DEPARTMENT OF HEALTH

Crisis Standards of Care Community Engagement Summary

FEBRUARY 2018

Background

When a large disaster strikes, what should health care providers consider as they determine how to use strained medical resources? To ensure that these complex decisions reflect the values and priorities of Minnesota's communities, the Minnesota Department of Health hosted a series of community conversations over the summer and fall 2017. Each session included a short presentation and a facilitated discussion. The following is a summary of ideas generated, which will help shape Minnesota's plan for providing health care in severe crisis conditions.

Patient ranking

Community members participated in an exercise to rank hypothetical patients before the facilitated discussion. They also responded to an electronic survey before and after the facilitated discussion with general questions about their views for handling difficult treatment decisions during a crisis. The questions in the pre- and post-discussion surveys were the same and used to track the impact of the facilitated discussions on participants' opinions. The facilitated discussion then explored why they chose to prioritize the patients they did, the thought behind their decisions, additional information they would have liked to have, the most important factors to consider when you can't save everyone, whether to give health care workers priority, and their perception as to the fairness of their decisions.

Pre- and post-discussion surveys

While most participants completed the survey questions, many did not provide their demographic data. Participants did not fully complete questions about their age group, race/ethnicity or household dependents. However, most participants did respond to questions asking if they worked in health care or in emergency response. About half of respondents stated they were health care providers, and almost half said they worked in emergency response. In total, 41 people participated in the pre- and post- surveys.

Overall, most participants' responses shifted between the pre- and post-surveys (Table 1). The most striking changes occurred for the following:

- "It is better to save the most lives—even if it means some people won't get all of the medical care they would get under normal conditions" increased from 76% agreement pre-discussion to 98% post-discussion.

- Disagreement with the statement "most medical care should go to save younger patients because they have the most years to live" went from 39% pre-discussion to 56% post-discussion. Agreement with the statement did not shift significantly (20% to 17%).
- Agreement with the statement "health care providers should be at the front of the line for treatment if they are risking their health and safety to care for others increased from 61% pre-discussion to 76% post-discussion.
- Disagreement with the statement "people who do jobs that keep society running (transportation workers, utility workers, etc.) should be at the front of the line for treatment changed from 42% pre-discussion to 20% post-discussion. Agreement with the statement increased from 24% to 34%.

Discussion summary

Patient ranking: decision making factors

Participants discussed the patients they selected to receive, and not receive, treatment, and provided the main reasons for their decisions. Several themes emerged, related to age; chance of survival; the concept of self-determination; the value of a person's contribution to society; and disability.

Age was a determinant for many participants, yet they differed in how they prioritized it. Overall, a majority of participants prioritized younger patients, saying they had more years left to live and were of greater value to society in the future. Several participants mentioned prioritizing the elderly, and the very young. Their rationale was that middle-aged patients would be more likely to survive without treatment. This idea was not universal, and some commented that middle-aged patients were more likely to be parents, and serving in important workforce roles and should therefore receive priority.

Participants frequently cited survivability as an important factor in their decision-making. Overall, a higher chance of surviving was a key factor in ranking patients: some said this was more important than age. There was broad agreement that those with a low chance of survival should not receive treatment. Some mentioned disability, but it seemed as if surviving was more important than any potential resulting disability. In addition, some participants discussed the degree of disability. If the resulting disability would be severe, and would result in a very low quality of life, participants considered the option of providing palliative, supportive care, but not lifesaving interventions.

Some participants mentioned the concept of self-determination - asking patients their preference as to whether or not they wanted treatment. This also applied when considering the wishes of those who might choose to refuse treatment.

Patient ranking: additional information wanted before deciding who to treat

Participants mentioned several factors regarding the need for additional information in order to make prioritization decisions. The most frequently mentioned factors were patient and family preferences, as well as whether the patient had an advanced health care directive/do not resuscitate order. Many participants mentioned prognosis, both in relation to co-morbidities, as well as in provider opinion. Participants also wanted to know whether the individual worked in health care or in another high priority role in terms of disaster response or important community functions. Prioritizing these patients for treatment could mean that they would be able to assist with disaster response once fully recovered.

