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Special Issue

Pandethics

M.J. Selgelid^{a,b,c,*}^a Centre for Applied Philosophy and Public Ethics (CAPPE), The Australian National University, Canberra, Australia^b Menzies Centre for Health Policy, The Australian National University, Canberra, Australia^c National Centre for Biosecurity, The Australian National University, Canberra, Australia

ARTICLE INFO

Article history:

Received 7 October 2008

Accepted 9 December 2008

Available online 14 February 2009

Keywords:

Ethics

Infectious disease

Pandemic

Influenza

Infection control

Duty to treat

Allocation of resources

Isolation

Quarantine

SUMMARY

This paper explains the ethical importance of infectious diseases, and reviews four major ethical issues associated with pandemic influenza: the obligation of individuals to avoid infecting others, healthcare workers' 'duty to treat', allocation of scarce resources, and coercive social distancing measures. In each case, ways in which the ethical issues turn on both philosophical and empirical questions are highlighted. The paper concludes that ethicists should play a greater role in identifying ethically important empirical questions, and that scientists should take the ethical as well as the scientific importance of such questions into consideration when choosing research projects.

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Introduction

The ethical importance of infectious diseases is partly revealed by the fact that their consequences are almost unrivalled.¹ Historically, they have caused more morbidity and mortality than any other cause, including war.² The Black Death eliminated one-third of the European population over the course of a few years during the mid 14th Century³; tuberculosis killed 1 billion people from 1850 to 1950⁴; the 1918 flu killed between 20 and 100 million people⁵; and smallpox killed between 300 and 500 million people during the 20th Century alone, i.e. three times more than were killed by all the wars of that period.⁶ Infectious diseases are currently the biggest killers of children and young adults, and the continuing threat of infectious diseases is revealed by the emergence of many new infectious diseases during recent decades [including human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), Ebola, severe acute respiratory syndrome (SARS) and avian influenza], the growing problem of drug resistance and the spectre of bioterrorism.

Second, infectious diseases raise difficult ethico-philosophical questions of their own. Although measures such as surveillance,

mandatory treatment and vaccination, isolation and quarantine may sometimes be important to the protection of public health, they may each involve infringement of basic rights and liberties, i.e. the right to privacy, informed consent to medical intervention, and freedom of movement. Given that most deny that either the goal to promote public health or the goal to protect individual rights and liberties should always take absolute priority over the other, a difficult ethical question is how to strike a balance between these two types of goals in cases of conflict.

Third, the topic of infectious disease is closely connected to the topic of justice. Malnutrition, dirty water, overcrowded living and working conditions, lack of sanitation and hygiene, poor education, and lack of access to health care make poor people more likely to become infected and more likely to suffer poor outcomes when infection occurs. As bad health, in turn, exacerbates poverty, a vicious cycle promotes both poverty and disease.

Fourth, infectious diseases are prone to promote fear, panic, stigma, discrimination, and emotional and irrational decision and policy making.⁷

Fifth, and finally, infectious diseases pose threats to security. Security dangers are associated with fast-moving infectious disease outbreaks that overwhelm response capacity and cause chaos. In 2007, the World Health Organization described pandemic influenza as 'the most feared security threat',⁸ and former US President George W. Bush suggested that a military response may be

* Corresponding author. CAPPE, LPO Box 8260, ANU Canberra ACT, 2601, Australia. Tel.: +61 4 3112 4286.

E-mail address: michael.selgelid@anu.edu.au

necessary in the event of a flu pandemic. Security may also be jeopardized for economic reasons in the case of slower-moving epidemics. HIV/AIDS, for example, has brought numerous African societies to the verge of economic collapse. Historical studies reveal that factors such as high infant mortality, low life expectancy and decreasing life expectancy – especially salient in sub-Saharan Africa at present, largely as a result of HIV/AIDS – are among the most reliable indicators of societal upheaval.⁹

Given the ethical importance of infectious disease, it is encouraging that public health ethics has emerged as a rapidly growing subdiscipline of bioethics, and that an increasing body of literature is focusing on ethical issues associated with infectious disease in particular. A majority of the ethics and infectious disease literature has focused on HIV/AIDS, SARS, pandemic influenza and bioterrorism. This article will review four major ethical issues associated with pandemic influenza: the obligation of individuals to avoid infecting others, healthcare workers' 'duty to treat', allocation of scarce resources, and the use of coercive social distancing measures. In each case, ways in which the ethical issues turn on both philosophical and empirical questions are highlighted.

