

# Infectious Disease Ethics: Limiting Liberty in Contexts of Contagion

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## Infectious Disease History and Status Quo

Infectious diseases are among humankind's worst enemies. They have historically caused more morbidity and mortality than any other cause, including war (Price-Smith 2001). Killing roughly 15 million people each year, they are currently the biggest killers of children and young adults worldwide.

Public health and medical progress—most notably with regard to improvements in sanitation, hygiene, and nutrition; and the development of vaccines and antibiotics—led to dramatic improvements in infectious disease control during the past two centuries,

especially in developed countries. Early in the second half of the twentieth century, modern medicine's power over infectious diseases appeared to be so great that it was commonly believed that it was “time to close the book on infectious disease” (Sasseti and Rubin 2007, 279).<sup>1</sup>

During recent decades, however, it has become clear that infectious diseases remain a major threat to humankind. Their continued danger is partly revealed by the phenomenon of “emerging and re-emerging infectious diseases”, whereby many new diseases (such as AIDS, Ebola, and SARS, to name just a few) have come into existence (or started spreading in humans, while transmission was formerly limited to other animals) and “old” diseases have been making strong comebacks. Related to this is the growing problem of drug resistance. For example, extensively drug resistant tuberculosis (XDR-TB) is resistant to so many classes of drugs that half of XDR-TB patients cannot be successfully treated (Stop 2007). In the context of tuberculosis (TB), therefore, it may soon be as though we have returned to a situation analogous to the pre-antibiotic era (Selgelid 2008). Unlike AIDS (which is only transmissible via exchange of bodily fluids), TB is an airborne disease that can readily be

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<sup>1</sup> Though this quote is routinely attributed to former US Surgeon General William Stewart, there appears to be no evidence that he ever actually said this. Whether or not Stewart himself said this, according to Sasseti and Rubin, “the sentiment was certainly widely shared”.

transmitted from person to person via casual contact: by coughing, sneezing, and even talking.

One of the worst pandemics (i.e., widespread global epidemics) in history was the great Spanish Flu, which killed somewhere between 20 and 100 million people in 1918–19. Experts have for many years warned that it is not a matter of if, but when, the next flu pandemic will strike. Although flu pandemics are not regularly cyclical, there were three pandemics in the last century; and with 40 years passed since the last pandemic of 1968, it is widely believed that the next pandemic is overdue. After several years of concern that a pandemic would arise from H5N1 avian influenza—which kills over 60% of humans it infects but has not, to date, led to sustained human-to-human transmission—at the time of this writing (in May 2009) it appears that we may suddenly be on the verge of a pandemic of H1N1 swine influenza, originating with a human epidemic in Mexico. On 29 April 2009, the World Health Organization declared that we had reached pandemic “phase 5”—meaning that an H1N1 pandemic may be imminent.

In some ways we are now better prepared for a flu pandemic than our predecessors were in 1918–19. Global surveillance for potentially pandemic-causing diseases is greater today than ever before. Moreover, antiviral drugs, vaccines, and antibiotics<sup>2</sup> may allow us to fight the next flu pandemic more effectively than was possible in 1918–19 (when such effective pharmaceutical interventions were not yet available). The supply of antivirals, however, will likely not meet demand; it may take 6 months before large-scale production of vaccine against a new strain of influenza is possible and several years before world population demand can be met (WHO 2009). Meanwhile, other aspects of the contemporary world may exacerbate dangers in comparison with the situation in 1918–19. Increased population densities, particularly in megacities, and the increase in trade and travel associated with globalisation, for example, may facilitate the speed at which the next pandemic will spread (Arinaminpathy et al. 2009; Brockmann et al. 2005).

<sup>2</sup> Antibiotics may be used to treat bacterial infections that sometimes accompany influenza.

## IDE: Infectious Disease Ethics

Though ethical issues associated with infectious disease have not been a traditional focus of discussion within the discipline of bioethics—and though it has been argued that the topic of infectious disease was for a long time grossly neglected by bioethicists (Selgelid 2005; Francis et al. 2005)—this has started to change. AIDS was perhaps an exception all along; it, at least, received substantial discussion among bioethicists since its emergence was first recognized in the early 1980s. More recently, the SARS crisis of 2003 and fears over (especially avian) influenza and bioterrorism (especially following the events of 11 September 2001 and the subsequent anthrax attacks in the US) have attracted additional attention to ethical problems posed by infectious disease. The growing literature on ethics and infectious disease is partly related to the emergence of public health ethics as a rapidly growing subdiscipline of bioethics; and a number of recent books have focused on ethical issues associated with infectious disease in particular (Selgelid et al. 2006; Balint et al. 2006; Lemon et al. 2007; Battin et al. 2009). We call this new field Infectious Disease Ethics (IDE).

Infectious diseases raise a relatively unique constellation of ethical problems. Because (in most cases) infectious diseases are spread from person to person, innocent individuals can present a threat to other innocent individuals. Issues of respect for liberty, responsibility, prioritization, discrimination, equality, and distributive justice arise acutely. Restrictions of liberty and incursions of privacy and confidentiality may be necessary to promote the public good.

