

Ethics in a Pandemic Influenza Crisis: Framework for Decision-Making

Ethical Decision-Making Processes

During a pandemic influenza crisis, difficult decisions will need to be made about access to pharmaceuticals, access to care, mobilization and re-allocation of resources, deployment of staff, and other measures to contain the spread of disease. A key lesson from SARS was the importance of having ethical decision-making processes to establish the legitimacy and perceived legitimacy of decisions in the eyes of affected stakeholders, e.g., staff, patients, members of the public, other health care organisations.³ Accountability for reasonableness provides a useful model for identifying the key elements of ethical decision-making processes.¹

Some may argue that these principles are too stringent or too unrealistic to implement under the crisis conditions of a pandemic influenza. Certainly, crisis conditions may place constraints on the extent to which each principle can be operationalised. However, efforts should be made to operationalise them to the fullest extent possible under the circumstances. The SARS epidemic taught many health care organizations about the costs of not using ethical decision-making processes: loss of trust, low staff morale, moral distress, fear, and misinformation. Under a crisis, ethical decision-making processes are more not less important.

Stakeholders are more likely to accept the ethical legitimacy of difficult decisions if the decision-making processes are:

- *Open and transparent* – Decisions should be publicly defensible. This means that the process by which decisions are made must be open to scrutiny and the basis upon which decisions are made should be publicly accessible to affected stakeholders. For example, there should be a communication plan developed in advance to ensure that information can be effectively disseminated to affected stakeholders and that stakeholders know where to go for needed information.
- *Reasonable* – Decisions should be based on reasons (i.e., evidence, principles, values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis and they should be made by people who are credible and accountable. For example, decision-makers should provide a rationale for prioritizing particular groups for anti-viral medication and for limiting access to elective surgeries and other services.
- *Inclusive* – Decisions should be made explicitly with stakeholder views in mind and there should be opportunities for stakeholders to be engaged in the decision-making process. For example, decision-making related to staff deployment should include the input of affected staff.

- *Responsive* – 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. For example, if elective surgeries are cancelled or postponed, there should be a formal mechanism for stakeholders to voice any concerns they may have with the decision.
- *Accountable* – There should be mechanisms in place to ensure that ethical decision-making is sustained throughout the crisis.

Core Ethical Values

Ten key ethical values should inform the pandemic influenza planning process as well as decision-making during such a crisis.¹ These values are intended to provide guidance to decision-makers and to supply them with commonly understood ethical concepts and language necessary for ethical deliberation. It is important to consider that more than one value may be relevant in any given situation. Indeed, some values will be in tension with others, and this tension between values is the cause of the ethical dilemmas that emerge in a pandemic influenza crisis. For this reason, decision-making requires careful consideration and deliberation in order that some degree of consensus can be reached over what moral weight to assign each value when values are in conflict. Moreover, these tensions underscore the importance of having a shared ethical language and ethical decision-making processes to establish the legitimacy of decisions in the eyes of stakeholders.

1. Individual Liberty

Individual liberty is a value enshrined in our laws and in health care practice under the principle of respect for autonomy. In a public health crisis, however, restrictions to individual liberty may be necessary in order to protect *the public* from serious harm.^{2,3,4} In community care, hospital and long-term care settings, patients, staff, and members of the public may all be affected by such restrictions. Restrictions to individual liberty should a) be proportional to the risk of public harm, b) be necessary and relevant to protecting the public good, c) employ the least restrictive means necessary to achieve public health goals, and d) applied without discrimination. Individual liberty can be preserved to the extent that we can ensure transparency about the imposed limits, the rationales for such limits, and the risks/benefits to health and well being of individuals and the public as a whole.