Patient lifestyle was briefly mentioned—one participant felt it didn't matter—while another wanted to know about patient self-care and whether they in general embraced a healthy lifestyle. Participants were more likely to comment on the potential for health inequities— specifically mentioning those without health insurance or inability to pay, which might prevent them from seeking treatment. Another participant asked about incarcerated individuals and how they would factor into treatment decisions.

When you can't save everyone, what matters most?

Several themes emerged on this topic, including identifying the most appropriate decision-maker(s), whether to embrace a first come/first served approach, taking a value-driven approach and not making determinations based on patient wealth or ability to pay.

Participants were consistent in stating that a predetermined decision-making structure should be in place that reflects agreed upon principles. Some suggested that health care providers were best able to determine an appropriate triage approach. However, participants cautioned that health care providers should make decisions based on clinical, rather than emotional reasons, and individual providers should consider their implicit biases. In addition, a participant mentioned wanting to know whether providers are invested in the community and aware of the local culture as this might affect decision-making.

The idea of a value-driven approach came up several times. Participants prioritized saving as many lives as possible with the best quality of life. Again, some questioned what the patients who receive treatment could contribute to society, and whether they could help in the disaster response once recovered. Patient contributions focused on their role in the workforce or parenting, but it did not focus on wealth or ability to pay. Universally, participants felt that ability to pay for treatment should not be a consideration.

Overall, the concepts of first come/first served or a lottery were not popular with participants. First come/first served could introduce issues related to lack of transportation and the ability of patients to seek care. Those with limited functional abilities may not be able to be among the first to seek treatment, but that should not influence the decision to provide treatment to them. The conversation of first come/first served also prompted some discussion about when/if to take patients off ventilators if they were not improving and other patients needed the

ventilators. Participants agreed that family members should be included in these conversations. They questioned whether there are state guidelines in place that speak to this topic.

Should health care workers have treatment priority?

Participants first asked for context—that knowing the scope of the disaster would influence their response to this question. In general, participants prioritized medical workers—especially those providing critical services—with the idea that if we did not have enough health care workers, more lives would be lost overall. A few participants disagreed that health care workers should receive priority treatment, and others said prioritization would depend on the type of health care worker. Another participant noted that medical staff might be able to better protect themselves, and take precautions, given their increased medical literacy and knowledge base and therefore should not be prioritized.

Many raised the question about other essential workers, for example community leaders, utility workers, police, fire and those who keep society running. It can be difficult to determine which services are essential services. One community stated that they already have a tiered approach written into their emergency plans. This statement supports earlier comments that these types of decisions should not be made during a time of crisis, particularly since other decisions will need to be made quickly. A few respondents reverted to basing decisions on a triaged approach, focusing on chance of survival, treating those at highest risk and considering preventable shortages.

Health care provider authority to reallocate treatment

Near the end of the discussions, facilitators gave participants a new piece of information. They told participants that two of the patients they chose to receive life-saving medications had not responded to treatment and doctors believed that they would almost certainly die. If doctors stopped treatment, there would still be enough of the drug left over to save one more patient. However, the families of the two dying patients would not agree to stop treatment. Participants were asked whether the hospital should go against the families' wishes and use the remaining doses to try to save another patient.

Several participants mentioned the need for legal counsel and ethics committees to make these types of decisions. Many comments focused on not putting doctors in the position of having to make these decisions themselves, but rather using a policy or approach agreed upon by the community. Although there was recognition that doctors may have a more realistic view of prognosis and the needs of other patients, in crisis situations it was important to consider the good of the community overall as opposed to individuals.

Other discussion focused on supporting the patients and families. Patients and families should be educated at the start of treatment on what to expect and on realistic timeframes for expecting progress. What happens if little improvement is noted, but other sick patients might benefit? Suggestions were made to provide palliative care and support for patients when treatment is discontinued, consider how faith may influence families, and being transparent with patients and families on the decision-making process.

