

SYMPOSIUM

Enhancing the Legitimacy of Public Health Response in Pandemic Influenza Planning: Lessons from SARS

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INTRODUCTION

The specter of avian influenza H5N1 has raised concerns globally and brought back memories of the feared 1918 influenza pandemic. Concerns about a newly mutated strain of avian influenza virus, with the capacity to become a pandemic organism with high morbidity and mortality, has spurred pandemic influenza plans at all levels of the public and private sectors across the globe. The World Health Organization is playing a central role in coordinating the development of plans and in urging member states to coordinate pandemic planning. Attendant to this rush to create pandemic plans is intense public scrutiny, including anxiety and fear. Media attention has been intense and has increased public worries about the avail-

ability of antiviral medications with individuals rushing to secure their own stock of antiviral medication. Nation states are taking actions to protect themselves and secure their borders from the incursion of avian influenza transmitted through bird species.

If one reflects on the roots of the term "pandemic" and engages in a little word play and deletes the "dem" from pandemic, the result is "panic," which is close to what we are verging on at this current time in our public fear of pandemic influenza. However, when one takes the "dem" out of pandemic (which represents the Greek word of "demos" or "people"), it becomes important that we try to re-insert some of the better aspects of human nature such as reason and reflection in our preparation. If there is

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any reason to include ethics in pandemic planning, it would be for the following considerations: How we respond to a pandemic strain of influenza virus, how we marshal our social resources, how we work collaboratively, and how we treat people who are infected or pose a risk of infection to others is a reflection of our own humanity. The measure by which we can say our response to pandemic influenza is a humane and ethical one will be judged and interpreted in light of the policies, prescriptions, and management plans that are put in place. We can be certain that all actions will be evaluated in light of our response.

It is my contention that ethics has a central role in pandemic influenza planning, and pandemic influenza plans in all jurisdictions should reflect deeply on the ethical issues raised by pandemic influenza. In this essay, I will outline the SARS outbreak in Toronto and the lessons we learned from SARS relating to ethics and infectious disease outbreaks. I will discuss the development of an ethical framework for pandemic planning that was developed by an interdisciplinary team of scholars at the Joint Centre for Bioethics at the University of Toronto and adopted by the province of Ontario's pandemic influenza plan.

SARS IN TORONTO

The SARS virus struck Toronto in the late winter of 2003. The index case was identified on the 23rd of February, and the outbreak was officially considered over by mid-June 2003. For the four months that SARS was present in Toronto, the social and economic impacts were remarkable. The impact on the health care system was also unprecedented, resulting in the virtual closure of many large tertiary-care hospitals, the foregoing of services to non-SARS patients, the implementation of stringent infection control measures within hospitals, and the marked alteration of the usual practice and operation of health care facilities [1].

SARS also put a tremendous strain on an under-resourced public health system. Several thousand Ontarians were placed in quarantine, requiring monitoring and support. There was an unprecedented need for contact tracing and outbreak investigation, requiring immense human resources being directed toward the control of the pandemic [2].

The SARS experience taught us that the health care system was singularly unprepared for an outbreak of a respiratory pathogen of any magnitude. Although there are similarities between SARS and pandemic influenza, there are similarly important differences. At the outset of SARS, the organism was uncharacterized. It was known to be a communicable agent and transmitted via respiratory secretions, but which specific virus and many of the important viral characteristics required for the rational management of the outbreak were unknown. How long was the incubation period? Could people shed the virus asymptomatically? Was immunity present after infection? However, even with the use of known parameters of disease control there will still be serious uncertainties on the optimal management of a pandemic influenza outbreak.

Another important consideration in SARS was its disproportionate impact on health care workers. Approximately 40 percent of probable cases in the Toronto outbreak were health care workers. Two nurses and one physician died in Toronto as a result of their infections. Many of those who were infected are still on disability or not at full health, even two years after the outbreak. Hundreds of health care workers were put in work quarantine. The psychological and psychosocial impact of SARS on health care workers was substantial. In a survey conducted by our unit, 45 percent of nurses scored above the General Health Questionnaire 12 cut-off point for psychological stress. Sixty-five percent of respondents reported SARS-related concerns for personal or family health. Many respon-

dents found the infection control measures were intrusive and detracted from the quality of their work. In the aftermath of SARS, many health care providers recognized that the amount of risk imposed by the SARS outbreak was greater than they were willing to countenance and subsequently pursued alternative employment [3].