Obligation to avoid infecting others

While bioethics has traditionally focused on the dyadic relationship between healthcare workers and patients and/or healthcare policy making, contagious infectious diseases raise issues of individual morality. In the event of a major flu pandemic, the failure of an individual to take precautionary infection control measures may endanger the lives of others. Such dangers are, of course, most obvious when an individual knows he/she is infected and contagious, but they also arise when an individual has reason to believe that he/she might be infected (and contagious) because he/she was or may have been exposed to someone else who was contagious. While the widely accepted 'duty to do no harm' would appear to require that infected or potentially infected individuals should take action to avoid (potentially lethally) endangering others, there surely must be limits to such a duty. We cannot, that is, expect everyone who is or just might be infected to do everything that they can to avoid the infection of others; that would unnecessarily bring too many lives to a standstill. What, then, are the limits to the duty in question? And to what extent should the duty be enforced by law?

Although these questions are both interesting and difficult, they have received surprisingly little discussion to date. The author is only familiar with two papers on this particular topic.^{10,11} No attempt will be made to answer such questions fully in this article, although a number of suggestions are offered. First, it is safe to say that the strength of an individual's duty to take precautionary infection control measures, e.g. submitting oneself to voluntary quarantine, limiting interaction with others, wearing a mask, etc., should be proportional to the risk that one is actually infected: the greater the probability that someone is infected, the more he/she should do to avoid exposing him-/herself to others. Second, more research should aim to establish evidence regarding the effectiveness of infection control measures. If evidence reveals that masks, for example, provide highly effective means of infection prevention, then the duty (of even those not especially likely to be infected) to wear masks would be higher than would otherwise be the case. Such research is scientifically important, but there is also an ethical imperative that more of this type of research takes place. Third, there is a need to raise greater public awareness of both the ethical imperative to avoid infecting others and the available means of preventing infection. Fourth, when an individual fails to voluntarily take morally required precautions against the infection of others, legal sanctions and/or the use of force may be justified. This follows

from Dworkin's suggestion that if actions are immoral, 'then the freedom to pursue them counts for less'.¹²

Duty to treat

An issue which has received considerably more attention, especially in the context of HIV/AIDS, SARS and pandemic influenza, concerns a healthcare worker's 'duty to treat' contagious patients when this poses risks of infection, and perhaps death, to the healthcare worker him-/herself.¹³ Many believe that facing such risks is part of a healthcare worker's job, just as it is a fire-fighter's job to face risks fighting fires, and that healthcare workers implicitly consent to such risk taking when they take up this type of employment. The duty in question is also often explicitly stated in health professions' codes of conduct. It is sometimes additionally argued that the duty is established via social contract. Healthcare workers receive special, often exclusive, education and training, and they are granted other privileges by society; the expectation is that they will provide health care, when needed, in return.¹⁴ If trained health professionals refuse to provide care in times of emergency, there is no one else to turn to.

Although it is plausible that healthcare workers do, in fact, have such duties, they often have other, potentially conflicting, duties as well. If a healthcare worker becomes ill or dies as a result of treating this particular patient, for example, then he/she may not be able to treat other patients to whom he/she also has duties, and he/she may not be able to fulfil duties to family members or other loved ones. Healthcare workers also have duties to co-workers. Healthcare provision involves teamwork, and if a worker refuses to work, someone else will be called in to do the job. If all workers refuse, the healthcare system will no longer function. Solidarity is, therefore, called for.¹⁵ While duties to other patients and family members may conflict with the duty to treat a particular (contagious) patient, the duty to fellow co-workers may support it. How to resolve conflict between duties is a difficult philosophical question.

