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# Bedside Ethics and Health System Catastrophe: Imagine If You Will . . .

*Jeffrey T. Berger, Guest Editor*

In view of recent public health challenges, *The Journal of Clinical Ethics* has collected articles that were originally published as "Clinical Ethics in Catastrophic Situations: Mapping a Standard of Care," written after Hurricane Katrina, Guest Edited by Jeffrey T. Berger, MD, FACP, FAAHPM, Professor of Medicine, NYU Long Island School of Medicine and Chief, Division of Palliative Medicine and Bioethics, Department of Medicine, NYU Winthrop Hospital. We thought it would be helpful to make these articles available to policy makers and practitioners, as the challenges remain salient.

## ABSTRACT

Preparations for large-scale disasters have tended to focus on triage schema, stockpiling of materials, and other logistical concerns. Less attention has been given to the myriad of distressing and almost unthinkable ethically charged dilemmas that will emerge at the bedside during a catastrophe, and how they may be best managed. Yet, it is these bedside issues that may limit or thwart the effectiveness of disaster planning, and, therefore, they ought to be carefully considered.

Rod Serling, the creator and narrator of the 1960s television program *The Twilight Zone*, often introduced its episodes with the words,

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"Imagine if you will . . ." followed by an imagination-bending scenario with weighty moral overtones. If he were writing this introduction, he might lay down this challenge: "Imagine if you will, a world suddenly gone mad. A world in which ordinary expectations for health and safety are hijacked; a world in which established norms of morality are upended; a world in which your very survival is no longer assured. You have entered the world of health system collapse, you have entered *The Twilight Zone*."

The dual phenomena of high population densities, and the increasingly technologic nature of basic services and medical care, create an enormous vulnerability for the public's health and profound challenges for health practitioners in times of catastrophe. Large-scale crises may be caused by natural phenomena such as hurricanes (Katrina, 2005), tsunamis (Indian Ocean, 2004), cyclones (Myanmar, 2008), earthquakes (China, 2008), and pandemics (influenza, 1918); and by industrial accidents (Bho-

pal 1984, Chernobyl, 1986). The specter of terrorists' use of conventional, biological, and nuclear agents also raises the threat of health catastrophes. These events can immediately transform large portions of a society by disabling electrical grids, communications systems, water utilities and sewerage systems, and by disrupting fuel supplies, transportation, and sanitation, in addition to directly causing illness. The delivery of healthcare services would likely collapse just when hospitals would be faced with a large spike in patient volume.

The health system may collapse from a large volume of incoming patients. For example, a viral pandemic may trigger repeated waves of patients, whereas a chemical attack may bring one large influx. Health systems may collapse due to infrastructure failure such as from a cyber attack that disables the electrical grid. A nuclear attack may cause both large numbers of casualties and infrastructure failure simultaneously. In any event, catastrophes that cause health system failure can be abruptly transformative. Of course, limited or absent healthcare services are common in some less-developed parts of the world, and people die because of it. This pernicious crisis is relatively ignored perhaps because of nothing more than the disempowered expectations of these populaces. Catastrophes in developed nations are anticipated and prepared for, perhaps for a similar reason — empowered expectations.

These disparities notwithstanding, our civilian, military, and medical communities have given a great deal of attention to disaster planning in recent years. These efforts include infrastructure development and logistical planning, such as projecting the need for material and human resources, and the stockpiling of supplies. Ethical analyses around disaster planning have focused great attention on approaches to triage, the ethics of allocating limited resources, and the like. Less attention has been given to the myriad of distressing and almost unthinkable dilemmas that will emerge at the bedside and how they may be best managed.

For example, during health system collapse, clinicians may be forced to operate under a different weighting of the ethical notions of au-

tonomy, justice, and utility. The rapidity of this shift may mirror the nature of the disaster. Will authorities prepare clinicians to accommodate a revised ethical calculus prior to a calamity? If so, how? How will they be briefed and coached during a catastrophe, and by whom? How will compliance be assured? Will some clinicians invoke conscientious objection to “martial ethics”? Will some passively object and others actively protest? Will such objection add to chaos and cause harms in addition to ones directly caused by the catastrophe? How will these protests be dealt with and by whom?

How will the public be prepared for a health system experience that will be less responsive to personal autonomy than it is in times of normalcy? Will patients and families accept non-voluntary discontinuation of life support — a feature of many disaster management proposals? How will order be maintained in hospitals? Who will assure clinicians', patients', and family members' safety? What obligations, if any, do hospitals have to victims who arrive at their doors when bed capacity is thoroughly exhausted? What degree of personal risk ought clinicians accept during system collapse? What is obligatory? What is supererogatory? What is reckless and should be prohibited?

How should obstetric care fit into catastrophe management? Should hospital-based deliveries be prohibited to free-up beds? Should an exception be made when the woman's life is in jeopardy? When the fetus' life is in jeopardy? Should midwifery be instituted as the standard of obstetrical care in order to free-up obstetricians whose surgical experience can be utilized elsewhere? Where do near-term and pre-term fetuses fit in to the triage hierarchy for scarce resources? Should an ill woman who is coincidentally pregnant jump the queue for life-supporting interventions because two lives are at stake, or would that discriminate against others not able to bear children?

How far should doctors, nurses, and other clinicians be expected to venture beyond their normal clinical competencies in catastrophe? How will clinicians practice under a dynamic “standard of care” while maintaining professionalism? What particular moral dilemmas

may be faced by physicians, other clinical staff, and even hospital administration, in small hospitals and communities in which many of the staff, patients, and family members are, unavoidably, also friends, neighbors, co-congregants, and relatives?

In order to best prepare for the ethical consequences of a catastrophe that causes health system failure, we will need to use our imaginations, and dare to think about the unthinkable; to consider the horrific, such as Katrina and the earthquake in Haiti, as well as the inconceivable. Certainly, triage systems and allocation protocols will be greatly needed to guide the delivery of care during a catastrophe. Yet, the bedside of Western catastrophic medicine remains a terrain that is poorly lit and largely uncharted.

This special section of *The Journal of Clinical Ethics* strives to imagine (if you will . . .) what may happen on the ground during health system collapse. This collection of articles addresses some of the questions I raise, and generates many more.

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# A Possible Application of Care-Based Ethics to People with Disabilities during a Pandemic

*Edmund G. Howe*

## ABSTRACT

Should people with exceptionally profound disabilities be given an equal chance of surviving a pandemic, even when their care might require a greater use of limited medical resources? How might an ethics of care be used to shape a policy regarding these patients?

*The Journal of Clinic Ethics* will publish special sections on ethical issues involving mass disasters such as hurricanes, pandemics, and terrorist attacks, edited by Jeffrey Berger, MD, in this issue and in the spring 2011 issue.

In these conditions, ethical problems that are particularly agonizing may erupt; for instance, many lives will be lost should resources become scarce. Questions such as, Who should get life-sustaining treatment when not everyone can? and, "When (if ever) should patients be

taken off respirators to save the greatest number of lives?" can arise. Griffin Trotter, MD, PhD, offers a different view regarding the scarce resource of ventilators in this issue of *JCE*; he states that claims about "the necessity of using full-feature ventilators, and about the priority of determining the ethical distribution of such ventilators — are flawed."<sup>1</sup> He argues that volunteers could manually ventilate (squeeze air bags to breathe for) patients who are removed from ventilators, and this would enable some patients, if not most, to survive, and that two volunteers, taking turns and spelling one another, should be sufficient for each patient. The volunteers would have to be highly committed. This kind of response could be seen as being primarily based on an ethics of care or on a model that emphasizes mutual interdependence and emotional responsiveness.<sup>2</sup> This may raise the question of other contexts in which an ethics of care could be applied.

In this essay I will consider one such possibility: during a pandemic, how an ethics of care might shape policy regarding patients with exceptionally profound disabilities, such as tetraplegia or, particularly, later stage dementia.<sup>3</sup> I

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will consider whether *all* people with disabilities should be given an equal chance of surviving a pandemic, even when their care might require a greater use of limited resources. This question is particularly important because, if these patients are treated and they do require a greater use of limited resources, fewer in the general population may survive, as a result.

In this context, I will discuss the views of Joan Liaschenko, Mary Urban Walker, and Nel Noddings. Joan Liaschenko has said that New Zealand, more than any other country, applies an ethics of care approach in pandemic planning.<sup>4</sup> I will review a document that New Zealand posted for public comment in 2006, *Ethical Values for Planning for and Responding to a pandemic in New Zealand: A Statement for Discussion*, that supports Liaschenko's views.<sup>5</sup> This document is particularly useful here, in that it provides several concrete examples of how an approach based on an ethics of care could be specifically applied during a pandemic. Then I will consider some of the work of Walker and Noddings, whose insights, like Liaschenko's, may bear particularly on whether an ethics of care should be applied during a pandemic for members of this group.

Liaschenko says that the work of Mary Urban Walker has influenced her more than anyone else. In her writings, Walker emphasizes the importance of removing any distinction between persons who are like us and those who are not: "us" and "them." Walker notes that removing this distinction is particularly important when a person has a more visible or evident disability; those who would like to eliminate barriers between "us" and "them" should try to change their attitudes and "habits of perception."<sup>6</sup> The policies that we adopt toward people with profound disabilities, especially when the policies are binding and explicit, may play a significant role in reducing the barrier that still exist, in many contexts, today.

In her work, Nel Noddings makes a critically important distinction between (1) emotions that may mislead us and (2) emotions that won't mislead us, but may actually *guide* us regarding what we should do in a particular situation. This philosophical and empirical distinction is

exceedingly important; from before the time of Socrates, many have viewed feelings as much inferior to reason. Noddings points out that the kind of emotion that may mislead us often occurs when we are under stress, and may be most pronounced when we are overcome by the need to survive. Through evolution, we may be hard-wired to respond in this way. When we are not stressed, however, our feelings may be more likely to reflect empathy, and to help us overcome tendencies we may otherwise have to deny or ignore others' needs.

With this background, I will discuss how Trotter's approach to disaster planning, the New Zealand pandemic plan, and an ethics of care could be applied during a pandemic to help those among us who have the most profound physical and mental disabilities. I will discuss why it may be warranted to offer an all-out effort to give persons with the most profound disabilities an equal chance to survive, even when it may result in fewer lives being saved. This may offer us a rare and unique opportunity to establish what many in our society want: to regard the interests of people with disabilities as equal to the interests that we accord to people of different genders, races, and ethnicities.<sup>7</sup> The ethical questions raised in this context are as profound as any we may ever face.

#### THE ETHICS OF CARE AND THE NEW ZEALAND APPROACH

My colleague, Carol S. Fullerton, PhD, conducts research, talking with hundreds of people who survived being in a hurricane. Many told her they chose not to leave their homes when asked to evacuate, even though they knew they might risk their lives, because they were unwilling to abandon their loved ones or pets.<sup>8</sup> These people gave priority to their feelings for others, even risking their lives. That many did this demonstrates the importance taking people's relationships with others into account when we craft public policy. I will now consider insights offered by Liaschenko, Walker, and Noddings on why and how we might do this, as well as the approaches used by policy makers in New Zealand, which provide concrete examples.

### Joan Liaschenko

At the 2008 annual meeting of the American Society of Bioethics and Humanities, Joan Liaschenko described the importance of giving greater priority to people's relationships during a pandemic. The title of her presentation, like the title of Trotter's article in this issue of *JCE*, speaks for itself: "When the Pandemic Comes, I Hope I'm in New Zealand."<sup>9</sup>

In her presentation, Liaschenko described New Zealand's wisdom in giving greater priority to "the community" and to people's interdependence and feelings for each other. She said to me later that, were she to be ill in a pandemic, she would be "much more concerned" with "who would feed my pets, get me water, and change my sheets" than she would be with whether or not she received a vaccine or access to a ventilator.<sup>10</sup>

To some degree, Liaschenko's preferences may match those of some of the people that Fullerton interviewed, who were unwilling to abandon their loved ones or pets during a hurricane. While the views of these individuals are important in their own right, they may also reflect the deep feelings that many — or even all — people hold. Some people may lose touch with these deep feelings or with their intensity during a disaster. During a crisis, other feelings that are fueled by a need to survive, as Noddings proposes, may arise.<sup>11</sup>

In any case, whether or not these feelings are or are not common, Liaschenko related that "New Zealand at least has such concerns on the radar screen — at least implicitly, whereas here they are seen as naïve or silly," at least by some people with whom Liaschenko has worked.<sup>12</sup> In her presentation at ASBH, Liaschenko gave examples of how these concerns were "on the radar screen" in a document published by the New Zealand National Ethics Advisory Committee (NEAC) in 2006, that invited public comment.<sup>13</sup> Even though the NEAC "end[s] up" with rationing, at least it starts at "a much different place," Liaschenko says. Like Trotter, the NEAC document puts "the community" first.<sup>14</sup> For example, NEAC would send volunteers to "rural people" to rescue them, when necessary, and would send volunteers to people's homes when

they couldn't be reached by phone. Liaschenko reports that NEAC also attempted to offset the wrongs done in a pandemic in 1918 to a group in New Zealand called the Maori. Members of this group will now receive priority during disasters. This special commitment and application of compensatory justice may be one manifestation of what Liaschenko refers to as NEAC's emphasis on "shared values," which includes moving the community "to do things for the good of others that they would not normally need to do."<sup>15</sup> NEAC also recognizes and makes explicit, she indicates, its commitment to respecting the Maori's view of "right or correct acting," as she says, "alongside" other values.<sup>16</sup>

She contrasts this commitment with the approaches taken by other countries, which all too often engage in what Mary Urban Walker, (the philosopher whom Liaschenko credits as having influenced her most) called "epistemic rigging." Liaschenko uses this phrase to describe how some countries "masquerade" their policies as objective and neutral, when the policies actually "serve the interests of some at the expense of others."<sup>17</sup> Liaschenko bases much of her thinking on her readings of the work of Walker, whose book, *Moral Understandings: A Feminist Study of Ethics*, is now in its second edition.<sup>18</sup> Liaschenko, like Walker, lists as among her most serious concerns "the deep, powerful beliefs in experts and expert knowledge, including ethicists."<sup>19</sup> This concern not only applies to the authors who are included in this issue of *JCE*, but also to herself, and me! Finally, Liaschenko expresses a profound doubt that even the most conscientious efforts to survey individuals' opinions may not capture their real feelings accurately: "To be seated at the table is a good thing but you are, nonetheless, at the mercy of the one extending the invitation and [thus] subject to the menu being served."<sup>20</sup>

### THE NEAC Document

As noted above, the New Zealand National Ethics Advisory Committee distributed its policy document, *Ethical Values for Planning for and Responding to a Pandemic in New Zealand: A Statement for Discussion*, to the New Zealand public in 2006, asking for comment.

The document includes statements of basic ethical assumptions and hypothetical cases. I will cite several portions of the document to illustrate why Liaschenko stated that she'd prefer to be in New Zealand during a pandemic. In the Foreword and first page of the document, NEAC states its special commitment to the Maori, mentioned above: "The Maori have been disproportionately affected by past pandemics . . . we must ensure this doesn't happen again."<sup>21</sup>

NEAC lists, among its primary, prioritized ethical values, "taking everyone's contribution seriously."<sup>22</sup> That statement might seem surprising, and it might be an example of the kind of statement that caused policy makers to see those who might try to pursue this kind of approach as naïve or silly, as Liaschenko mentioned. When viewed in the context of the entire NEAC document, however, the statement may be seen in a different light; the context may be best conveyed by describing some of the hypothetical scenarios that are included in the NEAC document, describing the response of a disaster team at different homes.

In the "third house" scenario, for instance, "a dog can be heard barking in the house."<sup>23</sup> Here, NEAC recognizes the concern that people may have for their pets (and perhaps also its concern for pets in general). In the "fourth house" scenario, "volunteers break in and control starving dog [*sic*]."<sup>24</sup> The document later asks, "Who looks after the dog?" and answers, "Dog-ranger collects the dog."<sup>25</sup> In the "seventh house" scenario, the document describes what the disaster team would do when it encounters a couple who insist they are "fine." Here, members of the disaster team inform the couple that although *they* are fine, they still can help others. The team slips a calling card through a "catflap" at the house, and hopes that the couple will volunteer to help others.<sup>26</sup> In the 13th scenario house, a "husband is delirious and violent with high fever." He refuses all treatment and no longer recognizes his wife and children. The team restrains him. His wife, then, *calls her husband's rugby club to ask a friend to come in and sit with him through the night.*<sup>27</sup>

The NECA document also presents an intensive care unit (ICU) "triage case."<sup>28</sup> Here, a

support team is developed to help *staff* cope with the many demands in the ICU. When ICU staff take on greater risks — for example, they may contract influenza when they care for patients — the NEAC document formally recognizes that staff take greater than normal risks, and such staff are given somewhat greater priority. If they acquire the illness, their hospital will contact their families, both to support the families and *to express their exceptional appreciation for the staff members' having taking on the additional risk.*<sup>29</sup>

Most notably, the NEAC document makes certain that the *public* knows that the needs of these staff members will be prioritized, should they become ill, and also that this priority is *not without bounds*. It states, explicitly, that if other patients' needs are significantly greater than those of staff members, the others' needs will prevail.<sup>30</sup>

Finally, how does the NEAC document resolve triage conflicts when resources are limited, and some individuals will receive medical care, but others won't? It allows making decisions regarding treatment based on the principle of benefit. When this is not useful, it recommends using the principle of randomness, to maximize fairness. The document provides, however, extra support to those who take on exceptional responsibility for others.<sup>31</sup>

In this regard, I think of caregivers I have known who care for patients with dementia. I recall one particular caregiver, who noted with delight a study she had found that reported that patients fare better when others relate warmly and in a focused way with them, even if it is only for 10 minutes a day.<sup>32</sup> I asked her why she felt such delight. She said that she was with her husband who had dementia 24 hours every day. This study meant to her that she could now take *some* time to be away from him, by herself, and not worry that her absence would harm him, as she had feared it would.

### **Margaret Urban Walker**

Margaret Urban Walker, like Liaschenko, is concerned that there may be too much of a discrepancy between the needs of the general population and those who most need the help of a

careprovider. We have to look carefully, she says, at all “relations of authority and power.”<sup>33</sup> She is most concerned about the treatment that is accorded to those who are the most vulnerable. She states that we must look beyond the paradigmatic moral example of whether people should rescue a “drowning child in the pond,” since, although rescuing a child in this situation is morally obligatory, the example doesn’t extend sufficiently to include others.<sup>34</sup>

On the other hand, Walker asserts, we must always ask, in any situation, who are “us” and who are “them?”<sup>35</sup> This question is particularly critical when it pertains to people who are disabled, as I shall discuss in the next section. Walker offers a way that she thinks we (meaning “us,” both with and without disabilities) can accomplish this. She writes that it is especially important to seek to tackle and overcome entrenched “attitudes and habits of perception. . . — that erase or deform moral kinship among human beings.”<sup>36</sup> She continues, “it is the very indisposition of some human beings to see quite the same — recognizably fully human — features in some (other) human beings that partly constitutes the problem in the first place.”<sup>37</sup>

There may be a biological basis for her contentions: research indicates that the hormone oxytocin can increase feelings of bonding between individuals, but may only increase feelings of bonding toward others whom individuals see as being like them and as being in their same “group.”<sup>38</sup> Obviously, seeing other people as “not the same as us” can pose ethical problems. The implications this has for the development of policy for pandemics regarding those who are most profoundly disabled will be discussed in the next section.

Finally, Walker earmarks what may be required for people to not “erase or deform” their moral kinship with others: “Ethical views that stress *feeling* as the wellspring of moral response,” she writes, “may [be] . . . promising in this regard.”<sup>39</sup>

This same need to *feel* is also often assumed to be necessary for change in psychotherapy. There, unless an individual feels, he or she may generate more and more thoughts, but stay the same. I will say more about how people may

change in their response to people who are greatly visibly disabled in the next section.

### Nel Noddings

As noted above, Liaschenko stresses the importance of people’s feelings for one another; Walker emphasizes the attitudes and habits of perception that may blind us from doing what we should. Their views leave open a core concern that may stop us from responding as they urge us to do: it is possible that our feelings may lead us greatly astray. How can — and, indeed, why should — we give any moral weight to our feelings, when we know that our feelings can be greatly biased and irrational?

Since Socrates and before, many have raised this same question and have concluded that reason, and reason alone, should prevail in these matters.<sup>40</sup> Nel Noddings addresses this obstacle to being more open, head on. She explains why we should trust *some* feelings, but not all feelings; we have feelings that can (and should) guide us, and that only such feelings, not reason, can move us to do what we should. Noddings describes how these “positive” feelings may arise: “Naturally, when an infant cries we react with the infant and feel that something is wrong. Something is wrong. This is the infant’s feeling and it is ours.”<sup>41</sup> She continues, “Usually we comfort first . . . before we begin to analyze what is the matter.”<sup>42</sup>

Noddings considers the quintessential question raised above: How can we give moral weight to our feelings when we know they can be biased and irrational? She asks, “How can I know? [There may be] . . . a failure somewhere in my movement from feeling to assessment.”<sup>43</sup> She answers, “What is offered here is not a set of knowledge claims to be tested but an invitation to see things from an alternative perspective.”<sup>44</sup> She adds, “When I care . . . there is a motivational shift. . . .”<sup>45</sup>

Noddings contrasts positive, motivating emotions with feelings of the “other kind.”<sup>46</sup> She writes, “When [our thinking mode breaks down] under pressure, we respond emotionally. . . .”<sup>47</sup> Jean-Paul Sartre called this a “‘degradation of consciousness. . . .’”<sup>48</sup> But, Noddings says, when we enter into a positive “feeling mode, [this] is

not necessarily an emotional mode. . . . We do not pass into [a feeling mode] under stress.”<sup>49</sup> Such positive feeling modes, she says, are “essential to living fully as a person. . . [they are] at the heart of human existence.”<sup>50</sup> “It is in this [feeling mode] that I see clearly what I have received from the other, and then I must decide whether to proceed in a state of truth or to deny what I have received and *talk myself into feeling comfortable with the denial*.”<sup>51</sup>

What Noddings is saying here, in speaking of denial, is of the utmost importance to the question of what we should do during a pandemic for people who have a profound disability. Put most simply, if we do not deny what we feel (or should feel) for these people, it may be that we should insure that they (who are also “we”) have the same chance to survive that individuals who are not disabled would have, who have the identical likelihood of getting well. There are several factors, some irrational, that may tend to reduce our openness to giving this group an equal chance to be able to live through and survive a pandemic. I will address these factors next.

### FEELINGS TOWARD PEOPLE WITH DISABILITIES

There are several reasons that society might not want to give people with severe or profound disabilities the same chance to survive that others have, who have the same likelihood of surviving with the same medical care. The main one is that people with severe or profound disabilities may need more scarce resources to survive, and, if they receive more scarce resources, additional lives may be lost.

In principle, giving individuals equal treatment, based only on their likelihood of being able to survive with identical treatment, would include a much larger group of patients. From the standpoint of utility or of saving the most lives, this would be prohibitively problematic.