RESPONSE TO THE ETHICAL ISSUES RAISED BY SARS: THE JCB WORKING GROUP

While the SARS outbreak was ongoing, a group of colleagues associated with the Joint Centre for Bioethics (JCB) at the University of Toronto formed a working group to reflect on some of the ethical issues raised by SARS. Five key issues were identified. A framework was created and proposed for analysis of issues and as a decision aid. Our report was submitted to and included in the Naylor Commission [4] and subsequently published in the *British Medical Journal* [5]. Our report identified five key issues:

- 1) Health care workers' duty to care, and the duty of institutions to support them;
- 2) Naming names and naming communities, privacy of personal information, and the public need to know;
- 3) Organizational issues: priority setting;
- 4) When public health trumps civil liberties, the ethics of quarantine; and
- 5) SARS in a globalized world.

Additional issues related to infectious disease outbreaks arise within the purview of research ethics. These, however, I will not discuss in any detail.

HEALTH CARE WORKERS' DUTY TO CARE AND THE DUTY OF INSTITUTIONS TO SUPPORT THEM

On the surface, health care workers' response to SARS was impressive and heroic. However, some health care workers

refused to work and in the aftermath of SARS have expressed concerns about exposing themselves and their families to risks from communicable diseases. With respect to the duty to care, several important lessons were learned. It is important to note that health care professionals have a duty to care for the sick and for themselves. They have a duty not to harm others by communicating disease. However, the limit to personal risk is unclear. More importantly, there are silences within current codes of ethics with respect to giving direction to health care workers regarding the extent to which they are obligated to put themselves at risk in caring for individuals with communicable diseases.

From the SARS outbreak, we also learned that institutions have a reciprocal duty to support and protect health care workers and to help them cope with very stressful situations. Institutions and organizations have an obligation to set clear expectations of employees, and there needs to be recognition of the potential risk run by individuals [6].

NAMING NAMES AND NAMING COMMUNITIES, PRIVACY OF PERSONAL INFORMATION, AND THE PUBLIC NEED TO KNOW

The control of health information and the privacy of information was an issue in the SARS outbreak. There was an avid appetite on behalf of the public to know where the disease was manifesting itself, including demands for identification of particular individuals who may have posed risks to the public. For example, Dr. Sheila Basur, the medical officer of health for the city of Toronto, released the name of the index case to the public. It was believed necessary to serve disease control, as she had contacted many people while ill, died from what was believed to be cardiac disease, and many had been at her funeral and in contact with family members who by that time were sympto-

matic. Later in the outbreak, it was reported that a nurse who worked at a hospital with SARS patients had used mass transit while febrile. In this case, public health authorities resisted pressure to provide identifying information as it served no legitimate public health goal.

In this context, we learned that the public health officials do have the right to override an individual's right to privacy in cases in which serious public health risks exist. Private medical information can be released to the public in situations that would help protect the public health or facilitate the conduct of an outbreak investigation and no alternative legitimate means exist to attain this goal [4]. However, privacy and confidentiality of individuals should be protected, unless a well-defined public health goal can be achieved by the release of this information to the general public and when there are no other means of achieving this end.

ORGANIZATIONAL ISSUES: PRIORITY SETTING

In terms of organizational issues, the important lessons learned were that control of the spread of disease is important and a primary goal of the public health system. However, as much attention must be paid to the needs of non-infected patients requiring urgent medical care; that is, the need for delivery of cancer services, cardiovascular services, and general primary care should be provided or there should be means of providing such care. Health planning and actually the design of institutions may need to reflect this.