2. Protection of The Public From Harm

A foundational principle of public health ethics is the obligation to protect the public from serious harm.⁷ This principle requires that citizens comply with imposed restrictions in order to ensure public wellbeing or safety.^{1,6,7} To protect the public from harm, public health measures such as containment strategies, including quarantine are sometimes necessary. It can also be necessary to ration scarce resources such as antivirals and vaccines in order to minimize serious illness and mortality, and to minimize societal disruption. Healthcare facilities

may be required to restrict public access to service areas (e.g., restricted visiting hours), to limit availability of some services (e.g., elective surgeries, regular vaccination programs), or to impose infectious control practices (e.g., masks or quarantine). The medical and moral imperative for compliance and the consequences of non-compliance should be transparent to all stakeholders. In addition, there should be mechanisms to review these decisions as the public health situation changes and to address stakeholders concerns or complaints. For example, when making the decision to quarantine individuals, protection of the public from harm must be weighed against the liberty and autonomy of the individual to be quarantined. It should be noted that while the ethical value of individual liberty (see above) is often in tension with the protection of the public from harm, it is also in individuals' interests to serve the public good and minimize harm to others.

3. Proportionality

Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk to, or critical need of, the community. This principle requires the use of least restrictive or coercive measures in limiting or restricting liberties or entitlements. It also justifies the use of more coercive measures in circumstances where “less restrictive means have failed to achieve appropriate [public health] ends”.^{1,6,7} For example, when deciding whether or not to close schools, it is important to consider whether or not the potential harm to the public, staff and families of school children of keeping the school open is significant enough to warrant such a response, given the potential (economic) impact of such a decision.

4. Privacy

Individuals have a right to privacy, especially with regards to their health information. In a public health crisis, it may be necessary to override this right to protect the public from serious harm. “Proportionality requires that private information be released *only* if there are no less intrusive means to protect public health.”¹ Moreover, in order to protect individuals or communities from stigmatisation, disclosure of private information should be limited *only* to that private information which is relevant to achieve legitimate and necessary public health goals. When decisions are made to breach confidentiality, proportionality is important to consider. Proportionality would require decision makers to determine whether the good that is intended is significant enough to justify the potential harm that can come from suspending privacy rights.

5. Protection of Communities from Undue Stigmatization

A key lesson from the SARS experience was the need to protect communities from undue stigmatization. In releasing information to the public during a pandemic crisis, care should be taken to minimise the impact of public health measures on communities, for example, by disclosing only that information which

is relevant to achieve legitimate and necessary public health goals and by providing public education to correct misconceptions about disease transmission and to offset misattribution of blame to particular communities. For example, during SARS, the Chinese community in Toronto was stigmatised when details of contact tracing were not kept confidential. This stigmatisation resulted in economic and social consequences for the Chinese community.

6. Equity

The principle of equity holds that, all things being equal, all patients have an equal claim to receive needed health care. Health care institutions are obligated and held accountable to be good stewards, to ensure sufficient supply of health services and materials. During a pandemic influenza however, tough decisions will need to be made about who ought to receive antiviral medication and vaccinations, and which public health services will need to be temporarily suspended whilst pandemic influenza public health measures are attended to. In addition as responsible stewards of limited human and material resources, hospitals will need to decide which health services to maintain and which to defer because of these extraordinary circumstances. Measures taken to contain the spread of a deadly disease will inevitably cause considerable collateral damage. In a pandemic influenza, this will extend beyond the cessation of elective vaccination clinics and elective surgeries and may limit the provision of emergent or necessary services. Under such circumstances, decision-makers must strive to “preserve as much equity as possible between the interests of patients [afflicted with the influenza] and those who need urgent treatment for other diseases.”¹ Decision-makers must also ensure procedural fairness in how these decisions are made. In allocating scarce resources like antivirals and vaccines, the value of equity could guide in developing fair criteria for allocation while consideration is given also to reciprocity (see # 8) towards those are entitled to receive antivirals or vaccines but are in priority groups for whom there is no supply of antivirals or vaccines. This may require offering those who fall into these priority groups alternative means of support and care.