Yet, from the standpoint of the ethics of care, it may be that a case for this could still be made. It could be possible, for instance, to highly limit a commitment to this equity, so that if and when a pandemic or other mass disaster occurred, the

outcome of a relative loss of lives would be both limited and rare. It might be, for example, that this practice of equity would be carried out only to a predetermined point, and if and when the numbers of patients who would die went beyond this, other additional criteria — for example, not only patients’ likelihood of benefit, but also the resources it would be expected they would need, relative to others — could be used. In any case, to require that equity be based on relative benefit, not resources required, would be one step among many that could be taken to treat people with disabilities more equally.

The specific wording of the NEAC document may be useful to consider here. It states,

. . . policies and services are often constructed with able-bodied people in mind, potentially disadvantaging those with disability. During a pandemic, people with disability would be vulnerable to being further disadvantaged by policies and interventions, unless particular consideration were given to avoiding such an outcome. Vulnerable populations may need particular support during a pandemic, and it is useful to anticipate these needs in pandemic planning. If pandemic planning caters only for people who are not vulnerable, then vulnerable populations are likely to be further disadvantaged.<sup>52</sup>

Perhaps the strongest argument for doing what NEAC has espoused may not be ethical principles, but an ethics of care, based, for instance, on the emotional imperative urged by Walker to remove all distinctions between “them” and “us.”

I would like now to discuss two considerations that, even though this approach makes sense, could preclude it. Both considerations involve nonrational, but well-documented, common proclivities. The first involves a tendency that some careproviders have of seeing people with disabilities as less likely to be happy with their life than is the case. The capacity of people to feel happy, despite being even greatly impaired, is profound, even if it is counterintuitive. In fact, because it is counterintuitive, this capacity to be happy is known as

the disability paradox.<sup>53</sup> Such unwarranted pessimism on the part of careproviders can come from caring for newborn infants born with special needs, and from patients who are adults with tetraplegia, but it may impair careproviders' ability to give a patient with a disability the care she or he needs during a pandemic.<sup>54</sup> Careproviders (and others) may be able to overcome this error by better getting to know people who have disabilities.<sup>55</sup>

A feeling that may be harder to overcome is a tendency in non-disabled persons to *reflexively* want to distance themselves from people with particularly visible and evident disabilities. Thus, a policy regarding equality of access to treatment during a pandemic may be particularly warranted. I would like to end this discussion, therefore, with a discussion of this proclivity, which may particularly create an "us" versus "them" dilemma for people who don't have disabilities, and for people who do have a disability, when they encounter each other. People want to look at someone who looks different, but, at the same time, they don't want to seem to stare, so they look away.

The best book on this dilemma, written for people who have disabilities and people who don't, is *Staring: How We Look*, by Rosemarie Garland-Thomson.<sup>56</sup> She writes, "If an arc of empathy is to leap across the breach opened by staring, persistence and generosity must prevail on both sides."<sup>57</sup> She says, "The atypical face is a failed face, perhaps an improperly human, irrationally organized face."<sup>58</sup> But, she says, there is "a stare of connection rather than separation. . . . This face-to-face engagement is an 'intimacy' akin to the I and Thou relation described by Martin Buber. But these starers are engaged with a face that differs so drastically from a proper face *as to call into question our shared understanding of humanity*."<sup>59</sup> Garland-Thomson continues, "bad staring, in short, is inadequate identification between starrer and staree. . . . This unethical stare, in other words, is looking without recognizing, a separated stare that refuses to move toward one's fellow human."<sup>60</sup>

It is this felt, reciprocal capacity for face-to-face intimacy and connection that is at the heart of, I believe, an ethics of care. Accordingly, this

may well be the strongest reason that we might wish to consider adopting a pandemic policy in which we ask only how likely an intervention is to keep a person alive. If there are not enough resources, and the likelihood of survival is equal for a patient who is profoundly disabled and one who is not, we might draw straws, but we would not discriminate on the basis of the resources each is likely to need.

It is a "move toward one's fellow humans," as Garland-Thomson describes it, that should move us to very seriously consider adopting such a policy, even if no other argument based on principles will; as Garland-Thomson notes, this "look of recognition constitutes us as equal citizens and equally reciprocal participants in the public sphere."<sup>61</sup> Although requiring this kind of equality in a pandemic might be immediately achievable, learning to find better ways to avoid bad stares and turn them to good stares will take time.

The same claim can be made for patients with dementia on both political and personal levels, although I will not make the claim here.<sup>62</sup>

Instead, I will provide an "unfair" hypothetical example. Imagine that you are a colleague of the famed physicist Stephen Hawking. A pandemic strikes. Can you look him in the eye, knowing that if you and he have the same illness, and have the same chance of surviving it with treatment, that you might well receive the treatment, and he might not?

## CONCLUSION

I have raised the possibility of adopting a pandemic policy in which people with even profound disabilities would be treated equally during a pandemic, when their likely benefit was equal to others without disability, whether or not this would require the use of more resources, and possibly result in saving fewer lives. Policies may already exist that do this, to some extent, but they do not go "all the way."

It is possible that, if such a policy is adopted and put into practice, some persons without disabilities might die who otherwise would survive, and this might cause a backlash. Still, the ethics of care — and, more prosaically, our be-

ing able to look persons who are disabled in the eye — may require us to at least consider it.

Noddings states, in this regard, “Everything depends . . . upon the will . . . to remain in caring relation to the other.”<sup>63</sup> Working through a scenario in which she must choose one person in a group to die, or else she and all members of the group will die, Noddings writes, “How shall I choose? The oldest? weakest? one with no family? Hmm. My eye falls on A. He is sick. . . . He will not struggle. Perhaps I can avoid his eyes. But as I reach toward him, I feel the life, and fear, and trust, and hope, and whatever else is emanating from him. . . . What am I doing? What irrationality is upon me? . . . So we all die. There are, after all, worse things than death.”<sup>64</sup>

## NOTES

1. G. Trotter, “Sufficiency of Care in Disasters: Ventilation, Ventilator Triage, and the Misconception of Guideline-Driven Treatment,” *The Journal of Clinical Ethics* 21, no. 4 (Winter 2010): 294-307. I have to admit, while reading Trotter’s piece, that I wondered what the limits of volunteers’ learning might be. I thought of a potentially lifesaving skill we were taught during medical school, called a cricothyroidotomy. If a person is unable to breathe after swallowing a hard, small object that is stuck in the trachea (windpipe), it is possible to jab a sharp object like a penknife into the throat, twist it, and then insert the straw-like, plastic part of a ball point pen into the hole so that the person can again breathe. I wonder whether I would succeed in something like this, much less a lay volunteer.

2. T.L. Beachamp and J.F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 2009), 37. “The core notion of an ethics of care . . . is caring and taking care of others” (p. 36).

3. “What it means to be disabled includes now, more, what it means to be viewed as disabled by others. . . .” J.E. Bickenback, “Disability, Culture, and the UN Convention,” *Disability and Rehabilitation* 31, no. 14 (2009): 111-24, p. 112. This understanding is embodied, for example, in the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD) (adopted 13 December 2006), p. 111. This document involves a conceptual shift from a “‘medical model’ to the ‘social model’ of disability” (p. 112). As the CRPD states in its preamble, “disability . . . results from . . . attitudinal . . . barriers that ‘hinder’ people with disabilities from being

‘on an equal basis with others’ ” (p. 1120).

Bickenback states, “The brute fact of scarcity is not a reason for denying rights, but rather for progressively realizing them” (p. 1122). This may be an instance, then, in which a significant attitudinal advance can be made, establishing that in this instance at least people with disabilities will have an equal chance at being able to continue to survive.

4. J. Liaschenko, “When the Pandemic Comes, I Hope I’m in New Zealand,” presentation at the 2008 ASBH Annual Meeting in Cleveland Ohio. Liaschenko kindly sent me a draft copy of her presentation. I quote it here and cite from its five pages.

5. National Ethics Advisory Committee (NEAC), *Ethical Values for Planning for and Responding to a Pandemic in New Zealand: A Statement for Discussion* (Wellington, New Zealand: Ministry of Health), [http://www.neac.health.govt.nz/moh.nsf/pagescm/521/\\$File/pandemic-planning-and-response.pdf](http://www.neac.health.govt.nz/moh.nsf/pagescm/521/$File/pandemic-planning-and-response.pdf), accessed 15 November 2010.

6. M.U. Walker, *Moral Understandings: A Feminist Study in Ethics*, 2nd ed. (New York: Routledge, 2007), p. 179. “. . . an ethicist has a special responsibility . . . [for knowing] nuances and complexities . . . [although] they probably won’t if they don’t.” M.U. Walker, “Keeping Moral Space Open: New Images of Ethics Consulting,” *Hastings Center Report* 23, no. 2 (March-April 1993): 33-40.

7. The American Bar Association Commission on Physical and Mental Disability has been working to establish disabilities on a par with other categories, especially subject to discrimination.

8. Carol S. Fullerton, PhD, is a Research Professor in the Department of Psychiatry at the Uniformed Services University of the Health Sciences School of Medicine in Bethesda, Maryland, and is the Scientific Director of the Center for the Study of Traumatic Stress, an interdisciplinary center that conducts research, education and consultation on the effects of terrorism, bioterrorism, trauma, disasters, and war on individuals, communities, and groups. Personal communication with the author, 15 November 2010.

9. Liaschenko, see note 4 above.

10. Joan Liaschenko, personal e-mail communication with the author, 9 August 2010. Liaschenko has worked in this area for a year and a half. She writes, “I was excited with the opportunity to introduce a new model of morality represented as an ethics of care to public health.” See note 4 above, p. 4.

11. N. Noddings, *Caring: A Feminine Approach to Ethics and Moral Education*, 2nd ed. (Berkeley: University of California Press, 2003), p. 35. Noddings contends, “This commitment to care and to define

oneself in terms of the capacity to care represents a feminine alternative to Kohlberg's . . . 'stage six' morality. . . . [These commitments] are not so concerned with principles; they are concerned, rather, with maintaining and enhancing caring" (p. 42). She cites Robert Frost's poem, "The Death of the Hired Man," as depicting this caring as imperative: "Home is the place where, when you have to go there, They have to take you in." R. Frost, *North of Boston*, 2nd ed. (New York: Henry Holt). Noddings adds that the "memory of our best moments of caring and being cared for sweeps over us as a feeling — as an I must" (p. 79). "Instead of 'average subjects' I will consider real persons about whom I care" (p. 54). "I may . . . lie regularly . . . for my son . . . I know the form [others arguing against this] will take. It will put principle over person, and we will be at loggerheads. . . . In arguing from principles, [however] one often suppresses basic feeling. . . ." (p. 57). "One is led to suppose that reason produces the decision. This is the ultimate and tragic dishonesty, and it is one that we shall try to avoid by insisting upon a clear-eyed inspection of our feelings, longings, fears, hopes, dreams" (p. 57). "The commitment that elicits the rational activity precedes it" (p. 61). "We can often make judgments from the outside, but there are disturbing and crucial situations in which we cannot" (p. 108).

12. Liaschenko, see note 10 above.
13. NEAC, see note 5 above.
14. Liaschenko, see note 4 above, p. 1.
15. *Ibid.*, 5.
16. *Ibid.*, 3.
17. *Ibid.*
18. Walker, see note 6 above.
19. Liaschenko, see note 4 above, p. 4.
20. *Ibid.*
21. *Ibid.*, 5.
22. Emphasis added. NEAC, see note 5 above, "Foreword" and p. 1.
23. *Ibid.*, 3
24. *Ibid.*, 9.
25. *Ibid.*
26. *Ibid.*, 9-10.
27. Emphasis added. *Ibid.*, 10.
28. Emphasis added. *Ibid.*, 11.
29. *Ibid.*, 14.
30. *Ibid.*, 17.
31. *Ibid.*
32. A.D. Basting, *Forget Memory* (Baltimore: Johns Hopkins University Press, 2009).
33. Walker, see note 6 above, p. 75
34. *Ibid.*, 85.
35. *Ibid.*, 179.

36. *Ibid.*

37. *Ibid.*

38. K. Carsten et al., "The Neuropeptide Oxytocin Regulates Parochial Altruism in Intergroup Conflict Among Humans," *Science* 328, no. 5984 (June 2010): 1408-11.

39. Walker, see note 6 above, pp. 179-80.

40. But see A. Nehamas, *Virtues of Authenticity* (Princeton, N.J.: Princeton University Press, 1999). "Xenophon portrayed in Socrates . . . a graceless composite of cynicism and bourgeois cynicism" (p. 106, note 28).

41. Noddings, see note 11 above, p. 31.

The ability to feel deeply with the other person "is a form of physiological arousal in which the worker experiences a vicarious emotional response while cognitively aware that the source of the affect in oneself emanates from the other person." S. Freedberg, "Re-Examining Empathy: A Relational-Feminist Point of View," *Social Work* 52, no. 3 (2007): 251-9.

42. Noddings, see note 11 above, p. 31.

43. *Ibid.*, 32.

44. *Ibid.*

45. *Ibid.*, 33.

46. *Ibid.*

47. *Ibid.*

48. *Ibid.*, 34.

49. *Ibid.*, 34.

50. *Ibid.*, 35.

51. Emphasis added. *Ibid.*, 35.

52. NEAC, see note 5 above, p. 32.

53. G.L. Albrecht and P.J. Devliger, "The Disability Paradox: High Quality of Life Against All Odds," *Social Science and Medicine* 48 (1999): 977-88.

54. F. Blanco et al., "Ensuring Accurate Knowledge of Prematurity Outcomes for Prenatal Counseling," *Pediatrics* 115, no. 4 (Apr 2005): e478-87; C.M. Curtin et al., "Opinions on the Treatment of People with Tetraplegia: Contrasting Perceptions of Psychiatrists and Hand Surgeons," *Journal of Spinal Cord Medicine* 30, no. 3 (2007): 256-62.

55. Curtin et al., *ibid.*

56. R. Garland-Thompson, *Staring/How We Look* (New York: Oxford University Press, 2009).

57. *Ibid.*, 94.

58. *Ibid.*, 104.

59. Emphasis added. *Ibid.*, 117.

60. *Ibid.*, 186.

61. *Ibid.*, 194.

62. Basting, see note 32 above.

63. Noddings, see note 11 above, p. 103.

64. *Ibid.*, 106.

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# Family Participation in the Care of Patients in Public Health Disasters

*Tia Powell*

## ABSTRACT

The ethical implications of disaster planning garner increasing scrutiny. The role of families in disaster efforts is a topic that requires additional ethical examination. This article reviews the potential roles for families before and during disasters, with particular attention to the impact on children and vulnerable elderly patients. The potential positive and negative impact of family participation in different aspects of healthcare and disaster efforts is assessed.

Public health disasters are anything but new. What is new, however, is an increased focus on ethical issues in disasters in the wake of several highly visible events in the last decade. The attacks of 11 September 2001 were followed within days by the terror of anthrax arriving through the U.S. mail system. Shortly thereafter we witnessed the devastating effects of the SARS (severe acute respiratory syndrome) epidemic, hitting especially hard in Toronto. Hurricane Katrina drew our attention to severe failures in planning that resulted in excess deaths and trauma to the residents of New Orleans. Fear of influenza pandemics has spread since the

emergence of the H5N1 strain several years ago and the 2009-2010 pandemic of novel H1N1. The January 2010 earthquake in Haiti underscored the devastating interrelationship of poverty, natural disasters, poor infrastructure, and lack of medical resources, and shocked us with the enormity of the resulting humanitarian disaster. This series of events helped crystallize thoughts about the ethics of disasters, both in our planning and in our response to them.

Ethical considerations have been an integral part of many recent discussions of disaster planning and response. Specific examples include the allocation of vaccines, ventilators, and personal protective equipment for healthcare providers, and the development of overall standards of care for disasters.<sup>1</sup> Yet new ethical issues related to disasters continue to emerge, including the potential role of families. Can and should families play a larger than normal role in the care of patients during public health crises? In what ways can families enhance the efforts of medical and other professionals? In what ways might the activities of family members increase risk to themselves, to patients, and to workers, or otherwise undermine disaster relief efforts? Should families be excluded from the hospital to limit the spread of deadly infections, or to maintain crowd control? Could families play a greater role in providing home care when

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hospitals are overwhelmed? This article will review the ethical implications of various roles for families in different phases of public health disasters. This preliminary effort will attempt to capture some of the significant ethical tensions facing our communities and public health officials as they plan for the next crisis.

### PRE-DISASTER ROLE

Families may prove critical in helping communities prepare for public health disasters in ways that enhance resilience and limit consequences. Not all disasters can be foreseen, but planning, including by families, can help mitigate negative consequences of some disasters. For instance, Tokyo, and indeed much of Japan, is a known earthquake zone. Each year local municipalities practice earthquake preparedness, reminding families to pre-select a public meeting place such as a local park to facilitate unification post-quake. Trained volunteers direct citizens in mock drills as schools and offices empty into local safe havens. Families stockpile water and a limited supply of food that requires neither refrigeration nor electricity.<sup>2</sup> Many families also store waterproof reflective blankets to protect against hypothermia in case of loss of shelter during winter weather.

Similar to earthquakes, hurricanes, tornadoes, and other forms of extreme weather are foreseeable in various parts of the world, and families could — and some do — protect themselves through advance planning. American families in areas with predictable weather or other emergencies may wish to emulate the Japanese and plan for assembly points or other contingencies, taking into account the potential disruption of public transportation and other services. Many families depend on mobile phones for communication, yet cell phone service may fail in an emergency, as occurred for many during the massive power failure of August 2003 in the northeast U.S. and Canada. Contingency plans for collecting children, frail elderly, and impaired relatives should not rely entirely on the availability of mobile phones or ordinary transportation options. Rather, cooperative arrangements planned in advance with

neighbors and colleagues may provide temporary safe havens until families can collect and protect their members. In the context of extreme poverty, daily living demands the use of more than the available resources, and additional disaster planning may be impossible at the level of the family. Nonetheless, many families in less-austere settings probably could set aside modest but effective disaster resources that would contribute to resiliency. Public education through schools, organizations like Scouting, or public health authorities could support families in designing and maintaining a basic survival kit and set of contingency plans that is appropriate to their family's needs and local conditions.<sup>3</sup> Currently, relatively few public health authorities have pediatric-specific disaster plans, although children are a particularly vulnerable sector of the population.<sup>4</sup>

### OUT-OF-HOSPITAL CARE

Some of the most vulnerable members of any community live at home with assistance from family, home care workers, and agencies like the Visiting Nurse Association. Disasters may prevent service providers from reaching homebound community members, including the frail elderly, the obese, and those with mobility impairments. In this context, family members may provide lifesaving support to these individuals by delivering food and medications and checking to see that they are safely sheltering in place. Those who usually live on their own may agree to live with family temporarily during the course of a public health disaster as an increased safety measure. When staying at home is no longer feasible, family members are often the ones to either transport these vulnerable community members to shelters or alert public authorities of the need for rescue. In the disaster context, families provide a vital link between vulnerable community residents and public health resources.

For patients who are only mildly or moderately affected by a public health emergency such as an influenza pandemic, receiving supportive medical care at home from family is often preferable to attempting to access scarce hospi-

tal resources. Staying at home provides many benefits to patients, families, and public health infrastructures for patients who have capable families and primarily require observation and therapies that can safely be delivered at home with minimal additional instruction. Patients are likely to be more comfortable at home and have less risk of exposure to infectious agents. Family members will have greater freedom to support a loved one and monitor his or her progress than might be possible in a hospital or other public setting. Given the predictable stress on resources in a disaster, public authorities are likely to ask families to provide more care for their own members at home whenever possible.

### HOSPITAL CARE

Especially in pediatrics, families are increasingly part of the context of hospital care. Decades ago, health professionals demanded that parents surrender custody of even small children upon entering a hospital. A child might stay overnight, for instance for a routine tonsillectomy, undergoing preparation for surgery and induction of general anesthesia without the comforting presence of a parent. Today parents are encouraged to accompany and comfort children throughout most of a hospital stay, only stepping aside during limited circumstances when a parental presence might increase danger to the child. The current practice of encouraging family involvement provides benefits to children, who will not experience the additional trauma of separation atop their burden of medical illness and treatment. Parents, too, benefit from greater access, for they will have far better information about their child's experience and can continue their standard role of advocate and protector of their child. Although the relationship of parent to minor child is special, similar conditions apply for family members who care for frail elderly or disabled patients. Here, too, patients with cognitive limits may derive great comfort, and be relieved of trauma, by maintaining access to familiar and loving caretakers.

For patients who are hospitalized during a disaster, family members or community volun-

teers who do not have healthcare expertise might help take on some labor-intensive but less-skilled aspects of medical care. When a disaster creates shortages of healthcare staff, such tasks as cleaning, handfeeding, and transporting patients or meals might be done by volunteers with relatively modest on-the-spot training. As resources are further strained, a reliable but nonprofessional person might be taught to monitor alarms or other devices, alerting a more-skilled person as needed, and thus free up trained staff to cover more patients or patients in more than one location. Volunteers might be employed to comfort agitated elderly, young, or cognitively impaired patients who become anxious due to extreme circumstances or unfamiliar surroundings. Family support would be especially effective in this task, for familiarity might greatly enhance the ability to comfort these vulnerable patients.

In some forums, additional roles for family members have been proposed, yet these options may prove unrealistic. A shortage of artificial ventilators is among the most troubling potential consequences of a disaster, and numerous guidance documents address this problem.<sup>5</sup> These documents generally propose combined strategies such as stockpiling extra ventilators, adapting transport or anesthesia ventilators for longer term use, and avoiding the elective use of ventilators, for instance by postponing non-essential surgery. If demand sufficiently overwhelms supply despite these adaptive measures, however, physicians will be forced to ration ventilators. Some critically ill patients who might otherwise receive ventilatory support will not have access to a machine, and some may die who might have survived their illness under ordinary circumstances.

In the face of this terrible situation, one could consider the use of family members or community volunteers to use hand-held bag-valve ventilatory devices to support patients without access to ventilators. Power failures force hospitals to rely on this strategy from time to time, although past disasters led to hospital regulations that require backup generators. Nonetheless, healthcare facilities vary widely in their capacity to supply energy during a

blackout. Some New York City facilities lost power despite backup generators in the massive power failure of 2003. Other facilities planned and fared better. Montefiore Medical Center, for instance, maintained an adequate energy supply throughout the 2003 blackout due to its cogeneration plant, and indeed accepted in transfer numerous patients whose mechanical ventilators were at risk of failure.<sup>6</sup> But when no such transfer or substitute is available, what are the benefits and risks of using manual bag-valve devices to ventilate patients? The potential benefits are obvious. The hope would be that the use of this human power would substitute for the lacking artificial ventilator; patients would have their breathing supported by a community of others committed to their welfare. Many people have family or community members who would gladly provide the labor if it could extend their lives.

