

Stand on Guard for Thee

Ethical Considerations in Preparedness Planning for Pandemic Influenza

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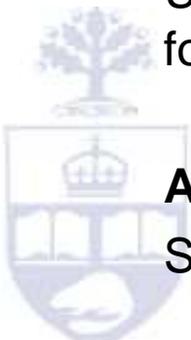
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Will it be a 'health tsunami' or 'health Y2K'?



Ethics and SARS: lessons from Toronto

Peter A Singer, Steven H Dellar, Mark Rothstein, Sheldon S Daar, Bernard H Dickson, Susan K MacIsaac, Roy E D Upton, Linda Wright, David Zook, Susan

The SARS epidemic offers a rare case study for infectious diseases to spread round the world. It has become an ethical minefield to be mined to improve response to the next epidemic.

The outbreak of severe acute respiratory syndrome (SARS) in the Toronto area earlier this year forced medical and government workers to make hard choices about what information and what health care interventions provides care on the one hand and some the people most affected by the disease? Doctors walked a tight line between individual freedom against the common good, but the personal duty against the duty to treat sick people and economic losses against the need to contain the spread of a deadly disease. Such decisions have to be guided by both scientific knowledge and ethical considerations. The SARS outbreak showed that Canada's countries are not fully prepared to deal with the ethical issues.

Evaluating ethical issues

We formed a working group to identify the key ethical issues and values most important for an analysis of ethical dimensions of the SARS epidemic. The final list of issues and values emerged from numerous private and formal interviews and discussions with 16 health care providers, a bioethicist, the leading academic ethicist in the province of Ontario, and two major ethical issues listed by decision makers.

We examined the underlying ethical values for the three major issues and then looked for how each was upheld. The following issues studies illustrate the issues and are an analysis of their responses.

Ethics of quarantine

A central ethical issue is public health officials to require at least to quarantine? It does because of public responsibility SARS. The main dilemma here that would be to limit the risk of the epidemic.

How ethical values were associated with this issue starting with individual liberty. Even the word liberty and individual liberties have to be balanced against



a second value— that of protecting the public from harm caused by the uncontrolled movements of people who may be infectious? Under the rubric of proportionality, authorities overseeing public health issues should do so in a way that is relevant, legitimate, and necessary. They should use the least restrictive methods that are reasonably available to limit individual liberties and should apply restrictions unless it is justified.

The rubric of transparency requires stakeholders to be fully informed about issues, including the risks and benefits, particularly if they affect their health, wellbeing, and personal liberty. Finally, the rubric of reciprocity requires a society to ensure that those quarantined receive adequate care and the most useful and reasonable possibilities.

Privacy of personal information and public need to know

A second ethical issue is the SARS outbreak raised the issue of weighing the risk of having the disease spread being contained (having a better system for surveillance) against the loss of privacy from SARS. The dilemma is that the public has the right to know people who may have been in the area that they should avoid for SARS.

Although the public did not have a right to privacy, the state can never take this right if it would greatly help protect the public from serious harm. As a general rule, the privacy and confidentiality of individuals should be protected unless a well-defined public health goal can be achieved by making personal information a public.

In the initial stages of the outbreak, authorities issued severe orders to quarantined SARS in Canada from China, and the case in the Ontario community because they believed it would provide a limited public health benefit. Although public health officials took great pains to avoid taking liberty and illness, the failure of SARS to its containment had worried from China,

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STAND ON GUARD FOR THEE

**Ethical considerations in
preparedness planning for pandemic influenza**

November 2005

A report of the
University of Toronto Joint Centre for Bioethics
Pandemic Influenza Working Group

Ontario Health

Pandemic Influenza Plan

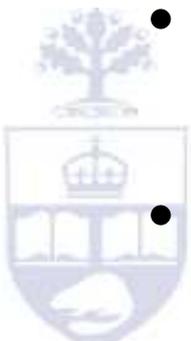


June 2005

 Ontario

Ethical Frameworks

- At the moment, 0 / 200 countries have an ethical framework in their pandemic plans
- All of them should
- We have produced a framework that can be adopted or adapted
- Canada can lead
- Initially by incorporating the framework into its own federal plan
- And then by assisting other countries to do so



Why ethics?