A study of hospital priority setting following SARS identified the following four key issues:

- 1) Patients and families did not have access to the reasons for many decisions, including the visitation policy and ramp up of clinical activities after the outbreak was over.
- 2) A formal revision/appeals mechanism could help improve the quality of decision making and alleviate the unfair reliance on the "squeaky wheel" phenomenon.
- 3) Operating room time was allocated by division, rather than by patient need, and these decisions should be discussed more fully.
- 4) Institutional leaders should maintain two-way contact with front line staff who are implementing priority setting decisions — this will provide support and enhance accountability for decision making by staff. [7]

There is also a need for accountability for making decisions, and transparency and fairness must be respected. There is a need also to communicate accurate information to the public, including the risks and benefits of strategies and decisions.

THE USE OF RESTRICTIVE MEASURES FOR DISEASE CONTROL

The imposition of mass quarantine during SARS for the first time in modern history raised important ethical issues, and there were several lessons learned. For the Canadian public, it was recognized that the interests of protecting the public health overrode some individual rights such as the freedom of movement. However, it was also recognized that when society imposes a duty on individuals to restrict their actions for the benefit of others, particularly for the benefit of public health, public health officials and society have a general duty to inform the individuals of the situation and to explain the reasons for the limitations of their freedoms. However, there is an important reciprocal duty to do as much as possible to assist the people whose rights are being infringed. This placed an onus on public health authorities to ensure that those quarantined had access to food, medication, and were psychologically and financially supported. The government of Ontario ensured workplace accommodation and income protection for those quar-

antined. Interestingly, the Canadian public believed that they were acting on the basis of performing a key civic duty.

We believe that the Siracusa principles are of value in illuminating these issues. In the Siracusa principles, public health may be invoked as a ground for limiting certain rights in order to allow the state to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care of the sick and injured. Within the Siracusa principles are a set of inviolable rights:

...no party shall even in time of emergency threatening the life of the nation derogate from the covenant guarantees of the right to life, freedom from torture, cruel, inhuman or degrading treatment or punishment, and from medical or scientific experimentation without free consent, freedom from slavery or involuntary servitude, the right not to be imprisoned for contractual debt, the right not to be convicted or sentenced to a heavier penalty by virtue of retroactive criminal legislation, the right to recognition as a person before the law, and freedom of thought, conscience and religion. These rights are not derogable under any conditions, even for the asserted purpose of preserving the life of the nation [8].

It is important to emphasize the last clause, "even for the asserted purpose of preserving the life of the nation." These non-derogable rights seem in some way to be a bedrock core of individual rights. The clause "and from medical and scientific experimentation without free consent" is also important, particularly for a future pandemic, because the use of a newly developed vaccine or the massive use of antivirals for the control of the disease would in some ways be an experiment. How one would secure consent freely in such exigent circumstances is an important issue requiring scholarly attention. Freedom of thought, conscience, and religion is also important and speaks to the role of mandatory treatment orders and

mandatory vaccination orders. Those who by conscience or thought assert the freedom not to be vaccinated may have a case grounded in human rights doctrine.

THE GLOBALIZATION OF COMMUNICABLE DISEASES

One of the important issues that we learned from SARS that is directly relevant to pandemic influenza is that we live in a globalized world. Many have noted that SARS was a wake-up call about global interdependence and increasingly rapid spread of infectious diseases. We think it also reinforces the fact that health is a global public good, and, therefore, there is a need to strengthen the global health system to cope with infectious diseases. This argument could be made on the grounds of enlightened self interest or of mutual regard. The outcome is the same either way. Cooperation globally will enhance everyone's security and reduce the spread of disease morbidity and mortality. When one invokes cooperation, we can use arguments of global solidarity to secure actions from nation states for global public health goods.

However, we also learned from SARS that transparency of communication also comes with economic and social costs. Toronto, which is relatively transparent in its reporting of disease status, suffered economically from cancellation of conferences, and general tourism fell off dramatically despite the fact that the probability of exposure to SARS outside the hospital environment was negligible. How we as a global culture will act so as to not disadvantage those unfortunately afflicted by a major infectious disease outbreak, again speaks to our humanity in a globalized world.