Unfortunately, the liabilities of this approach likely outweigh the hoped for benefits. Most importantly, we must ask if the use of hand-held ventilatory devices would in fact extend life. The answer is probably not, especially for patients with the severe type of pulmonary disease caused by an influenza epidemic. The simple bag-valve tool does not offer the sophisticated support needed for many critically ill patients; there is no way to monitor or adjust for air pressure or volume, among other factors. In particular, patients with acute respiratory distress syndrome (ARDS), which can be a consequence of pandemic influenza, are difficult to manage even with the sophisticated and flexible options provided by a mechanical ventilator.<sup>7</sup> For these reasons, guidance documents addressing ventilator allocation in disasters do not support the use of hand-operated bag-valve ventilators as an alternative to rationing mechanical ventilators.<sup>8</sup>

Unfortunately, lack of efficacy is not the only problem with using family or others to supplement respiratory support. The risk of infection for a volunteer is likely to be substantial. During the SARS epidemic in Toronto, a number of healthcare providers contracted SARS, and eight died.<sup>9</sup> Although it is impossible to prove at exactly which point healthcare workers were

exposed, activities like manual respiratory support bring a substantial likelihood of exposure to airborne infectious agents. Hospitals today focus on protecting staff from the risk of infectious disease by offering specific training in infection control, and, when necessary, using advanced personal protective equipment like N95 respirators. To work effectively, these masks need to be fit tested to the individual, and do not function effectively for those with beards. To send volunteers, even loving family members, into a context where they are at high risk of contracting disease without either appropriate infection control training or protective equipment would be an outrageous ethical lapse. In sum, the use of bag-valve devices operated by family or community members cannot be recommended, as this would be unlikely to extend the life of the original patient, and might well create substantial exposure to fatal illness for the would-be helpers.

But should policies forbid outright such voluntary activity, even for a devoted family member who is thoroughly informed and accepts the risk of exposure and death? One can imagine parents who would be willing to take on this level of risk on behalf of their children, and the anguish of staff who prevent them. However, there are substantial problems in permitting volunteers to accept this level of risk. If such activity is possible, it may create pressure on parents, spouses, or others to sacrifice themselves. Depending on the cultural background of the family, a low-status relative could be designated by a family leader to accept a potentially fatal risk, regardless of the personal choice of either patient or relative. Alternatively, persons who are famous, wealthy, or powerful might be able to enlist numerous “volunteers,” while isolated and vulnerable patients would do without. On balance, a more just policy appears to favor limiting the ability of volunteers to accept the risky and ineffective task of hand-ventilation. However, this is a topic likely to generate strong emotion and would be appropriate to submit to community review.

Rationing critical medical supplies like ventilators is a disastrous outcome, and one that planning efforts should strive to avoid. Such an

eventuality should not occur except in the case of a disaster so extreme it outstrips any prudent planning options. For instance, a repeat of a pandemic of the scale of 1918 would lead to this level of scarcity. In this horrific and rare set of circumstances, it is likely that access of family members to patients in critical care will be restricted. If some patients will go without life-sustaining treatment, as assessed by evidence-based protocols, some distressed family members will threaten staff and other patients with violence. Providing critical care in the disaster context is challenging to begin with. The additional threat to the personal safety of staff and patients would make it impossible to provide that level of care to any patient. When disasters reach this level, the presence of family members in the critical care setting, and possibly anywhere in the hospital, may need to be restricted in order to maintain safety for patients and staff. There will still be a vital role for family members in the community and in other settings. However, the benefit of family participation in disaster-related healthcare is likely to be inversely proportional to the critical care needs of the patient and the severity of the crisis. In other words, as a patient is more critically ill or the crisis is more severe, the role of the family diminishes.

### EVACUATION

The shadow of Katrina hangs over many issues in disaster planning, including family involvement in healthcare decisions. One of the most disturbing accounts of family members' activities appears in a Pulitzer-Prize winning article by Sheri Fink, describing the events at Memorial Hospital in the days after Katrina.<sup>10</sup> Fink describes shockingly different outcomes for two similarly situated elderly women who survived or perished in large measure because of advocacy by their adult children. In the first instance, 82-year-old Vera LeBlanc had a longstanding do-not-resuscitate (DNR) order that preceded her hospital admission; she cooperated fully with various medical interventions, but did not wish for cardiac resuscitation should her heart stop. Mrs. LeBlanc also was fortunate

in having a son and daughter-in-law who managed to get through the floodwaters to the hospital, bringing a small flotilla of boats to rescue not only Mrs. LeBlanc, but as many other patients as possible. Healthcare workers initially refused permission for Mr. LeBlanc to evacuate his mother from the hospital. They had determined that patients with DNR orders would be evacuated last, if at all. Mark LeBlanc, in command of the means of exodus for numerous patients, clearly held the stronger bargaining hand. He left with his mother, who survived Katrina.

Less fortunate was 70-year-old Wilda McManus, mother of Angela McManus, who also had a DNR order. The daughter attempted to rescue her mother from Memorial, but learned that patients with DNR orders were not slated for evacuation. She tried in vain to have the order rescinded. Her mother stayed at Memorial and was among the patients who perished there. (Indeed, it was alleged that Wilda McManus received a fatal dose of morphine in lieu of evacuation.)<sup>11</sup> In this case, family advocacy made a lifesaving difference for one woman, but not for another, when healthcare professionals erred in making triage decisions.

This complex tale of two elderly mothers contains many ingredients, including issues related to gender and power. One particularly disturbing element is the misuse of DNR orders, which are intended to mean a simple, single thing: that patients without a heart beat will not suffer attempts at resuscitation. Unfortunately, and despite many efforts to address this issue, DNR orders are subject to distortion. In this case and in others, they can serve as a proxy for limiting care in ways that were neither contemplated by nor acceptable to families and patients. While earlier disaster-related documents generally remained silent on the role of DNR orders in assessing access to critical care, the Institute of Medicine specifically addressed the inappropriate use of DNR orders in making triage decisions.<sup>12</sup>

The other striking factor in the stories of Vera LeBlanc and Wilda McManus, similar in many ways but tragically different in outcome, is the advocacy role played by family members. A relative wielding power during the disaster ignored

medical directives and secured a lifesaving means of exodus for one patient. Another relative lacked the authority to ignore orders, and her mother died. What lessons from this tragedy might improve disaster efforts in the future? First, the capacity of family members to protect and advocate for vulnerable patients is a real force, not lightly to be set aside. There may be disaster-related circumstances that require healthcare workers to exclude family members, but there are substantial risks to patients when we remove the crucial support provided by family members. When the safety of staff and patients demands it, for instance in the extreme circumstance of rationing critical care resources, it may be necessary to exclude family members in order to protect their own relatives, other patients, and staff. Finding the right balance between including and excluding family members from hospitals during disasters will remain challenging. A sober review of the ethical implications of the related choices provides the only route to a safe and acceptable solution.

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# Sufficiency of Care in Disasters: Ventilation, Ventilator Triage, and the Misconception of Guideline-Driven Treatment

*Griffin Trotter*

## ABSTRACT

This essay examines the management of ventilatory failure in disaster settings where clinical needs overwhelm available resources. An ethically defensible approach in such settings will adopt a "sufficiency of care" perspective that is: (1) adaptive, (2) resource-driven, and (3) responsive to the values of populations being served. Detailed, generic, antecedently written guidelines for "ventilator triage" or other management issues typically are of limited value, and may even impede ethical disaster response if they result in rescuers' clumsily interpreting events through the lens of the guideline, rather than customizing tactics to the actual context. Especially concerning is the tendency of some expert planners to mistakenly assume that medical treatment of respiratory failure: (1) always requires full-feature mechanical ventilators, (2) will always occur in hospitals, and (3) can be planned in advance without sophisticated public consultation about likely ethical dilemmas.

## INTRODUCTION

In disasters with large numbers of casualties suffering respiratory failure and requiring

positive pressure ventilation (PPV), questions arise about the most ethical way to distribute limited quantities of respiratory technology (especially ventilators) and how best to utilize key personnel (such as physicians, nurses, and respiratory therapists). Recently such questions have received considerable attention from disaster experts, concerned professionals, and policy makers. One setting in particular — an influenza pandemic producing mass casualties on a scale similar to the 1918 epidemic — has evoked brisk discussion of ethical issues in distributing scarce resources. Other possible scenarios are also concerning. For instance, the need for ventilatory support could overwhelm capacities to provide standard medical treatment in mass casualty situations resulting from chemical or biological attacks with agents such as botulinum toxin, *Francisella tularensis*, *Yersinia pestis*, or acetyl cholinesterase inhibitors (sarin, soman, VX, et cetera), or in outbreaks such as SARS (severe acute respiratory syndrome), or even in natural disasters in which large numbers of casualties and resource depletions make it impossible to provide standard ventilatory assistance to patients with CNS (central nervous system) or pulmonary injuries.

The typical response to this array of challenges is to begin with the assertion or assump-

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tion that, short of providing mechanical ventilation with full-feature ventilators, there is no medically feasible alternative for the treatment of casualties requiring PPV. On this basis, guidelines are produced that establish “ethical” procedures for triaging ventilators, typically specifying that those who do not qualify for mechanical ventilation should, until the time of their inevitable demise, receive “comfort” care and other supportive treatments, insofar as these can feasibly be provided.

In this essay, I will argue that both of the aforementioned claims — about the necessity of using full-feature ventilators, and about the priority of determining the ethical distribution of such ventilators — are flawed. I will also criticize current practices in constructing ethical guidelines for their insufficient attention to public input, and for the presumption that tactical operations in mass casualty medicine will be driven by antecedently constructed guidelines rather than improvised. To the contrary, a “sufficiency of care” model should replace the current doctrine that postulates only two alternatives: provide the standard of care or deny ventilatory support altogether. Alternative means of providing PPV are available, and can be applied when specific circumstances are appropriate. An ethically defensible approach to disaster operations in mass casualty situations involving large numbers of casualties suffering ventilatory failure will be: (1) adaptive, (2) resource-driven, and (3) responsive to the values of the population being served — features that will be explained in the course of this essay.

### VENTILATORY FAILURE

The term “respiratory failure” applies to patients with one or both of two typically inter-related but non-equivalent conditions. The first of these conditions is ventilatory failure; the second is oxygenation failure. My concern in this essay is primarily with ventilatory failure. Oxygenation failure pertains to pathology at the level of the alveoli, where, for whatever reason, efficient oxygen exchange to hemoglobin is not occurring.<sup>1</sup> Ventilatory failure, on the other

hand, occurs when the breathing mechanism is not properly aerating the alveoli. Oxygenation is frequently monitored by analysis of the oxygenation status of arterial blood (PaO<sub>2</sub>) or hemoglobin (SaO<sub>2</sub>), whereas ventilation is measured by parameters such as minute ventilation, PaCO<sub>2</sub> (partial pressure of carbon dioxide in the arterial blood), or end-tidal CO<sub>2</sub>.<sup>2</sup>

In the management of ventilatory failure, impaired alveolar gas exchange with concomitant oxygenation failure is typically also a challenge. There are instances, however (such as acute spinal chord injury or isolated neurological toxicity), in which that is not the case.

Professional rescuers talk about the ABCs — airway, breathing, and circulation — and point out that the “B” and “C” are not possible without “A.” Indeed, any complete discussion of ventilatory support would require a fairly robust treatment of airway maintenance, since nothing derails ventilation faster than an insufficient airway. However, because emergency airway techniques and tactical issues in field airway management are, in my opinion, already well worked out, I will not discuss these in this essay. For the same reason, I will not discuss temporizing measures for ventilatory support in the field — except insofar as these might be adapted in disaster situations for intermediate or long-term ventilatory support where better options are not available.

My focus will be on the management of overwhelming numbers of patients with ventilatory failure requiring PPV, specifically scenarios in which the standard of care for intermediate and long-term ventilatory management — full-feature ventilators — is not available for the majority of patients. Are there approaches, I ask, short of denying ventilatory support to such patients, that might prove sufficient in some scenarios?

Although there has been a glut of attention to pandemic influenza, the scenarios I have in mind are many and quite variable in the tactical challenges they present. Successful disaster response will hinge on the ability to adapt to the specific circumstances of a particular event. Several important contextual variables pertaining to the management of ventilatory failure can

be identified at the outset. First, it is important to assess the prevalence and nature of non-pulmonary complications and the likelihood of difficult airway-maintenance issues in affected populations. An outbreak of plague, for instance, would pose a very different challenge than a tornado in terms of the spectrum of patients with ventilatory insufficiency. Second, risks to healthcare personnel vary between events. Risks of infectious disease transmission, contamination, radiation, aftershock, violence, and so forth all have tactical relevance. In an influenza pandemic, for instance, using minimally ill or recovered patients for close-contact patient care duties might be an important innovation. Third, local events present different challenges than widespread events — the latter being more likely to be complicated, for instance, by difficulty in obtaining stockpiled supplies or problems in accommodating diverging cultural values. Fourth, the likelihood and nature of personnel shortages varies immensely in different scenarios. As a general rule, and contrary to much unreflective generalization among inexperienced disaster commentators, personnel excess, including sometimes even an excess of trained medical professionals, is a more frequent logistical issue in typical disasters than is personnel shortage.<sup>3</sup> Nevertheless, in the short term, and in cases when large numbers of casualties require very specialized treatment, shortages of trained personnel frequently are a critical problem. One of the crucial issues in some “sufficiency of care” situations is the extent to which untrained or minimally trained volunteers can be utilized (perhaps through just-in-time training) to perform functions that would optimally require specialists. Fifth, the localities and countries that have a state-of-the-art medical infrastructure, even though it may be damaged or otherwise insufficient for medical demands in a mass casualty situation, will present different challenges than those that never had such an infrastructure in the first place. And not all the advantages reside in the former. It might be more difficult, for instance, for pulmonary specialists in the U.S. to improve effective tactics in intermediate-term manual bagging than it would be for physicians

from rural Central American hospitals and clinics that currently use manual bagging as the predominant or exclusive form of in-hospital ventilatory support. Likewise, many U.S. physicians have difficulty grasping the fact that, elaborate hospital surge-capacity planning aside, in large scale and catastrophic disasters, most of the important medical work will be done outside hospitals. Sixth, in many disaster situations (Hurricane Katrina being an example), the majority of patients needing improvised PPV will be patients who were receiving PPV prior to the disaster, but, as a result of infrastructure destruction, lost access to full-feature ventilators. These cases, of course, differ tremendously from those in which the agent causing the disaster is simultaneously also the agent creating the need for PPV.

These are just a few of the vast number of contextual factors that will shape effective strategic and tactical decisions in disasters — even with respect to a specialized issue such as the management of ventilatory failure. In preparing for such an array of contingencies, crisp protocols with hard-and-fast guidance about choosing ventilatory treatments, utilizing personnel, or enacting triage are of little use and may even be counterproductive if they delay adaptive tactics. The best preparations focus on understanding the general features and variations characterizing possible disasters, on developing adaptive decisional capabilities, and on examining the resources that may be available to support tactical innovations.

With respect to the management of ventilatory failure, surveying possible options for PPV is a starting point. This has been done adequately elsewhere,<sup>4</sup> and can only be briefly summarized here. Sophistication in the provision of PPV runs the gamut from mouth-to-mouth rescue breathing, which has virtually no role in any disaster situation, to the use of full-feature ventilators or anesthesia machines costing up to \$40,000, with complicated settings and alarms. In between are bag-valve manual ventilators costing \$10, automatic resuscitators, and several different levels of portable ventilators ranging in price from \$1,500 to \$12,000. Most sophisticated discussions of ventilator supply

during disasters seem to regard at least some types of portable ventilators as adequate to constitute part of the inventory of “mechanical ventilators.” Indeed, the U.S. Strategic National Stockpile stores Uni-Vent Eagle 754 portable ventilators and distributes them in packages that includes the “Project XTREME” DVD for cross-training respiratory extender personnel.<sup>5</sup>

### STANDARD OF CARE VERSUS SUFFICIENCY OF CARE

After a harrowing experience establishing a medical facility at Louis Armstrong Airport in New Orleans after Hurricane Katrina, clinical personnel reported that medical supplies were quickly depleted due to early attempts to provide the standard of care. In response to this problem, Klein and colleagues suggest rescuers attempt to forecast shortages based on actual and anticipated demands, and apply supplies tactically where they can do the most good.<sup>6</sup> This approach, which is necessary for optimal success in a large diversity of disaster scenarios, requires that the traditional standard of care be abandoned in favor of another treatment model.

A “sufficiency of care” standard has been suggested for such circumstances.<sup>7</sup> Well-formed sufficiency of care models deviate from traditional treatment models in that: (1) the standard is dynamic rather than protocol-driven, shifting its functional conception of “sufficient care” as conditions change; (2) it focuses on pressing needs and available resources rather than on ideal practices; and (3) it is tactically open-ended and improvised, rather than confined to customary treatment sites and modalities, such that its primary operational virtues are innovation and adaptability.

Although this essay focuses on sufficiency of care issues in ventilatory management, better understanding and implementation of a sufficiency of care concept would immensely alter and improve disaster responses, not only at the tactical level, but throughout current disaster systems. For instance, I have argued that the usual taxonomical distinction in disaster medicine between “biological” and “chemical” threats should be de-emphasized in favor of a

threat classification scheme that conforms to tactical challenges presented by the respective threat agents. Hence, biological agents like botulinum toxin and ricin would be classified together with chemical agents such as mustards as “ $D_2L_1T_2$ ” agents: that is, of intermediate duration prior to onset ( $D_2$ ), likely to be lethal ( $L_1$ ), and nontransmissible ( $T_2$ ).<sup>8</sup>

At the tactical level, an emphasis on the sufficiency of care standard would decrease the tendency to rely on cumbersome preexisting protocols that hamper, rather than facilitate, effective disaster response. In responding to chemical terrorism, for instance, rescuers would quickly rule out the application of protocols that: (1) assume the majority of casualties could be assessed, decontaminated, and stabilized at the attack site, then transported via EMS (emergency medical services) to hospitals with the most available beds; (2) enact standard-of-care hazmat procedures tailored to industrial accidents;<sup>9</sup> (3) assert that all casualties should be thoroughly decontaminated by rescuers, even in cases when the survival of the walking wounded would be 100 percent with self-decontamination; (4) assume that asymptomatic patients will willingly comply with orders to strip naked, and so forth.<sup>10</sup>

The sufficiency of care concept is part of a larger rescue paradigm, which is an ethical orientation adopted in public health emergencies in which resources and/or personnel are insufficient to meet patients’ needs according to the usual standard of care. As I have argued elsewhere, the rescue paradigm is not a whole new ethics of medicine and public health (since ethical values don’t abruptly change with changing conditions), but rather the current ethics adopted to extraordinarily novel contexts. The equilibrium between security and liberty, which is the dominant problematic in public health ethics, temporarily shifts in certain time-compressed disasters — with imminent dangers precipitating a shift in emphasis toward security.<sup>11</sup> The focus for concern under the rescue paradigm is on survival and the minimization of long-term morbidity. Although these are also fundamental concerns in ordinary clinical medicine, they are tempered somewhat in ordinary

contexts by the effort to accommodate patients' preferences. In mass casualty medicine, on the other hand, it is frequently impossible to maintain maximal lifesaving efficiency while fully accommodating preferences pertaining to treatment variations, privacy, timing, choice of provider, and so forth.

### THREE SCENARIOS

In this section I will briefly sketch three disaster scenarios in which the needs for PPV overwhelm the supply of full-feature ventilators. These are not the only scenarios addressed in this essay, but they are useful for grounding the discussion in vivid cases that can serve as relatively detailed examples.

#### **Scenario #1: Small Town Is Severely Affected by H5N1 Influenza Pandemic**

The fictional town of Lone Hill, Washington, is situated on the west slope of the Cascade Mountains, near Mount Ranier and 70 miles from the closest major city, Tacoma, Washington. It has a population of 18,000 and has a small community hospital with 100 beds, including 18 intensive care unit (ICU) beds and 15 full-feature ventilators. The world is experiencing a 1918-magnitude influenza pandemic, and Lone Hill has been hit very hard. In a milder spring outbreak caused by the same virus, about 5 percent of Lone Hill's residents became ill, with no fatalities. Thus far this fall, another 45 percent (8,000 persons) have contracted the virus, and thus far 100 have died. Currently, there are 3,500 patients acutely ill with the virus, and 175 of them are ill enough to require PPV. A sizeable majority of the 175 patients who require PPV are previously healthy and relatively young (less than 55 years old). One hundred of these patients have SOFA scores<sup>12</sup> of less than 7, and there are 35 patients with stable or decreasing SOFA scores of exactly 3. Seven of the hospital's ventilators are currently being used by non-influenza patients with relatively good prognoses and SOFA scores less than 3 (several critically ill non-influenza patients were removed from their ventilators and subsequently died). Although portable ventilators from the U.S. Stra-

tegic National Stockpile have been distributed, none of these came to Lone Hill. Transfers to nearby Puyallup, Tacoma, or Olympia have typically not been possible, as these localities are also dealing with overwhelming numbers of casualties and are experiencing ventilator shortages comparable to those in Lone Hill.

#### **Scenario #2: Terrorists Attack with Aerosolized Botulinum Toxin**

The President of the United States is giving a campaign speech in the medium-sized, fictional town of Tickytask, Illinois. The event seems to go smoothly, but about 24 hours later massive numbers of patients present in Tickytask's three emergency departments and multiple clinics with bulbar palsies and acute flaccid paralysis. All of them attended the presidential speech, and it is learned that the President and most of his entourage are also experiencing the same syndrome. Definitive diagnostic test results (mouse bioassay) from the U.S. Centers for Disease Control and Prevention (CDC) are expected in one to two days, but features of the outbreak (tightly clustered cases, normal cerebro spinal fluid, progression of symptoms, and so forth) make it almost certain that the patients are victims of an attack with aerosolized botulinum toxin. In Tickytask, 16,000 cases present in the first 24 hours, and 12,000 of these patients require mechanical ventilation. There are 60 ventilators in Tickytask, and 40 of these ventilators are already in use. However, additional personnel and supplies, including 4,000 ventilators from the Strategic National Stockpile, are expected to arrive within 24 hours.

#### **Scenario #3: Hurricane Katrina Relief Is Offered at Louis Armstrong Airport**

This is a nonfictional scenario. As Klein and colleagues observe, when Hurricane Katrina struck New Orleans in August 2005, America for the first time experienced a disaster so severe that it resulted in the total collapse of governance and required evacuation of an entire metropolitan area. Yet, despite advance instructions to evacuate, when the levees failed on 29 August, about 250,000 persons remained in the

city. Two days later, DMATs (disaster medical assistance teams) arrived to provide medical services for the remaining population, choosing Louis Armstrong International Airport as an operations center. Here they encountered “exhausted airport fire fighters, extreme heat and humidity, no air conditioning, and no potable water or operating toilet facilities.”<sup>13</sup> They also had generator power sufficient only for minimal lighting. Three teams equipped with a capacity to see 250 patients daily were instructed to see 2,500 per day, but in actuality were confronted by far greater numbers of patients. According to DMAT leaders and the Federal Aviation Administration, 125 to 175 helicopters landed at Louis Armstrong delivering approximately 600 non-ambulatory patients every hour. Many more came via ambulance or private transportation, joined by throngs of volunteers, well people seeking transportation, and news media. Initially, DMATs employed their limited resources to “provide the usual standard of care.”<sup>14</sup> In very short order, supplies were depleted and the medical capabilities of the DMATs were completely overwhelmed. Much of the focus turned to meeting everyday human needs such as food, shelter, water, and sanitation. Standard triage protocols were ineffective, and after the initial rapid depletion of resources, triage decisions were based on available resources, not on medical condition. Patients who were not expected to survive were placed in the “expectant” category and received comfort care in a ward staffed by the DMAT chaplain. Some who were expected to survive, such as spinal injury patients, suffered ventilatory failure. They were ventilated for several days with bag-valve devices applied by exhausted, dehydrated medical personnel.