Another philosophical question concerns the limit to the duty to treat. Like the obligation to avoid infecting others, the duty to treat should not be considered absolute (even if there were, by hypothesis, no conflicting duties). Virtually everyone denies that a healthcare worker should be expected to treat if it is known that treating would (likely) be a death sentence for the healthcare worker. But what if the risk of death for the healthcare worker was 50%, 20%, 10% or 1%? For what X should a healthcare worker be expected to treat, so long as the risk of death for the healthcare worker is less than X%? The answer presumably depends on the expected effectiveness of treatment.¹⁶ The more likely that treatment would save the patient's life, the greater the level of risk that healthcare workers should be expected to face to provide treatment (which is not to say that healthcare workers should be expected to provide treatment even when the risks are especially high). However, they should not be expected to face as much risk when treatment would likely be futile or merely palliative.

Assessing the duty to treat in the event of a major flu pandemic would apparently require assessment of: (1) the risk to the healthcare worker in light of the particular strain of flu involved; and (2) the likely efficacy of treatment. In the context of HIV/AIDS, Daniels persuasively argued that refusal to treat AIDS patients involved invidious discrimination because the risks were less than those already routinely faced by healthcare workers.¹⁷ In the event of a flu pandemic, it will be important to assess whether or not, or the extent to which, risks exceed those which are already tolerated. Given that the duty also depends on effectiveness of treatment, evidence regarding likely efficacy of treatment against the particular strain of flu will be wanted. Early in a pandemic involving a novel strain of pathogen, however, such evidence may be

unavailable. Even if it was possible to specify the limits of the duty to treat, it is unclear what expectations should be in cases involving uncertainty, i.e. about whether or not the limits to the duty to treat have actually been exceeded.

Some of these quandaries could be avoided if working conditions were safer to begin with. Improving infection control in hospitals by increasing availability of respirators and isolation wards with negative pressure ventilation systems, for example, would make healthcare provision less dangerous. If society expects healthcare workers to provide care during times of emergency, it is reasonable for healthcare workers to expect health systems to minimize dangers. Healthcare workers willing to face dangers may also deserve higher pay and/or priority in the provision of drugs, vaccines and ventilators. Harmed healthcare workers – or their families, in the event of death – should likewise receive financial compensation. These are matters for reciprocity.¹⁸

Allocation of scarce medical resources

In the event of a major flu pandemic, it is likely that there will be insufficient supplies of drugs, vaccines and ventilators for everyone who needs them. What principle(s) should determine allocation of resources under such circumstances, and who, if anyone, should receive priority? Resources might, for example, be allocated by lottery or on a first come, first served basis. Or allocation decisions might aim to save the most lives, to treat those who are ‘worst-off’, to treat those who are most likely to recover, or to treat those who are most socially productive.¹⁹

The Australian Health Management Plan for Pandemic Influenza gives vaccine priority ‘first to people at high risk of exposure to the virus and providing essential services, then to people most vulnerable to severe illness from infection’.²⁰ During the maintenance phase of a pandemic, healthcare workers at high risk of exposure would receive antivirals (for prophylactic purposes) continuously. It is estimated that this would consume 65% of (2006) stockpiles in just 12 weeks.²⁰

There are numerous reasons for thinking that healthcare workers should be prioritized in the allocation of scarce medical resources in the event of a pandemic. As indicated above, this may compensate them for providing services under risky conditions and/or for harms suffered as a result. Prioritizing healthcare workers might also be justified on the grounds of social utility, i.e. because healthy healthcare workers will be needed in order to fight a pandemic. It is true that many others, including politicians and bus drivers, also play important social roles, but it would be impractical to prioritize each according to the importance of his/her social function.²¹ However, if it is practical and appropriate to prioritize those who play special roles regarding the pandemic emergency under consideration, in addition to healthcare workers, we might aim to prioritize ‘pandemic responders’ more generally. Grave diggers, for example, would play an especially important role, and those familiar with the history of the 1918 pandemic (when there was a serious shortage of such people) would recognize reasons for keeping them healthy too.

