TORONTO HEALTH POLICY CITIZENS' COUNCIL REPORT: PRIORITIZING VENTILATORS DURING AN INFLUENZA PANDEMIC IN ONTARIO

Introduction to the Toronto Health Policy Citizens' Council

Public policy decisions in any pluralistic democracy should consider the needs, values, and attitudes of its citizens. Since the public funds and uses the health care system, fairness and legitimacy demand that they be involved in the policy-making process. Public engagement in policy making can lead to better understanding, enhanced empowerment of citizens, and increased trust in the health system. Moreover, in the context of complex value-laden policy decisions, public engagement can enhance the quality of decisions by bringing to the deliberations the full range of relevant value considerations. One method for deliberative public engagement is a Citizens' Council. Although the benefits of public engagement in policy making are well documented, and there are examples of functioning Citizens Councils (e.g. National Institute for Health and Clinical Excellence), more needs to be known about what makes these initiatives work well in dealing with complex health policy decisions.

For these reasons, the Priority Setting Research Group at the University of Toronto established a Citizens' Council to engage members of the public in deliberation about complex health policy issues and, simultaneously, to study the 'basic science' of deliberative public engagement.

The *Toronto Health Policy Citizens' Council* consists of 26 individuals who represent the diversity of the gender, ethnic and socioeconomic characteristics of Torontonians. None are employed in health care related occupations. The purpose of the council meetings is to have ordinary citizens deliberate about important, value-sensitive issues in health care and to comment and make recommendations about those issues.

Introduction to the Topic

Large scale public health emergencies, like the current H1N1 pandemic, raise difficult moral questions. Some of the most difficult of these questions relate to the possible need to prioritize access to ventilators. Because of the severity of the respiratory infection, many patients during an influenza outbreak require access to a ventilator and need to be treated by staff in an Intensive Care Unit (ICU). Because ICUs usually run at near capacity in Ontario, a relatively modest increase in demand associated with a large influenza outbreak may result in the demand outstripping supply, even with the acquisition of extra ventilators and the best efforts of hospital staff to maximize the number of patients who can receive care. A major influenza pandemic could force physicians and hospital administrators to make difficult decisions about who should get access to a ventilator and who should be denied.

The council meeting was held on November 21 and 22, 2009. The citizens were presented with the situation in which there was a shortage of ventilators due to an influenza pandemic. The situation assumed that all attempts by hospitals to increase access to ventilators had been exhausted, but that the pandemic was not so severe that social chaos had ensued. The citizens were asked about the principles which should be used to allocate ventilators and about the role that members of the public should have in the process by which ventilators are allocated. Specifically, the council were asked to deliberate on the following two questions:

Q1. If there are an insufficient number of ventilators to provide them to everyone who needs one during a major influenza pandemic (e.g. H1N1), what principle(s) should be used to allocate ventilators?

Q2. How should the public be involved in the process of allocating ventilators during a pandemic? For example, should triage protocols be publicly available? Is there a role for the public in the valuation of whether a patient should be denied a ventilator and / or in any appeal of such decisions?

Expert Presentations

Three experts made presentations to the citizens during the two-day meeting, providing relevant information and various perspectives on the issues involved.

- **Dr. Vivek Goel, President and CEO, Ontario Agency for Health Protection and Promotion and a Professor at the University of Toronto, provided an overview of the current H1N1 pandemic and pandemic planning in Ontario.**
- **Dr. Robert Fowler, an internist, critical care physician, and an associate scientist at the Sunnybrook Health Sciences Centre (Toronto), discussed how decisions about ventilation are usually made in an ICU and what it has been like in an ICU during the current H1N1 outbreak.**
- **Dr. Andrew Baker, an anesthesiologist and the Chief of Critical Care at St. Michael's Hospital (Toronto), discussed a proposed process by which Ontario could prioritize ventilators during a major influenza pandemic.**

During the expert presentations, the citizens were informed that it is the lack of the expert staff needed to treat patients on ventilators (many of whom are suffering from failure to organ systems in addition to their lungs) that would be the most important resource limitation during a severe pandemic. Therefore, access to ventilation is really a proxy for

admission to an ICU. The problem of access cannot be solved simply by buying more ventilators.