### ASSESSMENT AND TREATMENT SITES

Disaster planners frequently focus on expanding surge capacity in hospitals and other healthcare facilities, expecting that such institutions will provide the primary sites for medical evaluation and treatment in mass casualty situations. For instance, the Task Force for Mass Casualty Critical Care has conducted a detailed

analysis of critical care in mass casualty events, including surge, chain of command, clinical evaluation, categorization, sorting, and equipping, without ever deviating from the presumption that all of this will occur in hospitals.<sup>15</sup> The reality, however, is that healthcare evaluation and treatment in mass casualty situations, including care for critically ill patients, frequently occurs outside established healthcare centers in improvised facilities,<sup>16</sup> and, in the most catastrophic disasters, hospitals play only a minor role in early management.

In each of the above three scenarios, non-hospital-based evaluation and treatment centers play, or should play, a large role. In the Lone Hill influenza scenario, there are more than twice as many seriously ill patients as there are total hospital beds. Given that many ordinary, non-influenza-related medical activities must continue during the epidemic, even the most ambitious plans for surge capacity could accommodate only a fraction of these cases. Furthermore, the transmissibility of the H5N1 virus presents a danger to other hospital patients — making it preferable, whenever possible, to treat influenza at a separate facility. One of the most important, but sometimes neglected, disaster-related duties of any hospital is to protect the integrity of its premises and the safety of non-disaster patients.

The Tickyack botulinum toxin attack is a situation in which the vast majority of critically ill patients will either receive aggressive treatment outside the hospital, or they will die. As we will discuss in a subsequent section, the nature of the botulinum syndrome is such that these patients would be far more likely than patients with other forms of respiratory failure to survive the provision of PPV outside the typical ICU setting. Furthermore, although evacuation would be the ideal management for many of these patients, the evacuation of so many critically ill patients in an expeditious manner would be unworkable.

Finally, the Louis Armstrong International Airport scenario is an example of large-scale operations conducted at an improvised facility. Yet in the response to Katrina, fixed-site improvised medical facilities were not the only strategy. For

instance, a single mobile medical unit — Carolinas MED-1, previously assembled in Charlotte, North Carolina, with the aid of a \$1.5 million grant — was rapidly deployed to Mississippi, where, within minutes, it set up a functional emergency department (seeing more than 100 patients a day) and within hours provided four ICU beds plus seven general medical beds. Health policy analysts should note that, for only about \$1 billion, 500 such units could be assembled and run continuously for 20 days — providing 2,000 ICU beds and seeing 50,000 patients a day.<sup>17</sup>

It is beyond the scope of this essay to discuss the multitude of options for improvised medical facilities. That work has only just begun.<sup>18</sup> But one point should be underscored. In some cases, such facilities have been the only apparent alternative to mass fatalities. Disaster planners and strategic decision makers should keep them on the agenda.

### VENTILATORY SUPPORT

Full-feature ventilators are the standard of care for patients in need of positive pressure ventilation. In a mass casualty event, when the need for PPV greatly outstrips the supply of full-feature ventilators, and possibly also the supply of medical professionals trained to administer ventilatory assistance, responders must address a critical question. Should patients with ventilatory failure be allowed to die, or should available resources be exploited to provide alternative forms of ventilatory support that will save some of these patients?

Some high profile analyses argue that when ventilators are not available, alternative measures such as manual ventilation are not indicated and patients with ventilatory failure should be allowed to die. Powell and colleagues, from the New York State Task Force on Life and the Law, write:

Manual support for extubated patients using hand-held devices such as ambu-bags provides a low likelihood of benefit from patients and a high risk for volunteers. Family members and others who might provide such support face a high risk for infection.

No individual can operate a manual device for long, and thus multiple volunteers would risk exposure in the likely futile attempt to help any single patient.<sup>19</sup>

On this basis, they recommend that patients who are not assigned to ventilators be relegated to palliative care. Unfortunately — or perhaps fortunately from the standpoint of those destined to need ventilatory assistance in a mass casualty event — this analysis is not credible. The general claim that extended-term manual ventilation is futile is false. To establish that an intervention is futile, one must show that there is virtual certainty that it will fail in achieving its clinical goal (in these cases, survival).<sup>20</sup> Since extended-term manual ventilation has succeeded in some situations in preserving many lives and in greatly diminishing the mortality in a mass casualty situation,<sup>21</sup> it is demonstrably not a generally futile intervention. To their credit, the authors are specifically concerned with the scenario of an influenza pandemic, in which patients needing ventilatory support are likely to suffer from a wide range of related conditions and airway-maintenance problems that greatly diminish the prospects for a successful outcome in manual bagging. But even in this scenario, it is plausible to hold that some patients needing ventilatory support (for example, some patients with SOFA scores of 3 or better) will have a significant chance of survival if they receive manual ventilation. Likewise, the analysis of risks for volunteers does not apply to all situations (since not all people needing ventilatory support have contagious illnesses) and wholly ignores the possibility of a pandemic scenario with large numbers of immune volunteers. In many cases, influenza patients' family members will have already contracted and recovered from the inciting virus. Furthermore, the claim about needing "multiple volunteers" to ventilate a single patient, although true, is misleading if it is taken to imply the need for large numbers of manual ventilators assigned to each patient. Two volunteers per patient arguably is sufficient.

Another influential task force, in providing general guidelines for mass critical care during

disasters of all types, writes, “There are no realistic substitutes for ventilators. Proposals to train hundreds of volunteers to provide manual ventilation to patients during a pandemic are naïve and fraught with serious logistical and scientific shortfalls.”<sup>22</sup>

This is an odd statement, given that what the authors call “naïve” is something that has already been done successfully. Logistical challenges can be daunting, but, contrary to unspoken assumptions that apparently structure this guidance: (1) large numbers of volunteers are the tendency, rather than the exception, in disaster operations;<sup>23</sup> (2) it is possible to quickly train even non-healthcare personnel to provide basic manual ventilation in an intubated patient;<sup>24</sup> and (3) it is not clear why a single, trained respiratory therapist could not, in some situations, provide supervision for a large multiplicity of volunteers, sufficient to significantly increase the odds of survival over and against the certain mortality resulting from no ventilatory support. Likewise, the statement that there are “no realistic substitutes” for mechanical ventilators is simply false. There are, in some circumstances, realistic substitutes. These substitute measures have been successfully employed in disasters. The emphasis should be on context. What is naïve is to believe that effective strategic and tactical decision making in actual disasters will, or should be, dictated by detailed treatment and triage protocols articulated in advance by content experts who are unable to foresee the contours of a particular mass casualty event. This point will become clearer as we revisit the three scenarios from above.

In Scenario 1, Lone Hill has more critically ill influenza patients requiring PPV (175) than it has total hospital beds (100). The town has eight available ventilators (out of 15 total), which amounts to one mechanical ventilator for every 22 patients needing PPV. In responding to this situation, providers will need to consider (among other things): (1) available alternatives to mechanical ventilation, (2) how available resources (including both equipment and personnel) will be exploited, and (3) how patients should be evaluated as potential candidates for available resources.

The latter consideration, evaluating patients’ candidacy for resources, potentially includes: (1) setting inclusion/exclusion criteria for candidacy for certain treatments, (2) triage, and (3) sorting. Inclusion/exclusion criteria are parameters that are used to determine whether a patient will enter the triage pool as a candidate for receiving a particular treatment or constellation of treatments. In most pandemic scenarios, standard exclusion criteria, such as end-stage organ failure, recurrent cardiac arrest, severe burns, and metastatic malignancy, are a reasonable starting point when it is possible to enact orderly inclusion/exclusion protocols,<sup>25</sup> although in particular situations or populations it will be helpful to refine these exclusion criteria (for example, by augmenting renal exclusion factors in a bacterial epidemic when the agent releases a nephrotoxic endotoxin). Triage traditionally involves assigning patients to one among a manageable number of priority units (typically based on their medical condition), and sorting is the means by which priority is determined within a single triage category.

At Lone Hill, there are more than four times more patients in a single high-priority triage category than there are total ventilators. Thirty-five patients present with a stable or improving SOFA score of exactly 3 that would place them in a highest priority triage category. These patients apparently need to be sorted.<sup>26</sup>

In reality, formal triage and sorting procedures are unlikely to be helpful in a scenario such as Lone Hill. Officials and rescuers will confront many persons who are critically ill and in the throes of various *ad hoc* treatments that have been improvised by whoever has happened to be available to offer help (paramedic students, hairdressers with grandfathers’ old black bags, dentists, high school gym teachers wielding first aid kits, and so on). The available ventilators will have been quickly allotted to those patients who met reasonable inclusion criteria, and the main ventilator-related problem, subsequently, will be when to remove patients from a ventilator in order to provide mechanical ventilation to somebody else. Because there are so few mechanical ventilators, this question is relatively trivial, analogous to ques-

tions about who should get a yacht in a disastrous flood.

The more pressing issues will pertain to the legions of patients who could possibly survive with PPV, but who do not have access to a ventilator. The key to success will be utilizing available resources where they can do the most good. Nearly half of the current population of Lone Hill has already survived influenza infection and is immune. Although this segment of the population provides manpower ample to provide bedside manual ventilation for all victims in need of PPV, the probability of survival in many of these patients will be practically zero. Who reasonably should be offered manual ventilation, and who shouldn't, will largely depend on the demonstrated tendency of certain categories of patients to survive (or not) with manual ventilation in this particular epidemic, supplemented by considerations about the availability of manual bagging equipment and of respiratory care technicians to oversee operations.

Mortality among mechanically ventilated patients with influenza has not been precisely determined, but it seems to run at about 40 to 50 percent overall, without stratification for age, co-morbidities, or severity of illness.<sup>27</sup> The mortality risk for low-SOFA patients who receive the standard of care will be lower — with the 20 percent range (80 percent survival) perhaps being a reasonable expectation. Let us suppose that the citizens of Lone Hill find that, with manual ventilation, low-SOFA patients meeting improvised inclusion criteria are four times less likely to survive than if they are maintained on full-feature mechanical ventilators — that is, that they survive at a rate of about 20 percent.<sup>28</sup> Presumably this survival rate, although markedly inferior to expected survival with the usual standard of care, would be sufficient to justify the use of manual ventilation in such patients. Under an improvised “sufficiency of care” standard, then, the treatment would be justified in low-SOFA patients.

Scenario 2 is far less complicated with respect to the question of which patients might benefit from manual ventilation. The airway problems, bacterial pulmonary infections, and

multi-organ failure that often complicate severe influenza infection will be rare in victims of a botulinum attack. Thus, we would expect that the vast majority of patients needing PPV in this scenario are candidates to benefit from manual ventilation, or from other possible means of providing PPV. Ventilator triage will not be a significant issue in this scenario, because there simply are not enough available ventilators to make a significant impact on mortality. For similar reasons, the expansion of hospital surge capacity will also be irrelevant. The only way to address such an event is with a large-scale effort to provide short-term PPV through alternative means, pending patients' clinical recovery (which is apt to be far quicker in this scenario than in scenarios involving pulmonary infection/acute respiratory distress syndrome) or evacuation to a facility that can provide the standard of care. Success will hinge on the ability to quickly appropriate supplies and to coordinate the large numbers of volunteers who will inevitably offer assistance.

Regarding nonfictional Scenario 3, the Hurricane Katrina experience at Louis Armstrong International Airport, it is useful to contrast what happened with what might have happened. In the absence of adequate supplies or a functional energy source, patients were ventilated manually for several days by exhausted medical personnel until the patients could be evacuated for definitive care. Apparently these efforts were successful in saving the lives of patients requiring PPV. However, the relief effort might have been more successful overall if: (1) some of the large number of volunteers were utilized to assist in manual ventilation, thus freeing medical personnel to perform more technically demanding tasks or even to get some rest; (2) on-site commanders had been quicker to reject standard triage and treatment protocols and commence resource-based tactical decision making; and (3) more of the advance-planning efforts had been dedicated to improvisational problem solving — especially pertaining to basic necessities such as communications and the provision of food, water, shelter, sanitation, and energy. In a hurricane or other natural disaster, some of the patients requiring PPV will be pa-

tients who suffered injuries during the physical event. The main problem, however, may be as it was in Katrina — namely, in finding the means to provide temporizing PPV to those who were receiving it prior to the disaster, until they can be evacuated. This is another general category of disasters in which manual ventilation has had, and in the future will have, a significant role in disaster operations.

### RESPONSIVENESS TO LOCAL VALUES

I have not examined particular ethical details impacting triage protocols, such as (1) whether urgently needed healthcare personnel should get priority over others in the same triage category; (2) whether patients on ventilators prior to a disaster, including those requiring permanent or long-term mechanical ventilation, should, because of their prior possession, receive priority for ventilators during a public health emergency; or (3) whether, and under which circumstances, patients with higher overall chances of survival should be denied access to full-feature ventilators because they are likely to survive with inferior means of PPV. Although individual commentators or committees will occasionally opine on such issues, and often provide helpful insights when they present arguments for their positions, this is not a realm in which matters can or should be decided by bioethicists, physicians, or expert panels.

In democratic nations at least, the articulation of public values is more authoritative when it issues from the public than when it issues from non-elected, nonrepresentative, non-qualified experts.<sup>29</sup> Expertise in reason, ethics concepts, and argument formation does not qualify a bioethicist or other purveyor of medical values to speak for the public, because reason alone cannot establish an ethical or political position.<sup>30</sup> Good reasons are, of course, important in establishing one ethical position as superior to competing positions, but what counts as a good reason, and which good reasons should trump other good reasons, is not a matter for reason alone. In the context of a polity, it requires public input. Ideally such public input should be a result of careful public deliberation,

which is a process in which bioethicists and others with training in ethical and political theory could be helpful in various capacities — but not as experts in identifying a definitive, correct position.<sup>31</sup>

In constructing their draft of “Allocation of Ventilators in an Influenza Epidemic” for public comment, the New York State Workgroup on Ventilator Allocation in an Influenza Pandemic often notes the presence or absence of disagreement between work group members. When there is disagreement, the reasoning behind the work group position is, at times, presented. For instance, consider the following passage from page 27:

Participants debated with great concern the question of offering enhanced access to ventilators to health care providers, first responders, or other special groups. Many participants argued that patients should be assessed on medical factors only, regardless of their work role, for various reasons. First, health care workers sick enough to require ventilators are unlikely to regain health and return to service during the pandemic. The predicted period of recovery will be at a minimum several weeks; the worst phase of the pandemic will likely end before a stricken individual can return to work. Second, workers in many occupations risk exposure and provide crucial services in a pandemic. Doctors and nurses face risks, but so do respiratory therapists, orderlies who keep rooms clean, morgue workers, laundry workers, ambulance staff, security personnel, fire fighters, police and others. Nor is it always easy to determine who is and is not a health care worker. Part-time volunteers staff ambulances in some communities; an unpaid family member may serve as the full-time caregiver for a disabled relative. These unpaid providers take risks comparable to or greater than some paid health care providers. Expanding the category of privilege to include all the workers listed above may mean that only health care providers win access to ventilators in certain communities. All other community members, including all children, would be denied access; this

plan was unacceptable to the work group. Participants also objected strongly to the appearance of favoritism, in which those who devised the rationing system appeared to reserve special access for themselves. Participants ultimately found that access to ventilators should depend on clinical factors only.<sup>32</sup>

It is notable here that: (1) only the work group's final position is explained, with no analysis of competing arguments; (2) no consideration is given to the possibility that the question of triage priority for healthcare workers may not have a single definitive answer covering all cases, but instead hinges in some cases on particular circumstances or particular local values; and (3) the group deliberation contains no assessment of public values. Regarding the final point, the work group has offered the document on-line for public comment, but responds to these comments (or not) entirely at its own discretion, without any apparent mechanism for ensuring fair or thorough consideration. Internet offerings of draft documents for public commentary are hardly an effective mechanism for obtaining balanced public input.<sup>33</sup> Serious efforts to articulate public values require more sophisticated techniques, such as deliberative polling.<sup>34</sup> Although personally I find the work group's deliberation on this particular issue cogent, and find that my own moral intuitions on the matter closely parallel those of the majority of work group members, there is no sound basis for holding that my moral intuitions, or those of the work group, are especially important for deciding such issues.

The diverse and unpredictable circumstances of actual disasters produce ethical dilemmas that are difficult to foresee. Advance guidance on ethical decision making is needed, however, just because real-time decisions in disasters are often time-compressed to a degree that precludes public input. Rescuers and officials must make decisions quickly. To a large degree, any effective advance guidance for ethical decision making in disaster medicine will consist of acquiring a general shared sense of things between likely rescuers and the public

they serve. Point-by-point guidelines that are intended to apply to all jurisdictions are less valuable. When rescuers operate in a relatively unfamiliar locale, they will need to rely on local contacts who can communicate local values. Sometimes the resulting accommodations are wrenching — as, for instance, when Haiti's Ministry of Health asked the medical crew of the USNS *Comfort*, serving in the 2010 earthquake, not to provide medical interventions that would result in a future requirement for healthcare services that exceeded what Haiti's local health systems "could offer or sustain."<sup>35</sup>

## CONCLUSION

The provision of ventilatory support in mass casualty situations is a technically complicated issue that begets serious ethical dilemmas. At the penumbra between ethics and technical medicine, planners need to recognize the need, in some disasters, to move from efforts to provide the standard of care toward a focus on sufficiency of care. In sufficiency of care medicine, triage is typically resource-driven rather than occupied with determining who shall receive a preconceived level of clinical support. Technically speaking, there are alternatives to full-feature mechanical ventilators, including manual bagging, that have been (and will be) successfully used for extended-duration PPV in disasters. For some reason, perhaps partly due to over-representation on expert panels by pulmonary specialists or other hospital-based clinicians who are not trained or experienced in disaster medicine, attention to these alternatives and to possible strategies for efficiently providing them is often truncated and inadequate. Ethically speaking, current guidance often suffers from the lack of public input.

In preparing for ethical dilemmas likely to pertain in future disasters, communities should pursue the same strategy that works best in preparing for technical and logistical dilemmas. They should work through a variety of dissimilar scenarios, identify controversial issues, and deliberate about how to approach them. Then they should practice context-specific decision making in realistic (that is, un-choreographed)

simulations that are designed to cultivate adaptive decisions.<sup>36</sup> Typically, the process of deliberation will be at least as illuminating for future decision makers as any conclusions it produces. Unlike discussions of technical and logistical dilemmas, deliberation about ethical dilemmas provides legitimate guidance only if the public is involved. In many cases, communities will be able to articulate general principles about ethical decision making in disasters. Such general principles require interpretation, however, and it is a broad array of hypothetical cases that imparts a general feel for correctly interpreting the principles. In any case, it is folly to think that effective, content-rich general guidelines can be constructed in advance to apply to all disasters, or to all disasters within a given class (for example, influenza epidemics), and then applied with algorithmic precision.

#### NOTES

1. Hypoxemia (low blood oxygen content) can also result from nonpulmonary sources, such as a right-to-left circulatory shunt or hemoglobinopathy, but in these cases the cause of the low oxygen status is not referred to as “respiratory failure.” Oxygenation failure also inevitably occurs with severe ventilatory failure, even when alveoli are fully functional, but in such cases it is secondary to ventilatory failure.

2. CO<sub>2</sub> exchange is more resistant to alveolar malfunction than is O<sub>2</sub> exchange. Hence, CO<sub>2</sub> content is a useful surrogate marker in the assessment of ventilation.

3. E.L. Quarantelli, “How Individuals and Groups React During Disasters: Planning and Managing Implications for Ems Delivery” (preliminary paper #138, University of Delaware, Disaster Research Center), <http://dspace.udel.edu:8080/dspace/bitstream/handle/19716/510/PP138.pdf?sequence=3>, accessed 15 October 2010; “A Half Century of Social Science Research: Selected Major Findings and Their Applicability” (preliminary paper #336, University of Delaware, Disaster Research Center, 2003), <http://dspace.udel.edu:8080/dspace/bitstream/handle/19716/297/PP%20336.pdf?sequence=1>, accessed 15 October 2010; T. Wachtendorf and J. M. Kendra, “Considering Convergence, Coordination, and Social Capital in Disasters” (preliminary paper #342a, University of Delaware, Disaster Research Center, 2004), <http://dspace.udel.edu:8080/dspace/bitstream/handle/19716/737/PP342A.pdf?sequence=1>, accessed 15 October 2010.

4. L. Rubinson et al., “Positive-Pressure Ventilation Equipment for Mass Casualty Respiratory Failure,” *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science* 4, no. 2 (2006): 183-94.

5. E.M. Malatino, “Strategic National Stockpile: Overview and Ventilator Assets,” *Respiratory Care* 53, no. 1 (2008): 91-5.

6. K.R. Klein et al., “Evolving Need for Alternative Triage Management in Public Health Emergencies: A Hurricane Katrina Case Study,” *Disaster Medicine and Public Health Preparedness* 2, no. 1 (2008): S40-4.

7. J.C. Farmer and P.K. Carlton, “Hospital Disaster Medical Response: Aligning Everyday Requirements with Emergency Casualty Care,” *World Hospital and Health Services* 41, no. 2 (2005): 21-24, 41, 43; C.J. Bonnett et al., “Surge Capacity: A Proposed Conceptual Framework,” *American Journal of Emergency Medicine* 25, no. 3 (2007): 297-306.

8. G. Trotter, *The Ethics of Coercion in Mass Casualty Medicine* (Baltimore: Johns Hopkins University Press, 2007), 80-3.

9. Industrial chemical accidents are typically caused by liquid agents, while most chemical attacks will involve vapors. Hazmat protocols are tailored to the former, in which two to three casualties are the norm, rather than the latter, in which several thousand casualties should be expected.

10. G. Trotter, “Chemical Terrorism and the Ethics of Decontamination,” *The Journal of Clinical Ethics* 15, no. 2 (2004): 149-60.

11. Trotter, *The Ethics of Coercion in Mass Casualty Medicine*, see note 8 above, pp. x-xi, 5-7.

12. The SOFA (sepsis-oriented organ failure assessment) score is calculated by assessing clinical and laboratory parameters (PaO<sub>2</sub>, platelet count, total bilirubin, blood pressure, mental status, and creatinine) that correlate with the severity of the patient’s condition. A perfect score is 0. The worst possible score is 24. Most influenza patients with scores of 3 would be regarded as having a good chance of survival, given optimum treatment.

13. Klein et al., “Evolving Need for Alternative Triage Management in Public Health Emergencies,” see note 6 above.

14. Ibid.

15. A.V. Devereaux et al., “Definitive Care for the Critically Ill During a Disaster: A Framework for Allocation of Scarce Resources in Mass Casualty Care: From a Task Force for Mass Critical Care Summit Meeting, January 26-27, 2007, Chicago, IL,” *Chest* 133 (2008): 51S-66S; M.D. Christian et al., “Defini-

tive Care for the Critically Ill During a Disaster: Current Capabilities and Limitations: From a Task Force for Mass Critical Care Summit Meeting, January 26-27, 2007, Chicago, IL,” *Chest* 133 (2008): 8S-17S. In the article on current capabilities and limitations, the Task Force writes that “although it is possible to convert off-site locations (*i.e.*, hotels, gymnasiums, sports fields) into medical treatment facilities, the ability to convert such areas to critical care facilities on a large scale is curtailed because of the functional requirements and logistical challenges, such as large-volume portable oxygen supplies.”