The newly drafted International Health Regulations promise to be an improvement on the antiquated structure of international disease control but still face challenges in implementation and agreement among member states. [9]

ETHICS AND PANDEMIC PLANNING

The SARS experience and our reflections from the perspective of ethics prepared us to participate in pandemic influenza planning. One hospital invited its ethicist to participate in the local pandemic planning process. It was recognized that resource allocation issues featured prominently in pandemic planning, specifically access to scarce technology such as respirators and intensive care units. There was also a need to have equitable and fair human resource planning. After an ethics component was added to a draft hospital pandemic plan, the Ministry of Health and Long-Term Care of the Province of Ontario invited the Joint Centre for Bioethics working group to join its pandemic planning process around issues of how to allocate vaccines and antiviral medications. As a consequence, the ethical framework that the group developed was adopted and included in the provincial plan [10].

The WHO has recommended attention to ethical issues in pandemic planning, but to our knowledge, we are unaware of any developed frameworks [11]. Indeed, there has been criticism published about the lack of ethical reflection in major pandemic plans [12].

The elements of the ethical framework for pandemic planning focused both on the decision-making process and the values in forming the process. There was an emphasis on inclusiveness, accountability, and transparency, which has been adapted and modified from current theory and priority setting, specifically Daniels and Sabin's accountability for reasonableness model [13].

Our model focuses on procedural values and substantive values. In terms of procedural values, the process of planning should be open and transparent, reasonable, inclusive, responsive, and accountable. In other words, it is important that decisions made in pandemic planning, particularly in a publicly funded health care

system, meet these criteria. Of note, we believe strongly that there should be opportunities to revisit and revise decisions as new information emerges throughout the crisis, as well as mechanisms to address disputes and complaints.

Substantively, we believe the pandemic plan must be guided by values of preserving individual liberty, but recognizing its limitations and recognizing that when restrictions to individual liberty are in place, they should be proportional, necessary and relevant, employ the least restrictive means to achieve the public health goal, and be applied without discrimination. We recognize the pre-eminent need of the public health system to protect the public from harm, but actions taken should be proportional to the threat and risk. Privacy should be respected but may be overridden to protect the public from harm. Equity is an important value in that all patients have an equal claim to receive the health care they need under normal circumstances. Provisions should be made as much as possible to provide these services; however, during a pandemic, some health services, such as elective surgery, may need to be deferred. Steps must be made and plans put in place to address these issues when the crisis is over.

One of the most important issues to be resolved is the duty of health care providers to provide care during times of infectious disease emergencies. Although many ethical codes speak to the duty to provide care and respond to suffering, we recognize that health care providers are humans and have to weigh demands from both their professional role as well as other competing obligations to their own health, to their family, and to their colleagues. We do also recognize that there will be an important need for institutions to reinforce their commitment to the best possible protection for those health care workers who are exposed to risk.

We recognize reciprocity as an important concept in the management of and

planning for an influenza pandemic. Reciprocity requires that society support those who face a disproportionate burden in protecting the public good and take steps to minimize burdens as far as possible. Reciprocity also requires that society ensure that those affected receive adequate care and do not suffer unfair economic penalties. If leaders expect people exposed to or suffering from communicable diseases to act in a manner that does not put others at risk, it is important that they create a social environment that does not leave people without supports. Measures to protect the public good are likely to impose a disproportionate burden on health care workers, patients, and their families. A more detailed account of the framework with illustrative examples has recently been published [14].

Infectious diseases underscore our mutual vulnerability. As Francis et al. have recently written, infectious diseases change our vision of agency because individuals are both vectors and potential victims [15]. This inherent relationality between individuals leads us to the notion of reciprocal caring for discharging our obligations and assisting those who are ill. This is also linked to the concept of solidarity. The solidarity is both within health care institutions, between health care institutions, and also for more distant support to our colleagues in the developing world.

Underlying the pandemic influenza plan is the need to enhance trust. Trust is an essential component of the relationships between clinician and patient, staff and the organization, between health care providers and organizations, and between organizations within a health system, as well as between municipalities, provinces, states, and nation states.