Supposing that healthcare workers and/or other pandemic responders should receive priority in the allocation of medicine, a further question is how much priority they should receive. If a major rationale behind the Australian plan is that healthcare workers should be prioritized because they are needed to fight the pandemic, then it may be counterproductive to have them consume such a large portion of the medicine supply. If the bulk of the medicine supply is used up by healthcare workers, they would not be able to fight the pandemic after all because there would be little or no medicines for them to provide treatment with!

Another popular idea is that the young should receive priority when allocation of resource decisions are made. Emmanuel and

Wertheimer, for example, argue for prioritization of the young on the grounds of a ‘life-cycle allocation principle ... based on the idea that each person should have an opportunity to live through all the stages of life’.¹⁹ A similar idea underlies what is sometimes referred to as the ‘fair innings’ argument, which suggests that everyone is entitled to some ‘normal’ span of life years. According to this argument, younger people have stronger claims to life-saving interventions than older people because they have had fewer opportunities to experience life.²² The idea that everyone should get the chance to enjoy a normal span of years, or to live through all the stages of life, appeals to considerations of fairness. The suggestion that one might be ‘entitled’ or have a right to such things, however, is controversial.

It is therefore important to recognize an additional, perhaps more powerful, reason for prioritizing the young when making allocation of resource decisions. As, other things being equal, saving a young person would generally lead to greater reduction in the burden of disease, there are straightforward utilitarian reasons for prioritizing the young. Burden of disease is usually measured in DALYs (disability adjusted life years).²³ The DALY is a ‘health gap’ measure of the number of years of healthy life lost to morbidity and mortality. The earlier in life a disease kills someone, the greater the number of life years that are lost (assuming that, as in the most recent Global Burden of Disease study, age weighting is not used in DALY calculations). Other things being equal, saving a younger person rather than an older person will avert a greater number of DALYs. If (as seems plausible) distribution of resource decisions should aim at maximal disease burden reduction, then fair innings considerations could play a role in age weighting, i.e. years of life lost in early life could be weighted more heavily than years of life lost later in life when DALY calculations are made. Without going into a technical discussion of DALYs, the point being made here is that there may be two distinct important reasons for prioritizing the young: (1) saving the young will save more years of healthy life; and (2) ‘saving one year of life for a young person is valued more than saving one year of life for an older person’²² (if the fair innings argument and/or the ‘life-cycle allocation principle’ is sound).

Coercive social distancing

Coercive social distancing measures such as isolation and quarantine raise some of the most controversial ethical issues associated with pandemic disease. As noted above, such measures are sometimes important to the protection of public health, but they conflict with basic rights/liberties. How should a balance be struck between the two?

Although rights to liberties such as freedom of movement are important, they must sometimes be over-ridden when the danger to society as a whole is sufficiently severe. How great, then, must the threat to public health be for confinement of an individual to be justified? For what disease burden X would confinement of an individual be justified (for a given period of time), so long as the free movement of the individual would (on average be expected to) lead to disease burden X ?²⁴ This is the key philosophical question raised by coercive social distancing measures, but it is rarely identified in such terms. Although answering this question with precision would be difficult, for now it suffices to say that the stakes would need to be high for coercion to be justified. Contra utilitarianism, rights should not be violated whenever this would benefit society as a whole.

Second, for coercive social distancing measures to be justified, there would need to be good evidence that they are likely to be effective in the context under consideration. The effectiveness of such measures, however, is notoriously difficult to study, and effectiveness will vary from context to context. Gostin claims that

isolation and quarantine would probably only have an early and limited role in the case of a major flu pandemic.²⁵ This might usually be true on large continents, but islands (and other isolated environments) may be a different story. History suggests that long-term social distancing was highly effective in American Samoa during the 1918 flu pandemic.²⁶ As the ethical acceptability of coercive social distancing depends on evidence regarding efficacy, there is an ethical imperative to carry out more research that explores the empirical basis for these policies.