16. D.H. Rice, G. Kotti, and W. Beninati, “Clinical Review: Critical Care Transport and Austere Critical Care,” *Critical Care* 12, no. 2 (2008): 207-14; P. Halpern et al., “Intensive Care in a Field Hospital in an Urban Disaster Area: Lessons from the August 1999 Earthquake in Turkey,” *Critical Care Medicine* 31, no. 5 (2003): 1410-14; A.R. D’Amore and C.K. Hardin, “Air Force Expeditionary Medical Support Unit at the Houston Floods: Use of a Military Model in Civilian Disaster Response,” *Military Medicine* 170, no. 2 (2005): 103-8; J.J. Schnitzer and S.M. Briggs, “Earthquake Relief — the U.S. Medical Response in Bam, Iran,” *New England Journal of Medicine* 350, no. 12 (2004): 1174-6; G. Trotter, “When the Trough Breaks,” *American Journal of Bioethics* 6, no. 1 (2006): W25-6.

17. Trotter, “When the Trough Breaks,” see note 16 above.

18. Rice, Kotti, and Beninati, “Clinical Review: Critical Care Transport and Austere Critical Care,” see note 16 above. Also helpful is specialized work from the U.S. Army Mass Casualty Decontamination Research Team, whose concept of an offsite triage, transportation, and treatment center can be adopted to numerous contexts other than chemical attacks. See W.A. Lake, P.D. Fedele, and S.M. Marshall, *Guidelines for Mass Casualty Decontamination During a Terrorist Chemical Agent Incident* (Aberdeen Proving Ground, Md.: U.S. Army Soldier and Biological Chemical Command (SBCCOM), 2000), [http://www.au.af.mil/au/awc/awcgate/army/sbccom\\_decon.pdf](http://www.au.af.mil/au/awc/awcgate/army/sbccom_decon.pdf), accessed 15 October 2010; Trotter, “Chemical Terrorism and the Ethics of Decontamination,” see note 10 above.

19. T. Powell, K.C. Christ, and G.S. Birkhead, “Allocation of Ventilators in a Public Health Disaster,” *Disaster Medicine and Public Health Preparedness* 2, no. 1 (2008): 20-6.

20. G. Trotter, “Mediating Disputes About Medical Futility,” *Cambridge Quarterly of Healthcare Ethics* 8, no. 4 (1999): 527-37.

21. J.B. West, “The Physiological Challenges of

the 1952 Copenhagen Poliomyelitis Epidemic and a Renaissance in Clinical Respiratory Physiology,” *Journal of Applied Physiology* 99 (2005): 424-32.

22. Christian et al., “Definitive Care for the Critically Ill During a Disaster;” see note 15 above.

23. E. Auf der Heide, “Common Misconceptions About Disasters: Panic, the ‘Disaster Syndrome,’ and Looting,” in *The First 72 Hours: A Community Approach to Disaster Preparedness*, ed. M. O’Leary (Lincoln, Neb.: iUniverse, 2004), 340-80. Volunteers frequently present a logistical problem through their sheer numbers. For instance, in discussing phone communications during disasters, a Red Cross operations manager commented on the importance of being “ready and able to handle a huge influx of untrained people wanting to help.” B. McDuffy, “How the American Red Cross Provides Local Disaster Services,” in *The First 72 Hours*, *ibid.*, 409-19.

24. The tendency in moderate-to-low casualty (including nondisaster) situations, where extended-term manual ventilation is being employed, is to utilize medical students. For instance, medical students worked in shifts providing manual ventilation during the Copenhagen polio epidemic of 1952 (West, “The Physiological Challenges of the 1952 Copenhagen Poliomyelitis Epidemic and a Renaissance in Clinical Respiratory Physiology,” see note 21 above). I recently talked to a medical missionary to Central America who reports that, in day-to-day operations of rural hospitals she visited, manual ventilation was the primary means of providing extended-term PPV, and this procedure was typically administered by medical students. She returned to the U.S. with photos of medical students bag-ventilating patients on the medical wards — sometimes while performing other tasks such as talking on cell phones. I have instructed medical students on manual bagging, and I have instructed nonmedical volunteers. In my experience, there is not much difference between the two groups. Both are clumsy at first, but learn quickly. On the other hand, many technical issues that pertain in the respiratory management of PPV patients — whether manually ventilated or not — will be beyond the scope of just-in-time trained volunteers. These issues could be addressed by a circulating respiratory therapist — who is perhaps available to multiple patients just because he/she has been freed from the labor of providing manual ventilation.

25. Devereaux et al., “Definitive Care for the Critically Ill During a Disaster,” see note 15 above. See also: New York State Workgroup on Ventilator Allocation in an Influenza Pandemic, New York

State Department of Health/New York State Task Force on Life and the Law, "Allocation of Ventilators in an Influenza Pandemic: Planning Document," draft for public comment, 15 March 2007, [http://www.health.state.ny.us/diseases/communicable/influenza/pandemic/ventilators/docs/ventilator\\_guidance.pdf](http://www.health.state.ny.us/diseases/communicable/influenza/pandemic/ventilators/docs/ventilator_guidance.pdf), accessed 15 October 2010.

26. I am inclined to favor "first-come, first-served" as the sorting method within a triage category, but will not argue for that position in this essay.

27. California state epidemiologic data for the H1N1 pandemic of 2009 reports that 95 of 193 adults (greater than 18 years old) receiving mechanical ventilation died (mortality 49 percent) and that seven of 34 children receiving mechanical ventilation died (mortality 20 percent), yielding an overall mortality of 40.5 percent among all patients receiving mechanical ventilation. See J.K. Louie et al., "Factors Associated with Death or Hospitalization Due to Pandemic 2009 Influenza A (H1N1) Infection in California," *Journal of the American Medical Association* 302, no. 17 (2009): 1896-902. Mortality rates among mechanically ventilated patients with SARS were similar. See R.A. Fowler et al., "Critically Ill Patients with Severe Acute Respiratory Syndrome," *Journal of the American Medical Association* 290, no. 3 (2003): 367-73.

28. In actuality, the survival rate on manual ventilation for such patients might turn out to be much better. In influenza and a variety of other critical pulmonary conditions, ARDS is a final common pathway for the critically ill. Yet the vast majority of patients dying with ARDS do not die of respiratory failure. This suggests: (1) that even inferior methods of providing PPV may be sufficient in a large number of cases, and (2) that it is not the availability of mechanical ventilators that is the crucial issue, but rather the availability of other interventions. If the latter is the case, then the current emphasis on delineating standards for the distribution of mechanical ventilators may be even more misguided than I have inferred. On the other hand, it is likely that, in many cases, mechanical ventilation is truly the most critical medical intervention, but still serves only as a temporizing measure while the body overcomes, or fails to overcome, the pathological insult through its own immune resources. Whatever the case, in the vast majority of patients with ARDS, attempts to keep patients adequately ventilated are successful. See A.B. Montgomery et al., "Causes of Mortality in Patients with the Adult Respiratory Distress Syndrome," *American Review of Respiratory Disease* 132, no. 3 (1985): 485-9; R.D.

Stapleton et al., "Causes and Timing of Death in Patients with ARDS," *Chest* 128, no. 2 (2005): 525-32. Interestingly, the World Health Organization reports that most deaths from H5N1 (avian) influenza have been due to "progressive respiratory failure" in a setting of acute respiratory syndrome (ARDS). If so, H5N1 constitutes an exception to the rule with ARDS. See Writing Committee of the World Health Organization (WHO) Consultation on Human Influenza A/H5N1, "Current Concepts: Avian Influenza a (H5N1) Infection in Humans," *New England Journal of Medicine* 353, no. 13 (2010): 1374-85.

29. For an extensive discussion of this issue, see chapters 2 and 3 of Trotter, *The Ethics of Coercion in Mass Casualty Medicine*, see note 8 above.

30. For a fairly exhaustive demonstration of why this is the case, see the first two chapters of H.T. Engelhardt, Jr., *The Foundations of Bioethics*, 2nd ed. (New York: Oxford University Press, 1996).

31. Trotter, *The Ethics of Coercion in Mass Casualty Medicine*, see note 8 above; G. Trotter, "Bioethics and Healthcare Reform: A Whig Response to Weak Consensus," *Cambridge Quarterly of Healthcare Ethics* 11, no. 1 (2002): 37-51.

32. New York State Workgroup, "Allocation of Ventilators in an Influenza Pandemic: Planning Document," see note 25 above.

33. G. Trotter, "Pragmatism, Bioethics and the Grand American Social Experiment," *American Journal of Bioethics* 1, no. 4 (2001): W11-30.

34. B. Ackerman and J.S. Fishkin, "Deliberation Day," in *Debating Deliberative Democracy*, ed. J. Fishkin and P. Laslett (Malden, Mass.: Blackwell Publishing, 2003).

35. M. Etienne, C. Powell, and D.E. Amundson, "Healthcare Ethics: The Experience after the Haitian Earthquake," *American Journal of Disaster Medicine* 5, no. 3 (2010): 141-47.

36. See chapter 6, on "Tactical Leadership," in Trotter, *The Ethics of Coercion in Mass Casualty Medicine*, see note 8 above.

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# Pandemic Preparedness Planning: Will Provisions for Involuntary Termination of Life Support Invite Active Euthanasia?

*Jeffrey T. Berger*

## ABSTRACT

A number of influential reports on influenza pandemic preparedness include recommendations for extra-autonomous decisions to withdraw mechanical ventilation from some patients, who might still benefit from this technology, when demand for ventilators exceeds supply. An unintended implication of recommendations for nonvoluntary and involuntary termination of life support is that it make pandemic preparedness plans vulnerable to patients' claims for assisted suicide and active euthanasia. Supporters of nonvoluntary passive euthanasia need to articulate why it is both morally different and morally superior to voluntary active euthanasia if they do not wish to invite expansion of end-of-life options during health system catastrophe.

## VIGNETTE

Highly virulent pandemic influenza has struck the United States. With an attack rate of 30 percent, the demand for critical care beds

exceeds supply by a factor of three. Triage protocols trigger the extubation of many patients whose prognoses for survival have worsened despite a trial of mechanical ventilation. These patients are transferred to palliative care areas where they join many other patients who are expected to die. One of the patients has been transferred from the intensive care unit after having been extubated against his wishes due to increasingly poor physiologic parameters. He is expected to survive less than one week if on mechanical ventilation and will now die within days. Having been forced to accept withdrawal of life support in order to free-up resources for patients more likely to benefit, he now asks to be actively euthanized to end his suffering and to further free-up resources for the many incoming patients. He asks why the hospital physicians are permitted to let him die against his wishes, but cannot help him die in accordance with his wishes?

## BACKGROUND

Over the past several years, state, national, and international bodies have issued reports on preparing for and managing a highly lethal influenza pandemic. Perhaps the most ethically

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charged and morally agonizing aspects of their recommendations involves the use of mechanical ventilation when the demand for this technology exceeds its supply. Each of these guidelines offers a schema to stratify patients according to clinical prognosis, and each provides for unilateral, extra-autonomous decisions to withhold and withdraw mechanical ventilation from some patients who might still benefit. The New York State Task Force on Life and the Law<sup>1</sup> and the Minnesota Pandemic Ethics Project<sup>2</sup> recommend nonvoluntary withdrawal of mechanical ventilation for patients whose conditions worsen during a stipulated time interval. The Task Force for Mass Critical Care also supports nonvoluntary withdrawal of mechanical ventilation,<sup>3</sup> and a report of the Veterans Health Administration<sup>4</sup> explicitly acknowledges that “patients who have a legitimate expectation of continued use of a lifesaving treatment may have the treatment withdrawn under circumstances of severe resource scarcity.” The World Health Organization (WHO) notes, “In the context of a pandemic, this means that it can be justified that patients are extubated who may still benefit from such treatment.”<sup>5</sup> A report of the Institute of Medicine states, “treatment could be withdrawn without or against the patient’s expressed wishes.”<sup>6</sup> Some of these cases of nonvoluntary withdrawal of ventilation will be, in fact, involuntary treatment termination. In times of normalcy, involuntary termination of life support for patients who could otherwise continue to live would be utterly unthinkable and considered the moral equivalent of unjustified killing.

Among these pandemic preparedness reports, several guiding ethical principles are invoked as the basis for nonvoluntary and involuntary withdrawal of mechanical ventilation. *Utility* and *stewardship* refer to maximizing the number of surviving patients through careful allocation of resources. *Fairness* refers to striving to provide equal access to mechanical ventilation to all patients similarly situated to benefit. These reports also recognize that the orthodoxy around individual autonomy will necessarily be altered for the good of the many. The New York State Task Force on Life and the Law

notes, “A public health disaster such as a pandemic, by virtue of severe resource scarcity, will impose harsh limits on decision-making autonomy for patients and providers. Allocation guidelines must reflect those limits. Nonetheless, a just rationing scheme must endeavor to support autonomy, when possible, in ways that also honor the duties of care and stewardship.”<sup>7</sup> The WHO states, “measures that limit individual rights and civil liberties must be necessary, reasonable, proportional, equitable, non-discriminatory, and not in violation of national and international laws.”<sup>8</sup> Obviously, pandemics can create a dramatic paradigm shift for medical care. The ethical arguments used to justify nonvoluntary and involuntary withdrawal of mechanical ventilation, however earnest, may have unintended implications.

#### **DOES INVOLUNTARY TERMINATION OF LIFE SUPPORT INVITE VOLUNTARY ACTIVE EUTHANASIA?**

Termination of life-supporting interventions is widely accepted as situations of “allowing to die” or passive euthanasia, rather than as commissive acts of killing. However, this passive-active distinction carries no inherent moral valence.<sup>9</sup> Cases of allowing-to-die may be unethical (for example, ignoring the pleas of a drowning person for a floatation device, withdrawal of mechanical ventilation based on the ill motive of a surrogate or physician), whereas killing may sometimes be ethically acceptable (for example, self-defense, active euthanasia according to Dutch society). In fact, some cases of allowing-to-die can be as morally bad as some cases of killing.

Under times of normalcy, withdrawal of mechanical ventilation consistent with a patient’s autonomous wishes is considered an ethically defensible act of allowing-to-die, whereas involuntary withdrawal is considered categorically unethical. For highly lethal pandemic conditions, there is an emerging consensus among the reports cited above that a practice of allowing-to-die that would normally be indefensible is ethically supportable. Of course, a schema is needed to determine criteria for “highly lethal.”

Nevertheless, highly lethal pandemic conditions justify a re-ordering of ethical imperatives, whereby substantial community benefit and commitments to fairness override, albeit reluctantly, important considerations of autonomy. The implications of this paradigm shift are serious and not fully appreciated.

Recommendations for involuntary termination of life support makes pandemic preparedness plans vulnerable to requests from patients for actively assisted death. The interface of active and passive death in pandemic is not addressed by pandemic preparedness reports. Nonetheless, if these requests for actively assisted death are to be rebuffed, the framers of pandemic protocols must be prepared to articulate why voluntary active euthanasia (VAE) is morally worse than involuntary passive euthanasia (IPE). Patients who desire VAE may well invoke the same core ethical arguments used in these reports to support IPE.

### **The Appeal to Utility**

*Utility* is a core justification for unilateral decisions for extubations in pandemic. Patients seeking support for VAE can also invoke the principle of utility. In times of pandemic, assumedly all health resources may be taxed, and patients who undergo VAE would free-up limited human and material resources. Arguably, the palliative medications foregone by now-euthanized patients will assist still-ventilated patients in tolerating this intervention, thereby enhancing its utility.

### **The Appeal to Fairness**

The imperative to fairly distribute resources is broad and does not only apply to ventilator access. In a true health catastrophe, multiple systems including those designed to provide palliative care will be overwhelmed. Palliative resources may also need to be rationed between patients who are expected to die and patients who may survive mechanical ventilation, as well as among groups of patients in which all are likely to die. Some patients, in the spirit of *solidarity* and *fairness*, may request VAE in order to give incoming patients a fair opportunity to receive palliative resources.

### **The Duty to Care**

The New York State Task Force report identifies a *duty to care* as fundamental to its recommendations. What actions does this duty obligate, permit, and excuse during a health catastrophe in which, perhaps, even palliative resources become inadequate?<sup>10</sup> Is acceding to a request for VAE a legitimate response to the duty to care, when system dysfunction or collapse precludes adequate symptom management for patients who are near death? If not, how will this duty be fulfilled?

Since the principled arguments in favor of IPE may not restrain VAE, do long-standing arguments against VAE serve to do so in the context of pandemic? States' strong interest in preserving life has served as an ethical defense to autonomy-based claims to the right to active euthanasia. Support for nonvoluntary passive euthanasia, in which the state makes relative valuation of one person's less-brief survival over another's more-brief survival, suggests that the state's interest in preserving patients' lives is not categorical, but is situational, in times of *extremis*. Opponents of VAE have long expressed concerns that involve autonomy and dignity, such as verifying voluntariness of choice and protecting the vulnerable. However, these concerns ring hollow in the face of support of treatment termination that is involuntary. Moreover, this claimed interest in preserving life at the expense of autonomy is weakened by the willingness of the state to facilitate one person's death at the expense of the individual's autonomy. Some pandemic patients may argue that acceding to requests for VAE restores respect for autonomy when it has otherwise been subjugated. In this respect, and in times of pandemic, could VAE be morally superior to IPE?

Another often-cited concern is that acceptance of VAE would initiate a slippery slope to nonvoluntary and then involuntary euthanasia. Certainly, the precedent of involuntariness created by IPE makes this concern more pressing, not less so. Lastly, opponents of VAE point to the fact that only a minority segment of the public and of the physician work force (albeit a not insignificant minority) support VAE.<sup>11</sup> While this is true for conditions of normalcy, attitudes

towards VAE in times of crisis or catastrophe are little known. However, in times of normalcy, VAE has some basis of support, whereas there is none for IPE, which suggests that VAE is less objectionable than IPE. We do not know whether this relative preference holds for pandemic and catastrophic conditions, but, if it does, ethical arguments that support IPE but proscribe VAE would be further undermined.

### CONCLUSION

Pandemic preparedness planning, however reasonable and responsibly crafted, includes a paradigm shift of extra-autonomous treatment termination, the ethical reverberations of which may extend far beyond what its framers intended. What ethical firewall will exist to resist requests for VAE during a health catastrophe in which precedents for IPE have already been established, and when VAE may be the most self-determinative and efficient and effective method of symptom palliation for patients otherwise doomed to death? If writers of reports that support IPE do not wish to invite expansion of end-of-life options during pandemics, they need to articulate why involuntary passive euthanasia is both morally different and morally superior to voluntary active euthanasia.

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# Should Palliative Care Be a Necessity or a Luxury during an Overwhelming Health Catastrophe?

*Philip M. Rosoff*

## ABSTRACT

In the event of a widespread health catastrophe in which either or both human and material resources were in critically short supply, rationing must take place, especially if the scarcity will last for some time. There are several tested allocation methods that are routinely used during emergencies. These include triage procedures employed by emergency departments and the military on the battlefield. The goal is to save the lives of as many as possible. When it is not possible to save all, or even most, who come for care, what should be done, if anything, with those whose fate is death?

The central tenet and goal of medicine is the relief of suffering. If we take this seriously as an axiom of practice, then healthcare providers and the institutions in which they work are duty-bound to provide comfort and relief to all, especially the dying. There are several ways this can be done. One is to prepare by training sufficient individuals to provide what might be called emergency palliative care. These people do not all have to be doctors but could (and should) include

people from a range of backgrounds including nursing, allied health, pastoral care, and social work. For them to be able to do their jobs effectively, some basic supplies should be stockpiled so the pain and suffering associated with untreated illness and injury can be relieved. However, what happens when there is a shortage of, say, opiates, so that relief of air hunger and pain cannot be eased? Then critical decisions must be made. Alternative sources of symptom relief not considered under ordinary circumstances might be used. However, it is possible to imagine a situation when all resources are in critically short supply. Those remaining resources, logically and morally, should be allocated to persons who can survive. In this scenario, what can be offered to the suffering dying? This might depend on the attitude of personnel caring for patients. In desperate circumstances, it is possible the proscription against active euthanasia could be justifiably overridden by concern for ongoing, relentless, and unmitigated suffering. Any justification that could be made for such action would be undermined by arbitrary or capricious administration. Thus, preparation for a catastrophic healthcare emergency should take into account all conceivable outcomes.

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## INTRODUCTION

Shortly after debarking from an airplane that had arrived from Southeast Asia, a 35-year-old businesswoman, who had become increasingly

sick with a respiratory illness during the flight, took a shuttle bus downtown to her hotel in a major metropolitan area in the U.S. Her condition deteriorated, but she continued to attend most of the sessions of her business convention. Eventually, with worsening shortness of breath and a high fever, she presented to a local emergency department and was hospitalized with acute viral pneumonia and respiratory failure, diagnosed shortly thereafter as influenza. This would prove to be the first case of a resurgent and virulent strain of influenza A, and was reported to the Centers for Disease Control and Prevention in Atlanta. Meanwhile, her colleagues at the convention wrapped up their meetings and headed home throughout the country: some of them developed a similar illness over the next few days. Within several weeks thousands of cases were reported and a pandemic was declared. Hospitals were quickly overwhelmed with very sick patients, and beds, especially those in intensive care units (ICUs), were in short supply, forcing institutions to begin to make critical decisions about who lived and who died.

Of course, this is an imagined scenario and, while it may seem fanciful, the assumption is that it will happen, and planning continues apace.<sup>1</sup> Discussions of how to confront such a desperate situation, in which lifesaving resources are limited and decisions about allocation cannot be avoided, raise important questions of rationing and what types of, and how much, healthcare services are owed to people during a catastrophic and prolonged medical emergency. Significantly, most of these discussions center on how to fairly and justifiably distribute such supplies as vaccines, ventilators, ICU beds and the like, and less so what to do for those who die despite our best efforts, or who are relegated to die by triage. Lack of preparation for such an eventuality could lead to potential tragedies, as the story of Dr. Anna Pou and Hurricane Katrina illustrates so vividly.<sup>2</sup>

When hospitals are overwhelmed with patients in a relatively short period of time, they are faced with the immediate problem of attempting to provide care for as many as pos-

sible. Whether this acute situation is due to a large traffic accident on the local freeway, a major weather event such as a hurricane, or even a disaster from a terrorist attack or widespread pandemic, the logistical challenges remain the same: the rapid development of a situation in which supplies, equipment, and personnel may be insufficient to meet demand. If the emergency is short-lived, then sustained shortages presumably would not develop. However, in any disaster that is either prolonged or widespread (or more likely, both), the result is that not all patients can receive the type and amount of care they have come to expect during normal times. There are obvious important clinical and ethical questions that arise and that must be addressed — preferably well before these circumstances arise — in order to adequately, fairly, and justifiably cope with such a state of affairs. For example, How is it decided who gets what and how much care? What type of triage system is most appropriate? and Are some patients more deserving of lifesaving care than others similarly medically situated, simply because of who they are or what they do? However, often ignored in the planning discussions to develop strategies to save as many lives as possible, is what to offer those patients who cannot be saved, either by design or by chance. Are they owed anything other than our sympathy? Should they expect to receive relief as a matter of course? Should they be specifically included in advance planning?