Even allowing or inflicting risk of harm on individuals may be morally required in extreme circumstances. Depending on the disease, imposition of quarantine may sometimes be necessary to prevent a major epidemic. However, in cases where an airplane, building, or region is quarantined, uninfected individuals held in (possibly close) confinement with infected individuals may themselves end up becoming infected—and perhaps die—as a result. Though this would be unfortunate, unintentional imposition of such harms may be justified (just as we tolerate killing of innocent individuals in times of war) if the stakes for public health are sufficiently high.

Part of the ethical importance of infectious diseases relates to the fact that their consequences can be so severe. Naturally-occurring epidemics have constituted some of the most devastating events in human history. For example, the Black Death eliminated one-third of the European population over the course of a few years in the middle of the fourteenth century.

The Astronomer Royal and President of the Royal Society, Martin Rees estimates that “the odds are no better than fifty-fifty that our present civilisation on Earth will survive to the end of the present century” (Rees 2003). One of the most significant threats to civilization this century will be the use of bioweapons and bioterrorism. We will require an ethics of infectious disease to deal not only with naturally occurring pandemics but also with those which will almost inevitably be caused by evil human beings. It has perhaps never been more urgent in the last 100 years to develop an ethical as well as a medical approach to dealing with widespread outbreaks of infectious disease.

Finally, we should recall that the topic of infectious disease is closely connected to the topic of international justice. The infectious disease burden (at present, anyway) is by far the highest in poor countries. For example, 95% of TB cases and 98% of TB deaths occur in developing countries. This is partly because things like malnutrition, lack of sanitation and hygiene, poor education, and crowded living and working conditions are factors which increase chances of becoming infected with such diseases. Furthermore, the poor are often more likely to suffer bad outcomes when infection occurs because they cannot afford medicines for which they must pay out-of-pocket, and healthcare systems in poor countries are usually weak. The fact that many poverty-stricken patients in poor countries cannot afford to finish courses of treatment they have started is part of the explanation for the rise of drug resistant disease. When drug resistant strains of disease emerge and spread, these pose increased risks to rich and poor countries alike.

### Oxford Conference

This Special Issue of *Journal of Bioethical Inquiry*—on “Infectious Disease Ethics: Limiting Liberty in Contexts of Contagion”—is one step towards support-

ing the development of IDE. It is largely a product of an interdisciplinary conference that took place at the University of Oxford on 4 July 2007. This conference was jointly organised by Julian Savulescu, Michael Selgelid, and Angela McLean and was jointly held by the James Martin 21st Century School (Program on Ethics of the New Biosciences and Institute for Emerging Infections) of the University of Oxford, and the Centre for Applied Philosophy and Public Ethics (CAPPE) of The Australian National University.

This conference strengthened our conviction that the interdisciplinary space between philosophers and scientists, where it exists, can offer fertile ground for collaborative efforts. Nonetheless, a lively discourse between both groups was lost in translation from the conference and journal review process to this edited volume. A recurring critique from philosopher reviewers during the journal review process was that papers by scientists were “naive” in their treatment of the ethical issues raised. The common riposte from scientists was “we are not ethicists, we’re just describing an ethical issue we have observed”. Furthermore, especially during the conference, scientists sometimes complained that the philosophers were not sufficiently informed about empirical matters and thus not realistic. This creative tension clearly points towards a rich potential for deeper, longer collaborations producing joint papers that can move these questions on from a cross-disciplinary discourse to a truly interdisciplinary one.

### This Volume

As our subtitle—Limiting Liberty in Contexts of Contagion—suggests, paramount among ethical issues associated with infectious disease are those that arise with conflict between the goal to promote individual liberty, on the one hand, and the goal to promote other legitimate social goals such as (equality or) utility in the way of public health, on the other. The papers in this volume focus on such conflicts and, *inter alia*, illustrate the diversity of ways in which such conflicts can arise and offer carefully argued, creative solutions for addressing them. They cover a broad range of topics including ethical issues associated with allocation of medical resources during an influenza epidemic (Verweij and Arinaminpathy et al.); liberty regarding prescription practices in light of

threats to drug resistance (Coleman); ethical issues associated with “syndromic surveillance” (Francis et al.); “reciprocity” and the moral imperative to compensate those subjected to liberty-infringing (and/or potentially harmful) public health interventions (Viens et al. and Holm); ethical issues related to research on, and deployment of, new TB vaccines (Fletcher et al.); the ethics of opt-out HIV testing (Jaffé and Wilkinson); and the obligations of the relatively affluent to contribute more to improve the situation of poor people in poor countries (Barry and Øverland). We also include reviews of recently published books on international public health ethics and IDE (Bayer and Dawson); and, finally, we invite responses to an ‘In That Case’ study regarding pandemic planning (Brock).<sup>3</sup> We hope that this volume stimulates the reader to appreciate just how urgent and significant IDE is.

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<sup>3</sup> Though also related to IDE, the other ‘In That Case’ study included (with responses) in this volume is part of regular journal material and thus not edited/solicited by us.