7. Duty to Provide Care

Inherent to all codes of ethics for health care workers is the duty to provide care and to respond to suffering. In a time of extraordinary need, demands on health care providers and the institutions in which they work could overwhelm resources. Health care providers will have to weigh demands from their professional role with other competing obligations to their own health, to family and friends. Moreover, health care workers will face significant challenges related to resource allocation, scope of practice, professional liability, and workplace conditions. As there is much controversy about the limits of a duty to provide care, institutions should work collaboratively with stakeholders and professional colleges in advance of a pandemic influenza to establish practice guidelines and to develop fair and accountable processes to resolve disputes. In addition, discharging a duty to provide care in a public health crisis may contribute to

moral distress “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.”⁵ In a pandemic situation discharging the duty to care may not be easily accomplished, especially when resources are scarce and and/or rationed. Supports should be in place to alleviate this moral burden and means developed through which institutions will handle claims from staff for work exemption.

8. Reciprocity

Reciprocity requires that society supports those who face a disproportionate burden in protecting the public good and takes steps to minimise the impact as far as possible.^{1, 2,6,7} In a pandemic influenza, measures to protect the public good are likely to impose a disproportionate burden on public health practitioners, other health care workers, patients, and their families. Health care workers, for example, may face expanded duties, increased workplace risks, physical and emotional stress, isolation from peers and family, and in some cases, infection leading to hospitalization or even death. Similarly, quarantined individuals or families of ill patients may experience significant social, economic, and emotional burdens. Decision-makers are responsible for easing the burdens of health care workers, patients, and patient’s families.

9. Trust

Trust is an essential component in the relationships between government and citizens, between health care workers and patients, between organizations and their staff, between the public and health care providers, and between organizations within a health system.⁶ In a public health crisis, stakeholders may perceive the measures required to protect the public from harm as a betrayal of trust (e.g., when access to needed care or medicine is denied) or as abandonment at a time of greatest need. Decision-makers will be confronted with the challenge of maintaining stakeholders’ trust while at the same time demonstrating responsible stewardship over limited human and material resources and stemming a pandemic influenza through various public health measures. It takes time to build trust. Decision-makers should take steps to build trust with stakeholders before the crisis hits not while it is in full swing. Transparency and early engagement with stakeholders during the pan-influenza planning phase may go some distance to justify stakeholder confidence in decision-makers’ trustworthiness.³ In part, the value of trust is respected and promoted by following the ethical *processes* outlined in Ethical Decision Making.

10. Solidarity

SARS heightened the global awareness of the interdependence of health systems and the need for solidarity across systemic and institutional boundaries

in stemming a serious contagious disease. Pandemic influenza will not only require a “new vision of global solidarity,”¹ it will require a vision of solidarity within and between community, health care institutions, public health units, and government. Solidarity requires good, honest communication and open collaboration within and between this group of actors to share public health information and to coordinate health care delivery, transfer of patients, and to demonstrate responsible stewardship through the deployment of human and material resources. By identifying that the health of the general public (and HCPs and other essential service providers) is a good worth promoting during a pandemic influenza, government decision-makers, public health workers and other health care professionals could model values of solidarity while encouraging others to broaden traditional ethical values focused on rights or interests of individuals.

¹ Daniels, N. Accountability for reasonableness. *BMJ* Nov. 2000, 321;pp.1300-1.

² Marer, S., Sutjita, M. & Rajagopalan, S. Bioterrorism, Bioethics, and the Emergency Physician. *Topics in Emergency Medicine* 2004, 26(1); pp. 44-48

³ Kotalik, J. Addressing Issues and Questions Relating to Pandemic Influenza Planning: Final Report and Recommendations: Part 1 Ethical Perspective. Health Canada April 16, 2003.

⁴ Upshur, R. Principles for the Justification of Public Health Intervention. *Canadian Journal of Public Health*; Mar/Apr 2002; 93, 2 pp. 101-103.

⁵ Jameton, A. *Nursing Practice: The Ethical Issues*. Englewood Cliffs, N.J.: Prentice Hall, 1984.

⁶ Goold, S.D. Trust and the Ethics of Health Care Institutions. *The Hastings Center Report*. 2001; 31(6): 26-33.