In this essay, I will first give a brief description of rationing lifesaving resources (including personnel) in a prolonged catastrophe. I will then characterize what I believe to be a pivotal role for palliative care in the response to such a situation. I will argue that the provision of palliative care cannot be considered a luxury, but is actually obligatory for several reasons: it is now increasingly a standard of care for the dying, and because of its unique character it can not only relieve symptoms, but may prevent the twin moral tragedies of either ignoring the sick who cannot be cured or resorting to active euthanasia in a misguided attempt to alleviate suffering.

## PALLIATIVE CARE AND HEALTHCARE DISASTERS

In either a regional or more generalized healthcare disaster, altered clinical approaches are routinely taken. Many plans have been created to cope with these situations, most recently those formulated in preparation for an influenza pandemic. Generally, they have employed variations of triage strategies in which either the sickest patients or those patients who are most likely to survive are treated first.<sup>3</sup> Of course there are modifications to these approaches, including plans that take into account preexisting co-morbidities or extremes of age (both the very young and the very old) that may not influence immediate survivability, but can affect critical decision-making policies in situations of extreme duress.<sup>4</sup> Underlying all of these approaches is the recognition that some types of care for some (but not all) people are crucial to maximizing good outcomes (usually defined as the percentage of lives saved), and hence considered necessary. Other interventions, both for those who are included in the curative intent group and those who are excluded, might be deemed luxuries, offered only if circumstances permit. Necessary care might include such therapies as emergency surgery, mechanical ventilation, and intensive care.

While many of the sick would be triaged to receive standard care, others would be deemed either too ill or too unlikely to benefit and hence be relegated to something else. We also must not ignore the fact that there are hundreds of thousands, if not millions, of people who are hospitalized each year in the United States, many of whom are gravely ill: what should be done with them, even those not directly affected by the disaster? People will still get sick from cancer, have heart attacks, premature babies will be born, and the like. Some others will obviously be scheduled for elective surgeries and others for procedures or interventions that could possibly be done as outpatients or delayed without untoward consequences. But many can truly benefit from the services a modern hospital has to offer, *benefit* being defined as a lessening of both morbidity and mortality. Very few plans

have considered the fate of these people, but presumably they would be triaged in much the same way as those with the flu (for example), taking into consideration preexisting conditions, age, et cetera. Nevertheless, presumably there will be vast numbers who will be ineligible for curative care and will also be assigned to the “other” group as well. What type of care, if any, should be offered or be available for these patients? What would, or should, that “something else” be? For these other patients, for those who lose the triage lottery, are there any forms of care that we could consider required, if not obligatory? I would suggest that palliative care is such a case, especially in situations in which there may be large numbers of critically ill, injured, and possibly dying patients for whom life-saving help will not be an option.

Illness is often, if not always, accompanied by suffering of one sort or another, sometimes lesser, sometimes greater. Indeed, people become patients when they begin to become aware of, and appreciate, their suffering, and thus approach the doctor seeking relief.<sup>5</sup> By so doing, they enter into a special relationship of trust and dependency with their physician, in which they place their confidence in the physician to understand and value their suffering as a vital demonstration of concern for their best interests. Hence, they rely on the expertise and compassion of the doctor to alleviate their pain. Although the ascendancy of modern technological medicine has led to cures for many ailments, very often accompanied by an easing or gradual disappearance of suffering, this is not always the case. In the latter situation, all the doctor has to offer is palliation, or the employment of techniques to moderate or reduce the degree of suffering. Thus we may justifiably state that the prime calling of the physician in the care of the sick is the reduction of suffering, no matter what its form or cause. Under ordinary conditions, the discharge of this duty is relatively straightforward; even when there are social or medical impediments such as lack of health insurance, cognitive impairment, or extreme poverty, it is rare that an educated and knowledgeable physician cannot intervene effectively to diminish pain.<sup>6</sup> Such approaches can and should be a

necessary component of every physician's therapeutic armamentarium. While we nowadays formally label this type of "caring about" and "caring for" palliative care, it is in reality no different from what compassionate and skilled physicians have been doing for many years.

Even so, over the last 30 years palliative care has emerged as a clinical medical specialty in its own right.<sup>7</sup> Palliative care services for adults, and, to a lesser degree, children, have spread rapidly throughout the U.S. Initially arising from the hospice movement in England, and still confused in most lay and medical observers' minds as being solely focused on terminal care, palliative care practitioners emphasize their involvement with complex symptom management throughout the course of illness.<sup>8</sup> Nonetheless, it remains true that most of their efforts are centered on the care of patients in the last months to weeks of life. In both community hospitals and tertiary care medical centers, their expertise has contributed to a significant easing of pain and suffering at the end of life.<sup>9</sup> While they are still relative newcomers to the pantheon of recognized medical specialties, it is fair to state that "official" palliative care has become a component of the routine panoply of medical therapies.<sup>10</sup> Hence, it is also reasonable to argue that it is (or should be) a constituent of the standard of care in the U.S. And, whether symptom relief is due to the efforts of palliative care specialists or other knowledgeable and trained healthcare providers, patients should expect that their suffering can be treated effectively.

If this statement is true, then one can assert that patients should have an expectation that, all things being equal, they will have access to some reasonable level of palliative care. While it is true that there is no legal right to any healthcare in this country *per se*, malpractice case law suggests that patients have a presumption to be treated according to the extant standard of care.<sup>11</sup> Consequently, hospitals, clinics, and the like should provide palliative care for patients who are being treated in their facilities. Many already do, and more are planning to do so every day. In reality, though, the accessibility and delivery of effective palliation often may be frustrated by a variety of structural and bureaucratic ob-

stacles. Nevertheless, the fact that the practical availability of the standard of care is frequently less than ideal does not diminish its status as a standard (notwithstanding the oft-stated dictum of "ought implies can").

For the overwhelming majority of patients and the institutions in which they receive their care, the provision of these quotidian resources is so carefully fine-tuned that shortages of supplies, equipment, and personnel rarely, if ever, occur. This may not be true, however, when a large health disaster like Hurricane Katrina rapidly overwhelms both local and regional healthcare facilities and their ability to provide even a modicum of care to both their regular, existing patient population and those additional patients who are affected by the novel circumstances of the catastrophe. Even a relatively minor disruption in the chain of supply lasting just several days may be sufficient to induce severe shortages in essential supplies in an institution that has not made plans to cope with such events. Few, if any, hospital disaster plans include strategies for providing palliative care for those injured and perhaps dying patients for whom there are either not enough resources to cure, or who are too sick to save. This situation was initially raised in connection with preparations for a possible influenza pandemic.<sup>12</sup> But only a very small number of hospitals have invested in the supplies, and, most importantly, training of personnel to meet such an egregious situation successfully. Even so, the very nature of preparation for an overwhelming disaster, or at least one that either temporarily or longer leads to an inevitable disruption in the normal balance between supply and demand, necessarily entails rationing of resources. Of course, such preparation would also require hospitals to keep their supplies up-to-date, periodically replacing drugs that have reached their expiration date with a fresh stock. This could necessitate a radical change in approach for most acute healthcare facilities whose preparation for disasters is centered on operational readiness for a self-limited and contained situation. Thus, it is assumed that there will be a continuing ongoing function of delivery on demand of perishables and other supplies. More germane to this dis-

cussion, though, is the fact that hospitals rarely stockpile reserves of resources that would be critical for the delivery of palliative (or other) care to large numbers of patients over a potentially prolonged period of time. Therefore, it would be incumbent upon facilities to maintain sufficient stores of anticipated equipment and drugs in preparation for a disaster of this type. While this may not first appear to be a component of the moral argument I have attempted to make, it is entailed by the idea of an obligation to provide this type of care.<sup>13</sup>

As the recent debate over the federal health care reform legislation has amply demonstrated, the very thought of pro-active rationing of healthcare in the U.S. is anathema. But, in the event of a widespread health catastrophe in which either or both human and material resources would be in critically short supply, rationing must take place. There may be some types of care that we may not be able to afford to ration. While it might be common sense to cancel elective surgeries and other non-essential care during prolonged emergencies, as was suggested in a number of pandemic influenza plans,<sup>14</sup> helping the dying and others who are too sick or who are otherwise ineligible to receive lifesaving interventions should not be optional, if at all possible. In a wealthy country, it is not unreasonable to expect that the therapies associated with pain and other symptom relief be available to all who require them, irrespective of other exigencies.

As already stated, the central tenet and goal of medicine is the relief of suffering. If we take this seriously as an axiom of practice, then healthcare providers and the institutions in which they work are duty-bound to provide comfort and relief to all, especially the dying. If we cannot always heal, we should always care. One could credibly argue that the provision of palliative care during an emergency would have added urgency, indeed, necessity. To fulfill that duty in a healthcare emergency would entail careful, but not elaborate, preparation. Hospitals and other facilities that would be involved in caring for the sick and injured must ensure that their personnel are at least minimally trained to provide palliative care, especially

pharmacological intervention. They could train sufficient individuals to provide what might be called emergency basic palliative care. These people do not all have to be doctors but could (and should) include people from a range of backgrounds including nursing, allied health, pastoral care, and social work. In order for them to be able to do their jobs effectively, some basic supplies should be stockpiled so that the pain and suffering associated with untreated illness and injury can be relieved. Providers would need to know not only what medications to give, but suitable dosing for children, adults, and the elderly, as well as the mechanics of administration (intravenous, intramuscular when IVs may be in short supply, orally, rectally, and so on). This would involve ensuring that adequate supplies of appropriate medications for the relief of pain and anxiety, in a variety of formulations, as well as a variety of devices to administer the medication, are easily available.

However, what happens when there is a shortage of say, opiates, so that relief of air hunger and pain cannot be eased in all who could benefit? Then critical decisions must be made. One possibility is to creatively use alternative sources of symptom relief, such as inhalant or intravenous forms of anesthesia that one might not consider under ordinary circumstances. If we take this analysis to its hypothetical endpoint, however, it is possible to imagine a situation in which all of these resources are in critically short supply. Those that still remain logically, and morally, should be allocated to those who can survive. In this scenario, what can be offered to the suffering dying? Then it might depend on the attitude of the personnel who are caring for these patients. In these desperate circumstances, it is possible that the proscription against active euthanasia could be justifiably overridden by our concern for ongoing, relentless and unmitigated suffering (see below). We may think that this could never happen, but events in New Orleans after Hurricane Katrina would prove us wrong.<sup>15</sup>

It is possible that this type of planning could prove to be insufficient, thus leading to shortages of trained doctors and nurses and/or supplies like morphine. If there is a failure of plan-

ning — for whatever reason — and there are insufficient personnel or medication to relieve the suffering of both those who are triaged to receive intensive care and those who are relegated to palliative care, can one create a defensible priority between the two? If there is a stark choice that must be made between these alternatives, is there a fair way to do it? Can one mark out a difference between the types of suffering between these two classes of individuals that would enable one to have a greater claim on pain medication, for instance? One could argue that those patients who are receiving life-saving care, and hence whose most precious resource — life — is potentially being preserved, may have less entitlement to morphine than those whose are relegated to a certain death. In this case, morphine could be considered as a form of compensatory support provided in lieu of a ventilator. I would imagine that most people, although not all, when offered a rational choice between a chance to live, with time-limited attendant pain and misery, versus death, painless though it may be, would opt for the former.

However, it may not be so simple. For instance, there can be no guarantee that those on ventilators will need them short-term, and some may require more advanced forms of ventilation in which total body paralysis is necessary to ensure adequate gas exchange; indeed, for those patients placed on arterial-venous ECMO (extracorporeal membrane oxygenation), paralysis is mandatory.<sup>16</sup> Even for regular mechanical ventilation, anxious patients can make ventilation problematic if they are “fighting the vent,” so one could argue that diverting morphine and similar drugs to those whose lives we are trying to save will maximize their chances, hence justifying denying these agents to patients who are dying anyway.

Finally, there is an important point to be made about the realism of the presumptions that have been described in this discussion. Throughout this essay I have spoken of disaster planning, specifically with reference to palliative care as an expected, if not obligatory, component of any coherent and morally defensible approach to care for the sick and dying. I have

outlined strategies to prepare for a variety of eventualities. But I have only referred in passing and perhaps obliquely to how this might (or would) play out in the real world. I believe that it is important to outline what our ideals should be, as goals to keep in mind and as a bellwether to which we can refer both during a crisis and after it has passed, perhaps as a gauge to mark our performance, good and bad. But, in reality, it is unlikely that even the best of preparations will be robust enough to withstand both the anticipated and unanticipated demands of a prolonged emergency. In addition, I have very little confidence that government(s) and hospitals will make the substantial initial investment and ongoing commitment in the resources, both human and other, to lessen the chances of catastrophic collapse from the start. The result would be Katrina *redux*. Even if institutions prepare, to expect that physicians, nurses, and allied health personnel, as well as all the other people required to make a modern healthcare facility minimally functional (such as food, environmental services, laundry, medical engineering, and maintenance staff, to name but a few), would be able to continue to do the jobs they were trained for (as well as those they were not) under the most trying of conditions, is senseless idealism in the extreme. That does not negate my attempt to outline what *should* be the case, only that we should also consider what alternatives might have to be acceptable if the more realistic scenario unfolds. Heretofore, I have mentioned the possibility of euthanasia without much further discussion, except for the need to consider its possibility, as a result of either accidental or purposeful action. But this is too important a topic to be regarded in passing, especially when its appearance may depend on how much preparation for a disaster is made and the fidelity with which such plans are followed. Most significantly, we must ask if active, intentional euthanasia can ever be regarded as a component of human, palliative care. Hence, we need to consider both callous disregard and euthanasia in more detail.

Can there ever be an acceptable or justifiable place for not responding the pleas, the cries, and the needs of the suffering, even in situa-

tions of such dire emergency when the technical means to alleviate or control suffering do not exist? In a simple word, no. To do so in any way would be to abandon any pretense of fealty to either the substantive basic tenets of clinical medicine or simple human compassion. It is inconceivable that those who profess to care about and care for other people would find such a circumstance palatable or even tolerable. It is certainly imaginable that a state of affairs could come about in which the ability to intervene in a medically effective manner was unavailable. Even then, failing to offer some form of help would be unsupportable. If we accept this as a statement of both belief and purpose, this of course raises the question of what to do when faced with such a dilemma.

I have previously alluded to the possibility that active intervention, up to and including euthanasia, may be acceptable in desperate situations. While some may think of this as an example of a Hobson's choice, I would suggest that it is not. If the available alternatives are a patient enduring suffering (such as unremitting air hunger or the pain from widespread bony metastases) or a (hopefully) quick and painless death, albeit at the hands of a physician or surrogate, which is better, not that either is truly preferable? I suspect that patients would more likely choose the latter course rather than the former. Both end in death, but one — euthanasia — has the advantage of neither abandoning nor ignoring suffering patients, and, while killing them,<sup>17</sup> has the virtue of compassion. While arguing for the potential moral acceptability of active euthanasia by physicians only under such extreme circumstances, it is also important to be cognizant of the relevance of the “slippery slope” argument that has frequently been advanced against any form of euthanasia. It would be all too easy for the definition of the dire straits justifying such exceptional action to become blurred or to erode, such that it could become much easier to euthanize more and more patients whose suffering could be relieved by less onerous means. Even more troubling to contemplate would be the lure of using such an emergency policy to rid the institution of “undesirables” of one sort or another, such as undocu-

mented immigrants, for example.<sup>18</sup> If there were to be any type of formal declaration or an official policy to regulate and restrict active euthanasia, it should not be created without due considerations for these concerns. Even so, while I have suggested that, theoretically, euthanasia can be morally justified in such drastic (and, it is hoped, rare or nonexistent) conditions, its inclusion in widespread catastrophic healthcare disaster planning should not be undertaken lightly. But it should be undertaken. Ultimately, though, the best defense against having to resort to euthanasia in a last-ditch, forlorn attempt to relieve human suffering is a robust preparation and planning for palliative care.

Finally, let me consider some arguments against my thesis. One argument that could be made against my claim that the provision of palliative care should be obligatory in the setting of a prolonged health emergency, in which resources are severely constrained and must be rationed, is that, even under the best of circumstances during normal times, the availability of comprehensive palliative care is far from ideal. Hence, how can we impose a mandatory duty to provide this resource that we functionally treat as if it were optional or elective? The observation about the scatter-shot nature of palliative care services in the U.S. is most certainly true. But the failings of our healthcare system do not diminish the strength of my proposal for at least three reasons. First, the fact that the American delivery of healthcare is neither democratic, nor comprehensive, nor fair, is not a convincing argument against the necessity for many services that most people would consider as vital components of basic healthcare, especially those who take seriously the proposition that the provision of a reasonable level of healthcare is a human right. Second, even if palliative care could be considered as a luxury rather than a component of routine care, the conditions constituent of a prolonged emergency make the relief of suffering, principally in those who are relegated to non-curative care, a primary moral objective, especially if the alternative is no treatment whatsoever: the choice is unconscionable. Lastly, providing accessible and effective palliative care provides the stron-

gest defense against resorting to active euthanasia as a possible option in a desperate attempt to alleviate pain and suffering for the dying. While euthanasia could be considered to be a legitimate alternative, and even morally justifiable should there be no other choices available, this does not have to be the case. Indeed, viewing palliative care in these dire circumstances as obligatory, and hence something to be prepared to deliver, avoids having to even consider such morally egregious choices as euthanasia.

### CONCLUSION

I have argued that the delivery of expert palliative care is a necessity, not a luxury, during an overwhelming healthcare catastrophe. It is so by virtue of the primary calling of medicine to relieve the suffering of patients, as well as having entered into the standard of care in most of the developed world.<sup>19</sup> Therefore, it should be a requirement of healthcare facilities and providers to make it available and deliverable. As a result, this would necessitate a radical reworking of most hospitals' disaster preparedness plans, thus leaving them well prepared to perhaps not save each of the injured and ill, but certainly to care for all. Not making palliative care obligatory in such circumstances could lead to situations in which doctors' only choice to alleviate pain would be to either ignore the suffering of the ill and dying or to turn to euthanasia, an outcome that no one would want, and a moral calamity.

### NOTES

1. <http://www.flu.gov/professional/states/tr319.html>, accessed 5 November 2010.

2. T. Quill, quoted in S. Okie, "Dr. Pou and the hurricane — implications for patient care during disasters," *New England Journal of Medicine* 358 (2008): 1-5. By specifically referring to this case, I by no means wish to imply any assignment of responsibility or blame to Dr. Pou or her colleagues for the events that transpired at Memorial Hospital. Far from it. My point is that what happened there vividly illustrates the immense medical and moral challenges raised by a healthcare catastrophe, and,

most particularly, the harrowing choices that may exist.

3. For example, D.B. White et al., "Who Should Receive Life Support During a Public Health Emergency? Using Ethical Principles to Improve Allocation Decisions," *Annals of Internal Medicine* 150 (2009): 132-8; B.I. Truman et al., "Pandemic influenza preparedness and response among immigrants and refugees," *American Journal of Public Health* 99, suppl. 2 (2009): S278-86; New York State Department of Health, "New York State Department of Health Pandemic Influenza Plan," 2008, <http://www.health.state.ny.us/diseases/communicable/influenza/pandemic/plan/>, accessed 5 November 2010; D. Talmor et al., "Simple triage scoring system predicting death and the need for critical care resources for use during epidemics," *Critical Care Medicine* 35 (2007): 1251-6.

4. White et al., see note 3 above.

5. E.D. Pellegrino, *Humanism and the Physician* (Knoxville: University of Tennessee Press, 1979); E.D. Pellegrino and D.C. Thomasma, *A Philosophical Basis of Medical Practice* (New York: Oxford University Press, 1981); E.D. Pellegrino and D.C. Thomasma, *The Virtues of Medical Practice* (New York: Oxford University Press, 1993).

6. This statement does not by any means imply that all, or even a majority, of physicians in the U.S. are adequately trained or experienced in delivering effective symptom relief and palliative care, although the situation is improving. For example, see D.L. Johnston et al., "Availability and Use of Palliative Care and End-of-Life Services for Pediatric Oncology Patients," *Journal of Clinical Oncology* 26 (2008): 4646-50; B. Breuer et al., "Pain management by primary care physicians, pain physicians, chiropractors, and acupuncturists: a national survey," *Southern Medical Journal* 103: (2010): 738-47; M.E. Billings et al., "Medicine residents' self-perceived competence in end-of-life care," *Academic Medicine* 84 (2009): 1533-9; M. Grant et al., "Current status of palliative care — clinical implementation, education, and research," *CA: A Cancer Journal for Clinicians* 2009; 59 (2009): 327-35.

7. D. Clark, "From margins to centre: a review of the history of palliative care in cancer," *Lancet Oncology* 8 (2007): 430-8.

8. C. Faull, "The Context and Principles of Palliative Care," chap. 1, and D. Willis, "Ethical Issues in Palliative Care," chap. 5, in *Handbook of Palliative Care*, 2nd ed., ed. C. Faull et al. (Oxford, U.K.: Blackwell, 2005).

9. S.A. Norton et al., "Proactive palliative care in the medical intensive care unit: effects on length

of stay for selected high-risk patients,” *Critical Care Medicine* 35 (2007): 1530-5; C.L. Hough et al., “Death rounds: end-of-life discussions among medical residents in the intensive care unit,” *Journal of Critical Care* 20 (2005): 20-5; A. Elsayem et al., “Palliative Care Inpatient Service in a Comprehensive Cancer Center: Clinical and Financial Outcomes,” *Journal of Clinical Oncology* 22 (2004): 2008-14; J.S. Temel et al., “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *New England Journal of Medicine* 363 (2010): 733-42.

10. See <http://www.aahpm.org/certification/abms.html>, accessed 10 September 2010.

11. D.M. Studdert et al., “Medical Malpractice,” *New England Journal of Medicine* 350 (2004): 283-92. This point holds true unless one is a prisoner of the legal system, in which case the Supreme Court of the United States has ruled that prisoners must be provided with healthcare to avoid violating their Eighth Amendment rights; whether this actually happens is another matter (see *Estelle et al. v. Gamble*, 429 U.S. 97, Supreme Court of the United States).

12. P.M. Rosoff, “A central role for palliative care in an influenza pandemic,” *Journal of Palliative Medicine* 9 (2006): 1051-3.

13. It should be noted that most (if not all) hospitals are loath to adopt this practice because of the expense this would entail, not only for the purchase of supplies and equipment that might not ever be used, as they would be bought for contingently, but also for the availability and maintenance of storage facilities and the stock itself.

14. For example, see Ontario Ministry of Health, “Ontario Health Plan for an Influenza Pandemic,” 2008, [http://www.health.gov.on.ca/english/providers/program/emu/pan\\_flu/pan\\_flu\\_plan.html](http://www.health.gov.on.ca/english/providers/program/emu/pan_flu/pan_flu_plan.html), accessed 5 November 2010; H.J. Roberts et al., “Pandemic influenza — how would you and your hospital cope?” *Clinical Medicine* (London, England) 7 (2007): 76-8.