- Need for a moral compass to guide difficult decisions that will have to be made in the context of a pandemic
- Moral analysis is part of good, accountable public policy formation or decision-making
- Ethical issues are one set of considerations among many: risk analysis, economics, law etc.,
- BUT often other sets of considerations involve moral evaluation, e.g. risk/benefit analysis



Rationale

- Government and health care leaders will need to make decisions based on values
- Values based leadership may be the glue that holds society together in an intense crisis
- History will judge today's leaders on how well they prepared for and acted during the crisis and whether they treated people in an ethical manner



Lessons from SARS

- SARS underscored the need for a clearly understood and widely accepted ethics approach to dealing with serious communicable disease outbreaks
- Health care systems had generally not prepared themselves to deal with the hard ethical choices that rapidly arose
- Lesson learned is to establish the ethical framework in advance and to do so in an open and transparent manner



An Ethical Guide for Pandemic Planning

- The JCB Pandemic Influenza Working Group has developed a 15-point ethical guide for pandemic planning
- Based in part on experiences and study of the 2003 SARS outbreak
- The guide is explicitly founded on both substantive and procedural values

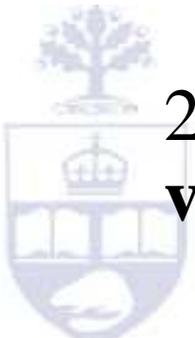


Two Ways for Ethics to Contribute

Decision-making for and during a pandemic influenza outbreak ought to be:

1) *guided* by ethical decision-making **processes** &.

2) *informed* by ethical **values**.



An Ethical Guide for Pandemic Planning

Five **procedural** values to guide ethical decision-making for a pandemic influenza outbreak:

- Reasonable
- Open and transparent
- Inclusive
- Responsive
- Accountable



An Ethical Guide for Pandemic Planning

Ten **substantive** values to guide ethical decision-making for a pandemic influenza outbreak:

- Individual liberty
- Protection of the public from harm
- Proportionality
- Privacy
- Equity
- Duty to provide care
- Reciprocity
- Trust
- Solidarity
- Stewardship



General Recommendations

1. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should **ensure that their pandemic plans include an ethical component.**
2. National, provincial/state/territorial, and municipal governments, as well as the health care sector, should consider **incorporating both substantive and procedural values** in the ethical component of their pandemic plans.



Key Ethical Issues

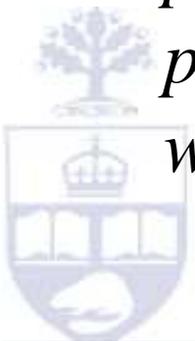
1. Duty to Care
2. Restrictive Measures
3. Priority Setting
4. Global Governance



Ethical Issue 1: Duty to Care



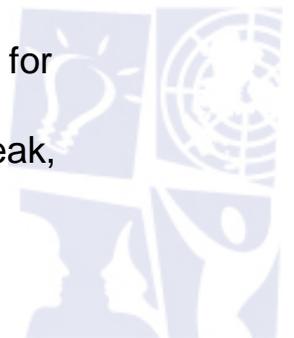
During SARS, some medical workers were afraid that they would be infected while caring for SARS patients, and that they would infect their families, friends and co-workers. The workers were torn between these fears and a sense of duty to their patients and solidarity with fellow workers. A flu pandemic will mean virtually all health care workers will face such difficult choices.



Ethical Issue 1: Duty to Care

Recommendations

1. Professional colleges and associations should provide, by way of their **codes of ethics**, clear guidance to members in advance of a major communicable disease outbreak, such as pandemic flu. Existing mechanisms should be identified, or means should be developed, to inform college members as to expectations and obligations regarding the duty to provide care during a communicable disease outbreak.
2. Governments and the health care sector should ensure that:
 - a. **care providers' safety** is protected at all times, and providers are able to discharge duties and receive sufficient support throughout a period of extraordinary demands; and
 - b. **disability insurance and death benefits** are available to staff and their families adversely affected while performing their duties.
3. Governments and the health care sector should develop **human resource strategies** for communicable disease outbreaks that cover the diverse occupational roles, that are transparent in how individuals are assigned to roles in the management of an outbreak, and that are equitable with respect to the distribution of risk among individuals and occupational categories.



Ethical Issue 2: Restrictive Measures



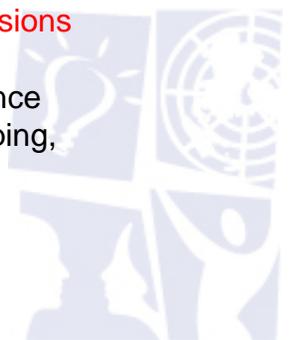
During the SARS outbreak, a number of people, including health care staff, were ordered to remain at home to prevent spreading the disease. People faced the loss of income and possibly their jobs. The number of people affected could be far higher during a global flu pandemic, and people subject to restrictive measures will need to have their basic needs met, including some protection for their income and jobs.