The Citizens' Deliberations

There was universal agreement amongst the group that "survivability" should be the main principle used to allocate scarce ventilators. The principle of survivability was interpreted to mean that those most likely to benefit from being in an ICU (i.e., whose chance of survival is most greatly increased) are the people who should get priority access.

Dr. Baker provided a Figure illustrating the chance of death according to a patient's severity of illness. Patients with relatively mild disease have a low chance of death, even if they do not receive ICU care. Conversely, patients with extremely severe disease are highly likely to die even if they are admitted to the ICU. The distance between the "No ICU care" and the "ICU care" lines indicates the likely magnitude of benefit from ICU care.

Based on the principle of survivability, patients falling in the middle of the chart in terms of severity of illness would be prioritized for a ventilator. Severity of illness is influenced by a number of factors including the nature of the disease requiring ventilation, the presence of other diseases (i.e., co-morbidities), and the patient's age.

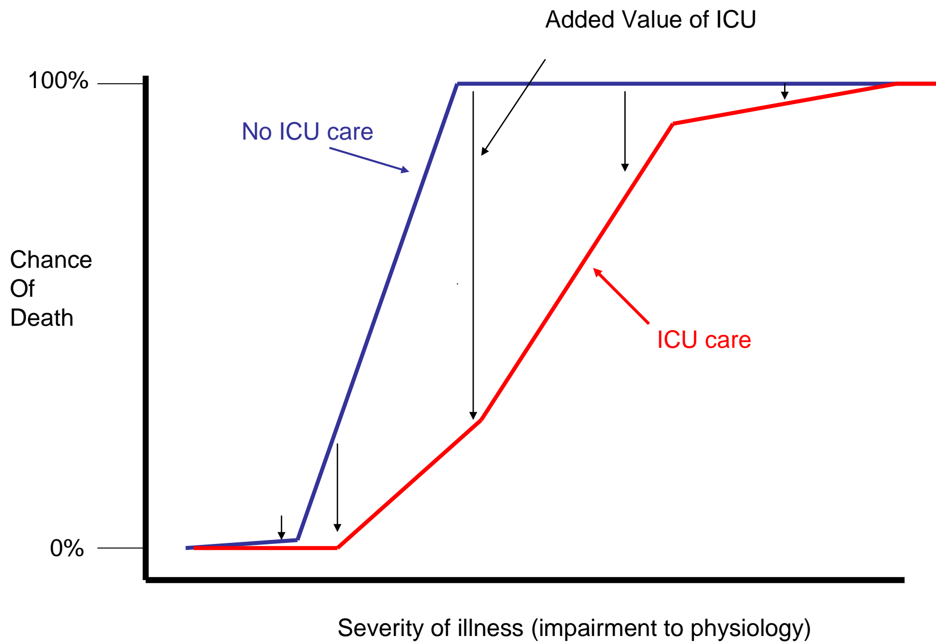

Figure: Benefit from ICU Care according to Severity of Illness

During an emergency situation in which ventilators need to be prioritized, survivability should be assessed for all patients, not just those presenting with influenza. It was also felt that survivability needs to be reassessed on a regular basis, so that patients already on ventilators are neither preferentially treated compared to newly presenting patients nor continue to remain on ventilators even though they have shown little sign of improving.

In normal circumstances, the role of health care workers is to advocate for their patients. The citizens recognized that asking health care workers to make allocation decisions that lead to their patients not receiving ventilation places health care workers in an extremely difficult position. However, it was felt that health care workers, particularly physicians, are best placed to make the determination of survivability.

It was recognized that assessing survivability is not an exact science. However, health care workers should use the best available tools (e.g., SOFA scores) and their clinical experience to make their best estimate of survivability. When doing so, all patients should be treated equally. Patient characteristics such as gender, race, social standing, etc., should not influence the assessment of survivability or access to ventilators.