15. See note 2 above.

16. It should be noted that these medical assumptions might be quite incorrect. For instance, the experience at my institution this past year with H1N1-associated respiratory failure suggests that very ill patients may need prolonged ventilation lasting weeks, often on oscillator-type machines that generally need patients to be paralyzed and heavily sedated. Furthermore, some patients may fail regulator ventilation and, if the resources are available, may be helped by ECMO. (S.G. Norfolk et al., “Rescue therapy in adult and pediatric patients with pH1N1 influenza infection: A tertiary center inten-

sive care unit experience from April to October 2009,” *Critical Care Medicine* 38 (2010): 2103-7). On the other hand, in a true major pandemic with resource shortages, ECMO, which is already only available in selected centers throughout the country, is likely to be used rarely, if at all. Finally, a number of plans for pandemic flu have suggested a “window of therapeutic opportunity” trial such that those patients who do not improve, or whose condition worsens, over a defined period of time (e.g., 48 to 96 hours) will have withdrawal of support. Hence, the period of time without pain medication and/or sedatives would be relatively limited. But the caution still has merit: being chemically paralyzed on a ventilator even for just a few days without the benefit of strong sedation would be horrible.

17. While the use of this term may be offensive, it does explicitly label the action I am discussing for what it is: the intentional (albeit one hopes with the best of intentions) killing of another human being. Under such circumstances it is difficult to also call this murder, but killing it most definitely is.

18. P.M. Rosoff and M. DeCamp, “Preparing for an influenza pandemic: Are some people more equal than others?” *Journal of Healthcare for the Poor and Underserved* (in press, 2011).

19. Of course, the fact that palliative care is (or should be) provided to all patients, as a matter of course, does not mean that is so, in either the developed or the developing world, anymore so than any other form of healthcare.

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# Taking Seriously the "What Then?" Question: An Ethical Framework for the Responsible Management of Medical Disasters

*Laurence B. McCullough*

## ABSTRACT

When healthcare resources become overwhelmed in medical disasters, as they inevitably will, we have to ask, in an unflinching fashion, the question: "What then?" or more precisely, "What should we do when we run out of resources?" In a mass casualty event worthy of the designation, we will indeed run out of resources, perhaps quite quickly. This article provides an ethical framework for the responsible management of medical disasters in which the "What then?" question must be asked. The framework begins with a critique of existing guidance from professional associations of physicians and then argues for an alternative approach that qualifies the obligation to preserve life, takes seriously the ethical challenges of overwhelmed healthcare resources, and countenances physician-assisted suicide as a last resort.

## INTRODUCTION

The ethics of responding to mass casualty events is a current controversy in planning for

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and managing medical disasters. This article will focus on medical disasters that overwhelm existing healthcare resources, even those of a very well-resourced entity such as the Texas Medical Center, where I teach. When healthcare resources become overwhelmed, we have to ask, in an unflinching fashion, the question: "What then?" The purpose of this article is to provide an ethical framework for the responsible management of medical disasters in which the "What then?" question must be asked. Ethical reasoning should be comprehensive; we should think ethical challenges all the way through, being open to arriving at conclusions we do not expect or that might even be unwelcome, as will be the case for the responsible management of medical disasters.

## DEFINITIONS AND STANDARDS

There is emerging in the literature on the response to mass casualties a set of definitions and standards. Two major contributors to this literature are the World Medical Association<sup>1</sup> and a consortium of the American College of Emergency Physicians, the American College of Surgeons Committee on Trauma, the American

Trauma Society, and other professional associations, that put forth the SALT triage decision-making process (SALT is an acronym for sort, assess, life-saving interventions, treatment and/or transport).<sup>2</sup>

The American College of Emergency Physicians has defined a medical disaster succinctly: “A medical disaster occurs when the destructive effects of natural or man-made forces overwhelm the ability of a given area or community to meet the demand for health care.”<sup>3</sup> In its “Statement on Medical Ethics in the Event of Disasters,” the World Medical Association (WMA) defines a disaster in greater detail:

The definition of a disaster for the purpose of this document focuses particularly on the medical aspects. A disaster is the sudden occurrence of a calamitous, usually violent, event resulting in substantial social disruption. This definition excludes situations arising from conflicts and wars, whether international or internal. . . . From the medical standpoint, disaster situations are characterized by an acute and unforeseen imbalance between the capacity and resources of the medical profession and the needs of survivors who are injured whose health is threatened, over a period of time.<sup>4</sup>

The WMA elaborates further, identifying five features of disasters:

2. Disasters, irrespective of cause, share several features:
  - a. their sudden and unexpected occurrence, demanding prompt action;
  - b. material or natural damage making access to survivors difficult and/or dangerous;
  - c. adverse effects on health due to pollution, and the risks of epidemics, and emotional and psychological factors;
  - d. a context of insecurity requiring police or military measures to maintain order;
  - e. media coverage.<sup>5</sup>

There is consensus that mass casualty triage will be necessary in medical disasters, because the

medical needs of patients will outstrip the available resources. The WMA states: “Triage must be carried out systematically, taking into account the medical needs, medical intervention capabilities and available resources.”<sup>6</sup> However, as the SALT Mass Casualty Triage statement notes, there is an “insufficient evidence base” for selecting one system of triage over others.<sup>7</sup>

### **AN ETHICAL FRAMEWORK FOR THE RESPONSIBLE MANAGEMENT OF MEDICAL DISASTERS**

In such circumstances, judgments must be made about the triage or other criteria that should guide clinical judgment, decision making, and action in patient care, as well as organizational policy. Ethics is an essential component of making such needed judgments in a disciplined and responsible fashion. I turn now to the first step in articulating the needed ethical framework: an ethical analysis and critique of the WMA and SALT criteria. This will set the stage for the second step: an argument for an alternative that takes seriously the central fact about mass casualty events: organizational resources will be overwhelmed, perhaps very quickly.

#### **Critical Assessment of WMA and SALT Triage Criteria**

The WMA proposes the following priority for triage in a disaster, that is, a mass casualty event:

3. The physician should separate patients into categories and then treat them in the following order, subject to national guidelines:
  - a. patients who can be saved but whose lives are in immediate danger . . . ;
  - b. patients whose lives are not in immediate danger and who are in need of urgent but not immediate medical care . . . ;
  - c. injured persons requiring only minor treatment . . . ;
  - d. psychologically traumatized individuals who do not require treatment for bodily harm but might need re-

assurance or sedation if acutely disturbed;

- e. patients whose condition exceeds the available therapeutic resources, who suffer from extremely severe injuries such as irradiation or burns to such an extent and degree that they cannot be saved in the specific circumstances of time and place, or complex surgical cases requiring a particularly delicate operation which would take too long, thereby obliging the physician to make a choice between them and other patients . . .”<sup>8</sup>

The SALT Mass Casualty Triage statement has a set of criteria that differ:

1. “Immediate”: “Patients who do not obey commands, or do not have a peripheral pulse, or are in respiratory distress, or have uncontrolled major hemorrhage . . . ;”
2. “Expectant”: “Patients who do not obey commands, or do not have a peripheral pulse, or are in respiratory distress, or have uncontrolled major hemorrhage . . .” and whose injuries “are likely to be incompatible with life given the currently available resources . . . ;”
3. “Delayed”: A third group, defined as not being in any of the other four. This group appears to be defined as patients with injuries or conditions that are not immediately life-threatening and are such that they can tolerate some period of time before intervention without increasing mortality;
4. “Minimal”: “Patients who have mild injuries that are self-limited if not treated and can tolerate a delay in care without increasing their risk of mortality . . . ;”
5. “Dead”: “Patients who are not breathing even after lifesaving interventions are attempted.”<sup>9</sup>

Implicit in these triage criteria is the ethical concept of the physician and the healthcare organization as fiduciaries of patients. The ethical concept of the physician as a fiduciary was invented by two British physician-ethicists at

the end of the 18th century, John Gregory (1724-1773) of Edinburgh, Scotland, and Thomas Percival (1740-1804) of Manchester, England. They invented the concept of the physician as the fiduciary of the patient in response to the mistrust of physicians and surgeons that had emerged over many centuries and reached a crisis point in the mid to late 18th century in Britain (and colonial America and other countries, as well).<sup>10</sup>

The ethical concept of the physician as fiduciary has three components:

1. The physician should be intellectually and clinically competent: routinely base clinical judgment, decision making, and behavior on the best available evidence;
2. The physician should use his or her knowledge and skills primarily to protect and promote the health-related interests of patients and keep self-interest systematically secondary; and
3. Physicians should maintain and pass on medicine to future physicians and patients as a public trust that exists primarily to benefit present and future patients (making research a major component of professional responsibility), not as a private guild concerned primarily to protect the economic and other self-interests of its members.<sup>11</sup>

The central health-related interest of patients is the preservation of life. The physician therefore has a fiduciary obligation to undertake clinical management that the best available evidence supports as reducing the risk of mortality. There is a parallel fiduciary obligation in public health ethics: to reduce the risk of mortality in a target population.

This fiduciary commitment to reduce mortality in the population of patients that will be created in a disaster is reflected in the WMA statement, which states that the goal of any reliable triage policy should be to “save the maximum number of individuals.”<sup>12</sup> The SALT statement’s apparent rationale is that resource use should be aimed at benefiting the largest number of individuals.<sup>13</sup> Moskop and Iserson, in their excellent analysis of the ethics of triage, point out, correctly, that this commitment

to reducing mortality in a disaster is consistent with allowing some patients to die.<sup>14</sup>

Moskop and Iseron identify two additional ethical considerations that form the justification for triage in disasters. The first is efficient use of resources. A reliable triage policy should “direct resources to the care of those patients whose needs are great and for whom treatment is likely to be successful, and . . . withhold resources from those patients who are not likely to benefit significantly from treatment. . . .”<sup>15</sup> The second is fairness or justice, which concerns both fair procedures of decision making and a fair outcome of decision-making processes. “Because triage decisions are made according to established rule,” they prevent “unfairness of decisions made arbitrarily or on the basis of personal prejudice.”<sup>16</sup> The outcome of triage policies is substantively fair, because it is based on public health ethics, the maximal reduction of mortality in a population of patients affected by a disaster.

Moskop and Iseron also, very usefully, identify ethical considerations that are discounted in a reliable triage policy.<sup>17</sup> These are three crucial respects in which the rules do indeed change in triage management of a mass casualty event. The first is patient autonomy, the patient’s right to participate in the informed consent process, and the obligation of the physician to undertake only that clinical management authorized by the patient. Triage management of a mass casualty event will eliminate these aspects of the informed consent process. The only remaining component will be informing patients of their status and what will or will not be done. Negotiation of alternatives will not be practical and therefore should not be part of triage management in a mass casualty event. The second is fidelity, the “unqualified commitment to any individual patient.”<sup>18</sup> The health-related needs of the population will become the focus of fiduciary responsibility, not the health-related needs of each individual patient. The third is ownership of resources. Consideration of who owns healthcare resources becomes irrelevant in triage decision making. In particular, wealth, and the influence and power it is known to command in hospitals, become irrelevant.

Both the WMA and the SALT Mass Casualty Triage statements make two mistakes, the identification and correction of which leads to a different set of ethically justified triage criteria than those set forth in the two statements. The first mistake is that both statements understand public health ethics to be based on a fiduciary obligation to reduce mortality. This fiduciary obligation is taken from patient care ethics. The mistake is to think that the health-related interests of an individual patient or a population of patients is the reduction of mortality *simpliciter*, that is, without qualification. This lack of qualification ignores the hard-won, indispensable lesson of critical care ethics over the past three decades: not every reduction of mortality in patient care is worth the disease/injury-related and iatrogenic morbidity, lost functional status, pain, distress, and suffering that result for an individual patient.

The public health ethics version of this lesson is that not every reduction of mortality in patient care is worth the disease/injury-related and iatrogenic morbidity, lost functional status, pain, distress, and suffering that result for a population of patients. The fiduciary obligation to reduce mortality in a population of patients resulting from a disaster must take this lesson into account. Failure to do so will result in unacceptable opportunity costs, that is, using resources for a patient not likely to benefit and denying access to those resources by patients who could clinically benefit from intervention.

The second mistake is that both the WMA and SALT Mass Casualty Triage statements do not take seriously a key component in the definition of a medical disaster: the inability of resources to meet the medical needs of all patients who are affected by a disaster. This inadequacy of resources, after all, is crucial for the invocation of triage, which otherwise is not required. Comprehensive ethical reasoning, that is, thinking an ethical issue all the way through, no matter how uncomfortable the conclusion may be, requires us to ask, “What then?” or, more precisely, “What should we do when we run out of resources?” In a mass casualty event worthy of the designation, the “What then?” question will be inevitable and unavoidable.

### **Argument for Alternative Ethical Criteria for the Responsible Management of Medical Disasters**

The replacement of an unqualified fiduciary obligation to reduce mortality in a population of patients resulting from a disaster with a fiduciary obligation qualified by the hard-won lessons of critical care ethics requires that the category of “expectant” patients be removed from the prioritization scheme. This is because treatment of these patients is highly likely to result either in death preceded by significant morbidity, lost functional status, and pain; in distress or suffering; or in survival with these ethically dubious (at best)/unacceptable (at worst) complications. Hospital triage policy for a disaster should apply this revised prioritization, not only to patients in the emergency department, but all patients in the hospital. There are in hospitals in the United States many “expectant” patients in critical care beds, the continuing treatment of whom does not create many, or many unmanageable, opportunity costs on a daily basis. In medical disasters, the continued use of critical care beds for these patients will create ethically unacceptable opportunity costs, that is, denial of access to those beds by patients with triage priority. These unacceptable opportunity costs will render the SALT triage criteria self-defeating. Life-sustaining treatment should not be initiated/should be discontinued for all expectant patients. The triage standard for expectant patients should be comfort/hospice care. It is worth noting that the WMA criteria do not include an “expectant” category. The WMA statement implicitly accepts the idea that fiduciary responsibility is to reduce mortality with qualifications. Ethically adequate policy, however, cannot rely on implicit concepts, but only on explicitly identified concepts and arguments based on them.

The “What then?” question will relentlessly press itself on us in a large-scale medical disaster. When the resources required to meet a priority are exhausted, fiduciary responsibility to the population of remaining patients requires that that priority should then be eliminated from a triage policy. In a mass casualty event, we should, therefore, expect that the resources re-

quired to meet the medical needs of the highest priority patients in both the WMA and SALT triage schemes will become exhausted, perhaps quite rapidly. At that time, the category of what SALT calls “immediate” should be removed from the prioritization. The standard of care for all patients remaining in this category should be palliative/hospice care.

Next, we should expect that the resources required to meet the medical needs of patients in the subsequent priority groups will also become exhausted. At that time, the categories of what SALT calls “delayed” and “minimum” should be removed from the prioritization. The standard of care for these patients should be palliative care, and informing them that the attempt to reduce the risk of morbidity and disability from intervention will not occur.

In the ethically worst — that is, very large-scale — disaster, we should, finally, expect that the resources required to provide palliative care will be exhausted. Fiduciary responsibility will then justifiably focus on those patients already in the emergency center and hospital. For them, we should do the best we can. For the injured or sick who are still arriving, there will be nothing to offer, at which point the emergency department and hospital should be locked down.

There will remain one question, “Should there be a role for physician-assisted suicide for gravely ill patients when the resources for palliative/hospice care are exhausted?” In addressing this question, we would do well to keep in mind that Dr. Gregory, the co-inventor of the ethical concept of the physician as fiduciary, argued that this concept created an ethical obligation of the physician to “smooth the avenues of death.”<sup>19</sup> In his day, that meant helping patients procure laudanum, self-overdosing with which was a common form of painless suicide. This has implications for the hospital formulary that an ethically comprehensive triage policy needs to address.

### **CONCLUSION**

In this article, I have attempted to articulate an ethical framework for the responsible management of medical disasters. For such a frame-

work to be adequate to the scale of large-scale disasters, the challenging but unavoidable question, “What, then?” must be asked. More precisely, an adequate ethical framework must provide a reliable answer to the question, “What should we do when we run out of resources?”

The ethical framework proposed in this article has three components. There is a fiduciary obligation to reduce mortality in the affected population under the constraint of preventing unacceptable opportunity costs, not a fiduciary obligation to reduce mortality in the affected population, *simpliciter*. When the resources required to meet a priority are exhausted, that priority should be eliminated from the triage decision-making process. When the resources required to meet the last remaining priority of palliative care are exhausted, the facility should be locked down and we should do the best we can. There will remain one ethically challenging question: Should there be a role for physician-assisted suicide?

This framework supports the responsible management of medical disasters. I have chosen the words “management” and “responsible” deliberately. “Management” in one of its meanings refers to the well-managed horse, a horse that has been broken and tamed for riders. Experienced equestrians know, however, that even a very well-managed horse can revert to its wild state and throw its rider without warning. The time to ask “What then?” is not while one is on one’s way to the ground, under the relentless force of gravity. It is before one gets on the horse. About medical disasters we need to ask and answer the “What then?” question before we are subjected to the relentless overwhelming of resources that will occur in a large-scale medical disaster.

“Responsible” means that we have sufficient justification for our judgments and the decisions and behaviors based on them. Making judgments is the process of classifying things, events, and people in ways, on the basis of which, we can act with confidence that we have good reasons for the classification. Judgments are not a matter of getting the classification right, or, as philosophers would put it, achieving a justified, true belief. A justified belief will do. This has

important policy implications. After a large-scale medical disaster has unfolded some day in some city in the United States, we should, in retrospective assessment, hold our clinical colleagues and the leaders and managers of our healthcare organizations to an uncomplicated standard: As the resources for each category of patients ran out and finally when those resources ran out altogether, “Did they do the best that they could?” Those who ask, instead, “Did they do the right thing?” should be asked, and if necessary, politically forced, to become silent.

### ACKNOWLEDGMENT

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### NOTES

1. World Medical Association, “Statement on Medical Ethics in the Event of Disasters,” adopted 1994, revised 2006, <http://www.wma.net/en/30publications/10policies/d7/index.html>, accessed 1 September 2010. No pagination.

2. “SALT Mass Casualty triage: concept endorsed by the American College of Emergency Physicians, American College of Surgeons Committee on Trauma, American Trauma Society, National Association of EMS Physicians, National Disaster Life Support Education Consortium, and State and Territorial Injury Prevention Directors Association,” *Disaster Medicine and Public Health Preparedness* 2, no. 4 (2008): 245-6.

3. American College of Emergency Physicians, “Disaster Medical Services,” originally approved 1985, reaffirmed 1997, revised 2000, reaffirmed 2006, [www.acep.org/PrintFriendly.aspx?id=29176](http://www.acep.org/PrintFriendly.aspx?id=29176), accessed 1 September 2010. No pagination.

4. See note 1, above.

5. *Ibid.*

6. *Ibid.*

7. See note 2, above, p. 245.

8. See note 1, above.

9. See note 2, above, p. 246.

10. L.B. McCullough, *John Gregory and the Invention of Professional Medical Ethics and the Profession of Medicine* (Dordrecht, The Netherlands: Kluwer Academic Publishers, 1998).

11. L.B. McCullough, “The Ethical Concept of Medicine as a Profession: Its Origins in Modern Medical Ethics and Implications for Physicians,” in *Lost Virtue: Professional Character Development in Medical Education*, ed. N. Kenny and W. Shelton (New York: Elsevier, 2006), 17-27.

12. See note 1, above.

13. See note 2, above.

14. J.C. Moskop and K.V. Iserson, “Triage in Medicine, Part II: Underlying Values and Principles,” *Annals of Emergency Medicine* 49, no. 3 (March 2007): 282-7.

15. *Ibid.*, p. 283.

16. *Ibid.*, p. 283.

17. *Ibid.*

18. *Ibid.*, p. 283.

19. J. Gregory, *Lectures on the Duties and Qualifications of a Physician* (London: W. Strahan and T. Cadell, 1772), 35. Reprinted in L.B. McCullough, ed., *John Gregory’s Writings on Medical Ethics and Philosophy of Medicine* (Dordrecht, The Netherlands: Kluwer Academic Publishers, 1998), p. 175.

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# Legal Briefing: Crisis Standards of Care and Legal Protections during Disasters and Emergencies

*Thaddeus Mason Pope and Mitchell F. Palazzo*

Readers who learn of cases, statutes, or regulations that they would like to have reported in this column are encouraged to e-mail Thaddeus Pope at [tmpope@widener.edu](mailto:tmpope@widener.edu).

## ABSTRACT

This article outlines current safe harbors in the law for healthcare practitioners who work in a disaster setting. It reviews available legal protection in crisis situations with respect to the Emergency Medical Treatment and Labor Act (EMTALA), criminal liability, and licensure.

## INTRODUCTION

The devastation of Hurricane Katrina caused more than 100 deaths in hospitals and nursing homes that were unable to handle disaster con-

ditions. This resulted in roughly 200 lawsuits against these institutions, primarily claiming negligence and medical malpractice.<sup>1</sup> A recent outbreak of influenza A subtype H1N1 has once again raised the issue of healthcare providers' liability during an emergency. Many providers have been wondering, "What exactly is our liability during a crisis or disaster?"

There are many different types of disaster scenarios. The threat to health can come from, among other sources: (1) infectious diseases (for example, SARS — severe acute respiratory syndrome, H1N1, or other emerging or reemerging infectious diseases), (2) natural disasters (for example, Hurricane Katrina, floods in the U.S. Midwest, earthquakes), (3) major industrial accidents (for example, nuclear energy reactors, hazardous substances), or (4) even terrorist attacks (for example, 11 September 2001, anthrax, sarin gas). Common to all these scenarios is the likelihood that the demand for healthcare resources will exceed capacity, such that hospitals will be unable to adequately meet the medical needs of the affected community. A recent article in *JCE* discussed triage protocols for emergency situations.<sup>2</sup>

Because a healthcare surge makes it difficult or impossible to meet an affected commu-

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nity's medical need, the surge also makes it difficult or impossible to comply with several types of standard legal obligations. First, shortages of staff and resources make it difficult for providers to use standard procedures, risking malpractice liability. Second, a risk of liability is created under EMTALA, when emergency departments are over capacity to screen and stabilize victims. Third, to help expand capacity, providers may travel from other states to give assistance. Once they cross state borders, however, new legal issues, such as licensing and privileging, arise. In short, as Koenig and Schultz stated, "Catastrophic disasters . . . challenge the legal basis of the medical system. Compliance with some legal requirements becomes impossible. . . ." <sup>3</sup> Healthcare providers across the United States are concerned about their rights and duties during a disaster. Unfortunately, their concerns are well-grounded.