Decision makers will be confronted with the challenge of maintaining stakeholder trust while simultaneously implementing various control measures. It takes time to build trust, and our belief is that the more inclusive the pandemic planning

process, the more trust there will be in the process that is agreed upon. As the pandemic is likely to occur in our lifetimes, according to the best expert opinion, it is important that planners should be involved in trust-building exercises earlier in the pre-pandemic phase rather than later in the crisis. Entrustment exercises are difficult to schedule when stretchers are filling the halls of emergency departments.

CONCLUSION

In conclusion, ethical considerations are essential to pandemic influenza planning. To my reasoning, these are intrinsic elements to the process, rather than simply desirable or superfluous. Our group believes that the principles outlined in the framework will help enhance the legitimacy of any public health response in pandemic influenza planning, particularly in democratic societies. The proof of the value of these principles, of course, will only be known after the pandemic rather than before its occurrence. However, there is time now for all planners to pay attention to the ethical dimensions of pandemic influenza planning and to include such considerations into their planning.

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REFERENCES

1. Naylor CD, Chantler C, Griffiths S. Learning from SARS in Hong Kong and Toronto. *JAMA* 2004;291:2483-7.
2. Svoboda T, Henry B, Shulman L, et al. Public health measures to control the

- spread of the severe acute respiratory syndrome during the outbreak in Toronto. *N Engl J Med* 2004;350:2352-61.
3. Nickell LA, Crighton EJ, Tracy CS, et al. Psychosocial effects of SARS on hospital staff: survey of a large tertiary care institution. *Can Med Assoc J* 2004;170:793-798.
 4. Learning from SARS: renewal of public health in Canada. A report of the National Advisory Committee on SARS and Public Health, October 2003. Available at http://www.phac-aspc.gc.ca/publicat/sars-sras/naylor/preface_e.html. Accessed November 29, 2005.
 5. Singer PA, Benatar SR, Bernstein M, et al. Ethics and SARS: lessons from Toronto. *Br Med J* 2003;327:1342-4.
 6. Reid L. Diminishing returns? Risk and the duty to care in the SARS epidemic. *Bioethics* 2005;19:348-61.
 7. Bell J, Hyland S, DePelligrin T, Upshur R, Bernstein M, and Martin D. SARS and hospital priority setting: a qualitative case study and evaluation. *BMC Health Serv Res* 2004;4:36.
 8. The Siracusa principles on the limitation and derogation provisions in the International Covenant on Civil and Political Rights: United Nations, 1984. Available at: <http://72.14.207.104/search?q=cache:ZApistK9VYkJ:www.article23.org.hk/english/research/ICCPR.doc+siracusa+principles&hl=en> (accessed November 14, 2005).
 9. Wilson K, McDougall C., and Upshur R. The New International Health Regulations and the federalism dilemma. *PLoS Med*. 2006;3:e1.
 10. Ontario health plan for an influenza pandemic. Ontario Ministry of Health and Long-Term Care, 2005. Available at http://www.health.gov.on.ca/english/providers/program/emu/pan_flu/pan_flu_plan.html (accessed November 14, 2005).
 11. WHO checklist for influenza pandemic preparedness planning. World Health Organization, 2005. Available at <http://www.who.int/csr/resources/publications/influenza/FluCheck6web.pdf> (accessed November 14, 2005).
 12. Kotalik J. Preparing for an influenza pandemic: ethical issues. *Bioethics* 2005;19:422-31.
 13. Daniels N and Sabin J. The ethics of accountability in managed care reform. *Health Aff (Millwood)* 1998;17:50-64.
 14. Stand on guard for thee: ethical considerations in preparedness planning for pandemic influenza. A report of the University of Toronto Joint Centre for Bioethics Panedemic Influenza Working Group. Available at <http://www.utoronto.ca/jcb/home/documents/pandemic.pdf>.
 15. Francis LP, Battin MP, Jacobson JA, Smith CB, and Botkin J. How infectious diseases got left out — and what this omission might have meant for bioethics. *Bioethics* 2005;19:307-22.