There was support for a province-wide approach to allocating ventilators, since this increases the likelihood that Ontarians will be treated equitably. At the same time, it was felt that health care workers at individual hospitals should have primary responsibility for making these difficult decisions, and should not be "second guessed" by a provincial body. So that these decisions are not left to individual physicians, the citizens felt that a small committee that reviews decisions and provides guidance on how decisions are being made would be appropriate. Such a committee should include non-physicians such as a social worker, nurse or clinical ethicist.

There was considerable discussion about whether other factors that maximize societal good should be considered in addition to survivability. Some of the citizens thought that, in circumstances of equal survivability, factors such as the number of dependents (e.g., a single parent looking after three children) should be used when making these difficult allocation decisions. As well, there was discussion about whether some occupations (e.g. a police officer) should be prioritized, since they might be more important to the functioning of society during a pandemic than other occupations. However, the majority of the citizens felt that these factors should not be considered since an individual's social circumstances can change markedly over time, that these types of criteria are extremely subjective and difficult to operate in practice.

It was felt that the principal of survivability should take precedence over a patient's religious beliefs. For example, if patients or their loved ones indicate that a patient's religious beliefs support aggressive ventilation at all costs, ventilation will not be provided if the survivability criterion is not met.

Some citizens felt that there should be a limit on the length of time patients are ventilated, perhaps developing some disease specific measure of average length of care. After receiving this length of care, if patients are not improving, they would be taken off the ventilator. Support for this idea diminished during the council meeting, however, especially after the group agreed that patients should be regularly re-evaluated for survivability.

All patients who either are not ventilated or who are taken off ventilators should be treated with compassion and be provided with all available non-ventilator therapy.

It was felt that if a pandemic is so severe that decisions to restrict access to ventilators are required, it would be important to protect health care workers and hospitals from legal challenges. This might be done by declaring a state of emergency, which provides health care workers and hospitals special powers and legal protection. The citizens also recognized that there are a number of other legal issues which need to be considered such as whether agreeing to be taken off a ventilator would impact a family's ability to collect life insurance. The citizens recommended further exploration of these legal issues.

Being told that a patient will not be ventilated will be a devastating message for many patients and their loved ones. The council felt that measures need to be in place to support both families and health care providers in these situations.

The citizens generally felt that there was little need for wide public engagement on this topic. Some council members expressed the view that further focus groups could be used to get more reaction to a proposed policy, but that wider public comment would likely only cause unnecessary concern.

In terms of the information which should be released publicly, the group felt that a brief, lay description of the process used to develop the policy; a general, non-clinical description of the selection criteria and a description of the supports provided to patients who are denied access to a ventilator would be sufficient. Some council members suggested that the option of providing more detailed information around the triage protocol could be made available by request for affected patients and families.

The citizens also discussed a process for appealing decisions to deny them or a family member a ventilator. Some supported the idea of an appeals process if it could be run in an extremely timely manner and not be so resource intensive that it distracts from the most important task, which is to care for the large volume of critically ill patients. The appeals process might provide some comfort to patients and loved ones that they are being treated fairly, and will also support local decision makers if they are pressured to ventilate individuals who do not meet the criteria of survivability. Other council members questioned whether an appeals process was practical in the circumstances of an emergency pandemic when patients need immediate access to ICU care.

RECOMMENDATIONS:

- **The citizens felt that the principle of survivability should be the basis on which ventilators are allocated during a pandemic. This principle means that those who have the greatest chance of benefiting from ICU care should access a ventilator first.**

- **While there should be provincial guidelines, frontline physicians are best placed to evaluate a patient's survivability.**

- **Patient characteristics such as gender, race, religious beliefs, social standing, etc., should not influence the assessment of survivability or their access to a ventilator.**

- **A hospital committee reviewing ventilator decisions could help provide timely guidance to physicians about making these difficult decisions.**

- **While recognizing that the legal consequences of such a policy need to be carefully examined, it is important to protect health care workers and hospitals if they have acted in good faith and in compliance with clear government guidelines from legal challenges related to their decisions on access to ventilators during a crisis.**

- **A brief, lay description of the process used to develop the policy; a general, non-clinical description of the selection criteria and a description of the supports provided to patients who are denied access to a ventilator would be sufficient information to release to the general public about a policy on ventilator access during a major pandemic.**