Perceived fairness on treatment decisions

Most participants felt they had been fair in their treatment decisions. One group noted that fairness is a subjective concept. They observed that decision-making might be less about being fair and more about being reasonable. Another said that the more factors that contribute to the decision, the harder the decision might be. Participants noted that no matter what, these decisions would be tough ones to make.

Additional comments on the decision-making process

Participants also made the following observations during the course of the facilitated discussions.

- It is important to make these decisions prior to the crisis: crisis is not the time for consensus building. Decision-makers need to feel empowered to make the decisions, since not everyone will agree.
- Questions were raised about gender and childbearing age: if it is an extreme crisis, is it important to think about future generations?
- Large county and health care systems may need to think about the needs of smaller health care entities. How could they support them in times of crisis, particularly around differences in access to resources?
- Remember that everyone will come into these discussions with their own biases and emotions: try to work as a team to come up with recommendations that everyone will own.
- In the end, try to save as many lives as possible. This requires structure with flexibility and trusting health care workers, while at the same time having guidelines that reflect shared ethics/morals. These guidelines need to be in place prior to the crisis.
- Opinion of the patient matters most if they choose to refuse treatment.

Next steps

Holding community conversations on Crisis Standards of Care ensures that the guidance reflects the values and priorities of Minnesota's community members. The following steps will be taken with this goal in mind.

- The community conversation participants will receive a copy of this summarized report.
- Feedback contained in this summary will be incorporated into the statewide Crisis Standards of Care Framework.
- Practices and gaps from this first set of engagement sessions will be assessed and steps for improving future sessions will be undertaken.
- The engagement team will hold additional community sessions through 2018, with a special focus on engaging communities experiencing health inequities, such as immigrant populations and the disability community.
- Lessons learned from the community engagement process will be shared to inform other aspects of preparedness planning in Minnesota.

Table 1. Pre- and post-discussion questions

	Response Options	Pre-Discussion	Post-Discussion
It is better to save the most lives—even if it means that some people won't get the medical care they would get under normal conditions.	Agree Neutral Disagree I don't know	76% 7% 2% 2%	98% 2%
More medical care should go to save younger patients because they have the most years to live.	Agree Neutral Disagree I don't know	20% 32% 39% 	17% 15% 56% 2%
The sick and injured should be treated "first come, first-served" whether or not they are likely to survive.	Agree Neutral Disagree I don't know	10% 15% 66% 2%	5% 7% 78%
People should not get limited medical resources if they will survive but end up severely disabled.	Agree Neutral Disagree I don't know	17% 27% 39% 5%	20% 34% 34% 2%
Health care providers should be at the front of the line for treatment if they are risking their health and safety to care for others.	Agree Neutral Disagree I don't know	61% 10% 17% 5%	76% 7% 5% 2%
A person's ability to pay should not matter when deciding who should receive limited medical resources in a crisis	Agree Neutral Disagree I don't know	98% 	85% 5% 2%
People who do jobs that keep society running (transportation workers, utility workers, etc.) should be at the front of the line for treatment.	Agree Neutral Disagree I don't know	24% 29% 42% 2%	34% 29% 20% 5%
Elderly patients should get more medical care than younger patients because they have important wisdom and experience.	Agree Neutral Disagree I don't know	5% 5% 78% 7%	2% 5% 76% 2%
Doctors and nurses should be free to make their own decisions about which patients get treatment and which ones will not.	Agree Neutral Disagree I don't know	32% 17% 39% 7%	20% 34% 32% 10%
The best way to decide who should be treated is to do a lottery or draw straws.	Agree Neutral Disagree I don't know	 2% 63% 	2% 95% 2%

*Percentages calculated using a denominator of 41. Not all participants answered every question (response varied by question), so for percentages within each question that do not add up to 100%, this reflects missing responses.

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