Ethical Issue 2: Restrictive Measures

Recommendations

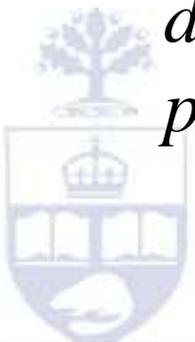
1. Governments and the health care sector should ensure that pandemic influenza response plans include a comprehensive and **transparent protocol** for the implementation of restrictive measures. The protocol should be founded upon the principles of proportionality and least restrictive means, should balance individual liberties with protection of public from harm, and should build in safeguards such as the right of appeal.
2. Governments and the health care sector should ensure that the **public is aware** of:
 - i. the rationale for restrictive measures;
 - ii. the benefits of compliance; and
 - iii. the consequences of non-compliance.
3. Governments and the health care sector should include measures in their pandemic influenza preparedness plans to **protect against stigmatization** and to safeguard the privacy of individuals and/or communities affected by quarantine or other restrictive measures.
4. Governments and the health care sector should institute measures and processes to **guarantee provisions and support services** to individuals and/or communities affected by restrictive measures, such as quarantine orders, implemented during a pandemic influenza emergency. Plans should state in advance what backup support will be available to help those who are quarantined (e.g., who will do their shopping, pay the bills, and provide financial support in lieu of lost income). Governments should have public discussions of appropriate levels of compensation in advance, including who is responsible for compensation.



Ethical Issue 3: Priority Setting



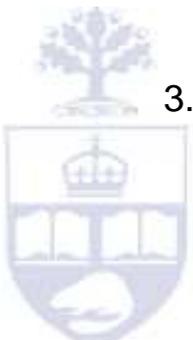
One of the side effects of SARS was that people scheduled for important treatments, such as cancer surgery, had their care postponed. A number of hospital beds, staff and equipment were redirected to the public health emergency. These kinds of decisions will be even more prevalent during a flu pandemic.



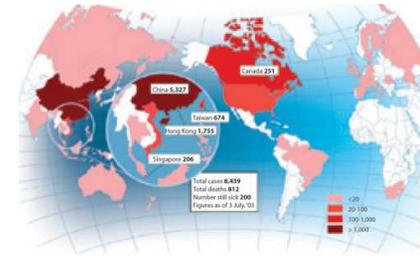
Ethical Issue 3: Priority Setting

Recommendations

1. Governments and the health care sector should **publicize a clear rationale for giving priority** access to health care services, including antivirals and vaccines, to particular groups, such as front line health workers and those in emergency services. The decision makers should initiate and facilitate constructive public discussion about these choices.
2. Governments and the health care sector should **engage stakeholders** (including staff, the public, and other partners) in determining what criteria should be used to make resource allocation decisions (e.g., access to ventilators during the crisis, and access to health services for other illnesses), should ensure that clear rationales for allocation decisions are publicly accessible and should provide a justification for any deviation from the pre-determined criteria.
3. Governments and the health care sector should ensure that there are **formal mechanisms** in place for stakeholders to bring forward new information, **to appeal** or raise concerns about particular allocation decisions, and to resolve disputes.



Ethical Issue 4: Global Governance



In rural China, a farmer developed a chest infection and then family travels began a chain of events that spread the SARS virus around the world. In Geneva, WHO officials weighed the risk of further spread and issued travel warnings for several countries. The current avian flu virus is moving across vast distances, carried by wild birds. If this virus mutates to become transmissible among humans, the WHO will have to carefully consider travel advisories.



Ethical Issue 4: Global Governance

Recommendations

1. The World Health Organization should remain aware of the impact of travel recommendations on affected countries, and should make every effort to be as **transparent and equitable as possible when issuing such recommendations.**
2. Federal countries should utilize whatever mechanisms are available within their system of government to ensure that relationships within the country are adequate to **ensure compliance with the new International Health Regulations.**
3. The developed world should continue to **invest in the surveillance capacity of developing countries**, and should also make investments to further improve the overall public health infrastructure of developing countries.



Other Ethical Issues

- research ethics during a public health emergency
- ethical treatment of animals, such as the mass culling of poultry flocks
- compensation for affected farmers (loss of income resulting from mass culls)



For further information...

Full report available at:



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