appropriate and adequate information in order to strengthen individual obligation to do no harm, as well as to prevent community panic and emotionally-driven decision making which can lead to public health policies that infringe upon the rights of the individual.

References