How much evidence would be needed to justify the use of coercive social distancing measures? Kass argues that '[a]s a rule of thumb, the greater the burdens posed by a [public health] program—for example in terms of cost [or] constraints on liberty...the stronger the evidence must be to demonstrate that the program will achieve its goals'.²⁷ The more basic the right or liberty at stake, therefore, the higher the level of evidence that should be needed before imposing intrusive public health measures. As freedom of movement is one of the most basic rights, one might conclude that isolation and quarantine require the highest level of evidentiary justification, i.e. systematic review/meta-analysis on the Cochrane scale of evidence-based medicine.²⁸ Although it is plausible that (other things being equal) higher levels of evidence should be attained before infringing upon the most basic rights, the magnitude of utility threatened is another relevant consideration. If anecdotal evidence strongly suggests that isolation and quarantine may be necessary to save thousands or millions of lives, and if this is all the evidence there is to go on, it may be imprudent to insist on the highest level of evidence (which would be especially difficult to come by during early stages of an epidemic involving a novel strain of disease). The greater the amount of utility that is threatened, therefore, the lower the level of evidence that should be demanded before imposing coercive social distancing measures.

Third, it is commonly argued that the 'least restrictive' means should be used to achieve healthcare goals. A related idea is that coercive isolation and quarantine should only be used as a 'last resort'. If the latter entails that all other (less restrictive) measures must be tried before resorting to isolation and quarantine, this may not be feasible, because in the event of a public health emergency, there might not be time to try everything else that just might have worked. It is plausible, however, that we should use the least restrictive means that there is good reason to believe will be effective in achieving the goal in question. If there is reason to believe that voluntary quarantine would be just as effective as coercive quarantine, then we should not resort to the latter. Again, more research is needed to establish evidence about what would be the least restrictive (effective) means in various circumstances.

Fourth, if it is determined that their use is necessary, coercive social distancing measures must be used in an equitable manner. One idea is that they should not be used, as they have in the past, in a discriminatory fashion against the marginalized and disempowered. Another idea is that the grounds for their use must be strongest when those being considered for confinement are among the worst-off groups of society. Just as research ethics aims to provide special protection for vulnerable members of society, the ethics of isolation and quarantine should arguably do the same.

Fifth, confinement should be minimally burdensome. Those subjected to isolation and quarantine should be made as comfortable as possible, and they should be provided with basic necessities and health care insofar as possible. A related point is that those who are coerced should receive financial compensation for inconvenience, lost wages (if they are unable to work), and simply for having their liberty restricted. Coercive social distancing is only justified if it results in net benefits to society as a whole. Some of these benefits should be returned to the victims of coercive measures. In the absence of compensation, those coerced would

suffer a disproportionate share of the burdens required to benefit society, and this would be unfair. Compensation is a matter of reciprocity.¹⁸ In addition to promoting fairness, a system of compensation would likely promote trust in the public health system and cooperation with public health policy.²⁹ Given the importance of trust to the success of public health programmes, compensation may have substantial health benefits.

Conclusion

This review of ethical issues associated with pandemic disease highlights ways in which the issues turn on both empirical and philosophical questions in need of further research and analysis. Although those with an interest in health ethics have traditionally focused on philosophical and/or legal questions, the importance of the empirical questions that the ethical questions turn on should not be underestimated. This suggests that those concerned with health ethics should, in addition to engaging in philosophical analysis, play a greater role in identifying ethically important empirical questions and advocating that relevant research gets done. A message for scientists is that there are many empirical questions which are not only scientifically important but also crucial to the making of ethically sound policy. This should be taken into consideration when scientific/empirical research projects are chosen. Given the potential consequences of a major flu pandemic, for individuals and society as a whole, the need for sound policy is especially pressing.

Ethical approval

None sought.

Funding

None declared.

Competing interests

None declared.

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