In the past five years, experts from a range of disciplines have devoted significant effort to developing disaster plans. There are now more than a few federal <sup>4</sup> and state government reports <sup>5</sup> that outline frameworks for allocating scarce resources in disaster situations. The reports delineate the clinical and ethical considerations to be used in emergencies. In addition, hospitals are required to develop and maintain disaster plans by Joint Commission accreditation standards, <sup>6</sup> by Medicare Conditions of Participation, <sup>7</sup> and by state licensing regulations. <sup>8</sup>

Unfortunately, laws governing the delivery of medical treatment have not kept pace. Following the standards and guidelines regarding triage and allocation included in many disaster plans could raise liability concerns. Gostin described one plan, prepared by a task force for mass critical care, <sup>9</sup> as "a legal minefield" that would most likely violate federal antidiscrimination laws. <sup>10</sup> For example, not treating someone older than 85 (age is a common triage factor), probably violates both EMTALA and non-discrimination statutes. As Hodge and Courtney noted, "Facing a precarious liability landscape, legal clarity . . . is needed." <sup>11</sup>

This clarity is needed not only for the good of healthcare providers, but also for the good of the community. The absence of legal protections

may seriously impede efforts to encourage healthcare professionals to offer their services. <sup>12</sup> The need for legal certainty among providers is crucial to their participation during crisis circumstances. Hodge observed that some healthcare providers "will fail to act because of their legal concerns, which can stymie some public health interventions." <sup>13</sup> As Koenig and Schultz noted: "It is harder to act confidently if liability is a concern. The knowledge that authorities will grant a waiver of a compliance rule when a disaster has rendered compliance much more difficult would improve a responder's ability to care for patients." <sup>14</sup>

With these considerations in mind, this article outlines current safe harbors in the law for healthcare practitioners who are working in a disaster setting. This legal briefing provides a landscape of the law, as it concerns disaster scenarios, and analyzes that law by dividing it into the following four topics:

1. Medical malpractice
2. Criminal liability
3. EMTALA
4. Licensure.

### MEDICAL MALPRACTICE

An emergency situation presents several potential medical malpractice scenarios. Changes in the usual standards of medicine may be necessary to save as many lives as possible. First, because of a lack of time and/or resources, providers may give treatment that is different from that which the "reasonably prudent physician" would normally provide. Second, providers may cease to treat some patients so that they can focus their time or resources elsewhere. They may, for example, withdraw life support without consent from a patient who is expected to have a lower chance of survival. Third, providers may refuse to treat patients outright. In short, in a disaster scenario, the focus may change from doing the best for each patient to maximizing the most lives saved. <sup>15</sup>

The first scenario may give rise to ordinary negligence claims. Deviation from the normal standard of care need not give rise to malpractice liability in crisis situations. The negligence

standard of care — to act in the same manner as a reasonably prudent physician would in similar circumstances — bends the law to the scenario. Therefore, it is possible that healthcare practitioners will be protected under the normal negligence standard.<sup>16</sup> This standard does not provide blanket security, however, and the standard of care in an emergency situation is open to interpretation. As Gostin and colleagues stated, experience has shown that “existing medical standards of care are not sufficiently flexible to encourage healthcare professionals to act appropriately and decisively in a public health emergency.”<sup>17</sup>

The second scenario opens up liability concerns regarding claims of abandonment. A physician may not discontinue treatment of a patient as long as further treatment is medically indicated without giving the patient reasonable assistance and sufficient opportunity to make alternative arrangements for care.<sup>18</sup> The third scenario runs afoul of EMTALA and its state counterparts.

Several federal and state laws, however, provide protections for healthcare practitioners in crisis circumstances. These laws include: (1) the Model State Emergency Health Powers Act, (2) the Federal Volunteer Protection Act, (3) the Uniform Emergency Volunteer Health Practitioners Act, (4) state good Samaritan laws, and (5) governmental immunity laws.<sup>19</sup>

### **Model State Emergency Health Powers Act**

The Model State Emergency Health Powers Act (MSEHPA) is a piece of proposed legislation that was drafted in 2001, by the Center for Law and the Public’s Health at Georgetown and Johns Hopkins Universities. MSEHPA provides protections for volunteers who are appointed by a public health authority.<sup>20</sup> According to the Center for Law and the Public’s Health, 38 states and Washington, D.C., have passed bills that mirror language in MSEHPA.<sup>21</sup> MSEHPA gives civil liability protection, except in the instance of willful misconduct or gross negligence, to those persons or entities who give assistance at the request of the state or other health authority.<sup>22</sup> This immunity includes liability protection from property and contract claims.<sup>23</sup>

But while MSEHPA grants broad protection, it is limited. MSEHPA is triggered only once a state government requests help from a healthcare practitioner. Therefore, it does not provide protection for hospital employees acting in their normal capacity. For example, MSEHPA would not have protected Anna Pou, MD, or other providers at New Orleans’s Memorial Medical Center who were working as on-duty staff physicians. On the other hand, several states have materially broader immunity provisions in their public health emergency statutes.<sup>24</sup>

### **Federal Volunteer Protection Act**

Like MSEHPA, the Federal Volunteer Protection Act (VPA), enacted in 1997, provides liability protection for volunteers. But instead of protecting volunteers who are appointed by a public health authority, VPA protects volunteers at nonprofit organizations.<sup>25</sup> Protection is afforded if: (1) the volunteer was working within the scope of her or his duty for the nonprofit during the emergency, (2) the volunteer was properly licensed, and (3) the volunteer did not perform criminal or willful misconduct, gross negligence, recklessness, or flagrant disregard to the safety of the victim.<sup>26</sup>

Like MSEHPA, however, the scope of protection afforded by VPA is limited. First, like MSEHPA, VPA protects only volunteers, not healthcare providers working in their regular non-emergency roles and capacities. Second, a nonprofit or any government agent can still bring civil claims against a volunteer. Third, VPA does not preempt certain state laws that put conditions on volunteers such as: risk management requirements, vicarious liability, and a financially secure form of recovery for intended victims.<sup>27</sup>

### **Uniform Emergency Volunteer Health Practitioners Act**

The Uniform Emergency Volunteer Health Practitioners Act (UEVHPA) provides liability and vicarious liability protection for those who do not commit willful misconduct or gross negligence.<sup>28</sup> UEVHPA has been enacted in Arkansas, Colorado, Illinois, Indiana, Kentucky, Louisiana, New Mexico, North Dakota, Oklahoma,

Oregon, Tennessee, Utah, the Virgin Islands, and Washington, D.C.<sup>29</sup> Connecticut, Georgia, Mississippi, and Washington State have introduced legislation that would adopt it.<sup>30</sup> But, like MSEHPA and VPA, liability protection under UEVHPA is limited.<sup>31</sup>

### **State Good Samaritan Laws**

Like MSEHPA, VPA, and UEVHPA, state good Samaritan laws also provide some liability protection.<sup>32</sup> Almost every state has some form of good Samaritan protection, both in common law and by statute. Generally, good Samaritan laws preclude liability for physicians who render medical assistance in good faith at the scene of an emergency. Many of these statutes were enacted in the 1970s and 1980s. Some states, however, such as Illinois and Nevada, have continued to update them in the last five years.<sup>33</sup>

Unfortunately, the effect and scope of good Samaritan laws vary dramatically from state to state.<sup>34</sup> Some states, such as Alaska<sup>35</sup> and Arizona,<sup>36</sup> include hospital settings as an emergency scene in their statutes. Kentucky,<sup>37</sup> Louisiana,<sup>38</sup> Ohio,<sup>39</sup> and Oregon,<sup>40</sup> on the other hand, expressly exclude hospitals from their statutes. Florida<sup>41</sup> and Illinois<sup>42</sup> specifically include declared emergencies, although Illinois's statute only provides protection for volunteers. The Nevada<sup>43</sup> and Oklahoma<sup>44</sup> statutes are drawn broadly to cover all emergency situations, although Oklahoma's statute requires that an act is done voluntarily and is required to prevent death or serious injury. Two states, Vermont and Minnesota, place an affirmative duty on citizens to render service to those in need.<sup>45</sup> Vermont's statute provides broad liability protection to those acting in an emergency. Minnesota's statute restricts immunity to volunteers and actions taken outside of the hospital setting.

While good Samaritan laws do provide some protections to healthcare practitioners, they also have several limitations. First, like MSEHPA and VPA, many good Samaritan statutes only apply to volunteers, and not all states have systems that allow healthcare providers to be designated as such.<sup>46</sup> Therefore, receiving compensation would take a provider outside the scope of the

statute.<sup>47</sup> Second, with the exception of those statutes noted above, most states only shield action taken at the scene of an accident.<sup>48</sup> Immunity would not extend to a hospital emergency room, or in the aftermath of an emergency, as normal conditions slowly return. Therefore, good Samaritan liability protection would apply to the more common good Samaritan action of assisting at the scene of a car crash, but not necessarily to treating individuals in the emergency department after a deadly hurricane or during pandemic influenza.

### **Model Intrastate Mutual Aide Legislation**

MSEHPA, VPA, UEVHPA, and good Samaritan laws afford immunity to volunteers on the basis of their volunteer status. In contrast, the Model Intrastate Mutual Aide Legislation (MIMAL) provides certain protections for healthcare professionals who work in other states during an emergency, by considering such providers as employees of the state government.<sup>49</sup> Drafted in 2004, the movement for mutual aide legislation has been growing. Currently, 15 states have passed, or are in the progress of passing, some sort of intrastate legislation.<sup>50</sup> These include Alabama,<sup>51</sup> Arizona,<sup>52</sup> Arkansas,<sup>53</sup> Connecticut,<sup>54</sup> Delaware,<sup>55</sup> Indiana,<sup>56</sup> Iowa,<sup>57</sup> Mississippi,<sup>58</sup> Montana,<sup>59</sup> North Dakota,<sup>60</sup> Ohio,<sup>61</sup> Oklahoma,<sup>62</sup> Oregon,<sup>63</sup> Virginia,<sup>64</sup> and Wisconsin.<sup>65</sup> The most recent legislation was passed in Arkansas in 2009.<sup>66</sup> As such, providers are not liable for death, injury, or property damage unless actions are done with willful misconduct or gross negligence or in bad faith.<sup>67</sup>

While MIMAL does provide valuable protection to those who go out of state to aide in an emergency, it is also subject to several pitfalls and limitations. First, the legislation is only triggered once an actual emergency has been declared. Second, there can be control and operational issues as the state receiving the aid gains authority over a worker who is giving aid. This transfer of power between states can be disconcerting, given the already existing confusion of a crisis scenario.<sup>68</sup> Finally, MIMAL is only as strong as the number of states that adopt it. Therefore, its greatest limitation is that it now only applies to 15 states.<sup>69</sup>

### **Emergency Management Assistance Compact**

Like MIMAL, the Emergency Management Assistance Compact (EMAC) allows the states entering the compact to provide mutual assistance during an emergency.<sup>70</sup> Currently every state, Washington, D.C., Guam, and Puerto Rico have signed into the agreement.<sup>71</sup> EMAC has several of the same effects and limitations as MIMAL. EMAC provides that responding officers of a state become the agents of the requesting state for tort liability and immunity purposes. It also states that these individuals will not be liable for acts or omissions rendered in good faith.<sup>72</sup> But EMAC does not provide liability protection for actions constituting willful misconduct, gross negligence, or recklessness. It also only becomes effective once an emergency has been declared and applies only to those responding providers who then become agents of the state. Furthermore, the EMAC places no obligation on participating states to actually provide aid.<sup>73</sup>

### **CRIMINAL LIABILITY**

While medical malpractice may be the most salient legal risk, it is not the only one that might inhibit providers from responding to an emergency. The highly publicized case of Anna Pou, MD, has brought to the forefront a different worry for healthcare providers practicing in disaster areas: criminal liability. Dr. Pou and two nurses were charged with four counts of murder following their role in relief efforts during Hurricane Katrina. Dr. Pou and the nurses were accused of administering morphine and midazolam to kill four elderly patients. A grand jury refused to indict Dr. Pou, but she still faces three civil suits brought by members of the families of the deceased.<sup>74</sup>

Criminal liability resulting from Katrina is not limited to Dr. Pou. Salvador and Mabel Mangano, owners of Saint Rita's Nursing Home, were charged with negligent homicide for failing to evacuate 34 residents when they were warned that the hurricane was going to hit. After a full criminal trial, the Manganos were acquitted of all charges.<sup>75</sup> However, the Manganos

still face more than 30 lawsuits stemming from the storm.

As discussed above, some state and federal laws afford some civil liability protection to providers under some circumstances. But no law provides criminal immunity. For example, sections 608 and 804 of MSEHPA extend only liability coverage for civil charges. MSEHPA does not mention criminal liability immunity.<sup>76</sup> Likewise, MIMAL also does not provide a criminal shield.<sup>77</sup> Furthermore, as noted previously, many of the acts granting civil protection do not extend to willful or reckless misconduct or gross negligence. Therefore, finding a provider guilty of reckless misconduct or gross negligence could lead to civil liability as well.

### **EMTALA**

EMTALA provides that hospitals and their on-call physicians must treat or screen all patients who seek emergency medical treatment.<sup>78</sup> When the U.S. Department of Health and Human Services (DHHS) and the President declare an emergency or disaster pursuant to the National Emergencies Act or the Stafford Act, however, DHHS can issue an "1135 waiver." This waiver "temporarily suspends sanctions for noncompliance with certain provisions under EMTALA."<sup>79</sup> The waiver generally lasts until the emergency that brought it into effect has been terminated, but the DHHS can request a 60-day extension of the waiver.<sup>80</sup>

An 1135 waiver does come with some limitations and requirements. Several conditions must be met for a hospital to receive an 1135 waiver to transfer patients who will be screened.<sup>81</sup> First, a transfer must be necessitated by the circumstances of the declared emergency in the emergency area during the emergency period. Second, the direction or relocation of an individual to receive medical screening at an alternate location must be pursuant to an appropriate state emergency preparedness plan, or, in the case of a public health emergency that involves a pandemic infectious disease, pursuant to a state pandemic preparedness plan. Furthermore, the hospital may not discriminate on the basis of an individuals' source of payment

or ability to pay. Also, the hospital must be located in an emergency area during an emergency period, as those terms are defined in section 1135(g)(1) of the act. Finally, there must be a determination that a waiver of sanctions is necessary.<sup>82</sup>

The EMTALA 1135 waiver provision allows a provider to transfer or relocate patients in violation of EMTALA, but does not grant a provider the broad privilege of simply turning patients away.<sup>83</sup> Furthermore, while an 1135 waiver can be implemented quickly, it does not apply to analogous state laws, which may be more restrictive.<sup>84</sup> Finally, it is important to note that there is no EMTALA exception to the duty to care when a patient poses a health risk to a physician.

### LICENSURE

Another issue confronting healthcare practitioners during a crisis scenario is licensure. This issue arises when providers are forced to act outside the scope of their licensed authority, due to lack of resources or staff. It also comes up when doctors move to new hospitals and act outside of the privileges granted to them. The federal Social Security Act allows for the modification of state licensing requirements. The only limitations are that a provider be licensed to practice in another state and is still qualified in that state.<sup>85</sup> Still, the modification of licensure requirements is primarily a matter for the individual states.<sup>86</sup>

### MSEHPA and EMAC

Licensure issues are addressed in MSEHPA section 608. One controversial section requires physicians, in order to be licensed, to administer vaccinations.<sup>87</sup> It also allows a healthcare authority to waive the requirements of licensure in the state.<sup>88</sup> Section 804 grants immunity to providers who act within their scope of power under the act.<sup>89</sup> As of 2006, there were 13 states that had adopted section 608 of MSEHPA, but some differ in which parts they have adopted.<sup>90</sup> For example, South Carolina has adapted the full text,<sup>91</sup> while Maryland states that the governor may order a healthcare provider to serve.<sup>92</sup>

The EMAC also allows for reciprocity of licensure between agreeing states. It has been sued nearly 100 times since 1999. Still, EMAC only applies to a declared emergency situation in which the governor of the state that receives assistance has requested help from the state that provides assistance. Furthermore, the reciprocity provision is also subject to any limitations or conditions the governor of the requesting state puts on the license.<sup>93</sup> MIMAL also provides for reciprocity amongst participating states.<sup>94</sup>

### Uniform Emergency Volunteer Health Practitioners Act

The Uniform Emergency Volunteer Health Practitioners Act also provides licensure protections. UEVHPA regulates services during an emergency, establishes a registry system, and recognizes registered providers who are licensed in other states.<sup>95</sup> UEVHPA, however, does have limitations. The licensure recognition does not apply when the provider's license has been suspended or revoked in any state.<sup>96</sup> It also does not prevent hospitals from granting or waiving privileges.<sup>97</sup> UEVHPA does not expand the scope of practice within which the provider is licensed, but allows the agency that the provider works for to expand or limit this scope. It also allows for sanctions and penalties to be imposed for unauthorized practice.<sup>98</sup>

### State Executive Orders

Some states have taken a different approach to disaster scenario preparation. Colorado, for example, has created a set of draft executive orders that are to be put into force during a healthcare emergency.<sup>99</sup> Most of these orders, which range from shifting licensing requirements to broadening the practice range of physician assistants and emergency medicine technicians, are similar to what other states have done by adopting the model acts referenced above. These orders are not actual laws, but would become effective only when the governor signs them at the time of an emergency.

In Maryland, the governor, after declaring a state of emergency, may "suspend the effect of any statute or rule or regulation."<sup>100</sup> Similarly, California allows the governor to suspend all

statutes during a state of war or emergency.<sup>101</sup> This also applies to regulations promulgated by any state agency. Thus, during a natural disaster or pandemic influenza, the Governor of California could completely suspend any licensing requirements if he or she feels that they would hinder mitigation of the effects of the emergency.

Despite the sometimes conflicting laws and potential legal liabilities, providers faced with people losing their lives may reasonably choose to err in trying to help save lives. There are several potential legal risks, but, as when providers act to help a patient instead of acting to protect themselves from suit, the law has tended to favor providers who put a patient's needs ahead of their own.

## NOTES

1. S. Fink, "The New Katrina Flood: Hospital Liability," *New York Times*, 31 December 2009, <http://www.nytimes.com/2010/01/03/weekinreview/03fink.html>, accessed 4 November 2010. Just which of these theories is correct has yet to be seen. One case, *LaCoste v. Pendleton Memorial Methodist Hospital*, was allowed to continue as a negligence case, instead of a medical malpractice case, which has a \$500,000 cap in Louisiana. The case was eventually settled, leaving many of the legal questions unanswered. "New Orleans Hospital Settles Post-Katrina Wrongful Death Lawsuit," *Insurance Journal*, 28 January 2010, <http://www.insurancejournal.com/news/southcentral/2010/01/28/106964.htm>, accessed 4 November 2010. A similar case against Methodist Memorial Hospital was settled after trial had begun. See A. Rios, "Katrina Wrongful Death Case Settles," *Southeast Texas Record*, 27 May 2010, <http://www.setexasrecord.com/news/227183-katrina-wrongful-death-case-settles>, accessed 4 November 2010.

2. C. Kaposy, "Accounting for Vulnerability to Illness and Social Disadvantage in Pandemic Critical Care Triage," *The Journal of Clinical Ethics* 21, no. 1 (Spring 2010): 23-29.

3. K.L. Koenig and C.H. Schultz, *Disaster Medicine: Comprehensive Principles and Practices* (Cambridge University Press, 2009), 151.

4. AHRQ, "Altered Standards of Care in Mass Casualty Events, Bioterrorism and Other Public Health Emergencies," 2005, [\[search/altstand/altstand.pdf\]\(http://search.altstand/altstand.pdf\), accessed 4 November 2010; Institute of Medicine, \*Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations: A Letter Report\* \(Washington, D.C.: National Academies Press, 2009\); "Brief Report : Terrorism and Emergency Preparedness in State and Territorial Public Health Departments — United States," \*MMWR\* 54, no. 18 \(2004\): 459; S.J. Phillips and A. Knebel, "Mass Medical Care with Scarce Resources: A Community Planning Guide," 2007, <http://www.ahrq.gov/research/mce/>, accessed 4 November 2010.](http://www.ahrq.gov/re-</a></p></div><div data-bbox=)

5. *Interim California Disaster Health Operations Manual*, 2009, <http://bepreparedcalifornia.ca.gov/NR/rdonlyres/2BAB4C5B-D482-4D94-BBBE-2E93ECC40C52/0/CDHOM10142009.pdf>, accessed 4 November 2010; R.E. Upshur et al., *Stand on Guard for Thee: Ethical Considerations in Preparedness Planning for Pandemic Influenza* (Toronto: University of Toronto Joint Centre for Bioethics, 2005), <http://www.jointcentreforbioethics.ca/>, accessed 4 November 2010; "Hospital Association of California Health Care Emergency Codes: A Guide for Code Standardization," 2009, <http://www.calhospitalprepare.org/category/content-area/emergency-codes>, accessed 4 November 2010; Florida Department of Health, "Pandemic Influenza: Triage and Scarce Resource Allocation Guidelines," 2009, [http://propublica.s3.amazonaws.com/assets/docs/ACS\\_GUIDE\\_Ver8.pdf](http://propublica.s3.amazonaws.com/assets/docs/ACS_GUIDE_Ver8.pdf), accessed 4 November 2010; "Critical Resource Shortages Planning Guide — Implementation Toolkit, Developed for Virginia Department of Health, Funded by Centers for Disease Control and Prevention Essential Services Grant #EHS25VA," 2009, <http://www.vdh.virginia.gov/criticalresource-shortagesplanning>, accessed 4 November 2010.

6. Joint Commission Standard MS 4.110 (2007).

7. 42 C.F.R. §§ 482.41 and 485.623. Some states also have similar provisions in their licensing requirements.

8. See 22 Cal. Code Regs. 71539(a) (2010).

9. L. Rubinson, "Definitive Care for the Critically Ill During a Disaster," *Chest* 133, no. 5 supp. (2008): 185-215.

10. L. Tanner, "Triage Plan Details Whom to Let Die During a Pandemic," *San Francisco Chronicle*, 5 May 2008, [http://articles.sfgate.com/2008-05-05/news/17153864\\_1\\_critical-care-task-force-health-care](http://articles.sfgate.com/2008-05-05/news/17153864_1_critical-care-task-force-health-care), accessed 4 November 2010.

11. J.G. Hodge, Jr. and B. Courtney, "Public Health Emergencies and Legal Standards of Care — Reply," *Journal of the American Medical Association* 303, no. 18 (12 May 2010): 1811-2.

12. S. Rosenbaum et al., "State Laws Extending Comprehensive Legal Liability Protections for Pro-

Professional Health-Care Volunteers during Public Health Emergencies,” *Public Health Reports* 123 (2008): 238-41.

13. J.G. Hodge, “Legal Triage during Public Health Emergencies and Disasters,” *Administrative Law Review* 58, no. 3 (2006): 627-644. Professor Hodge’s work in this area is extensive and authoritative. Readers looking to deepen and expand their research in this area should consult his latest work.

14. See Koenig and Shultz, note 3 above, p. 162. For example, the Disaster Response Committee of the American Red Cross had such strong concerns about the potential scope of liability that it instructed its Response of Recovery Division not to deploy volunteers during a pandemic influenza event without assuring adequate liability protection. See Koenig and Shultz, note 3 above, p. 153.

15. AHRQ, see note 4 above.

16. M.A. Rothstein, “Malpractice Immunity for Volunteer Physicians in Public Health Emergencies: Adding Insult to Injury,” *Journal of Law, Medicine and Ethics* 38, no. 1 (2010): 149-53; G.J. Annas, “Standard of Care — in Sickness and in Emergencies,” *New England Journal of Medicine* 363, no. 14 (2010): 1380.

17. L.O. Gostin et al., “Standard of Care — in Sickness and in Emergencies,” *New England Journal of Medicine* 363, no. 14 (2010): 1378-9.

18. *AMA Code of Medical Ethics*, Opinion 8.115, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8115.shtml>, accessed 4 November 2010.

19. S. Hoffman, “Responders’ Responsibility: Liability and Immunity in Public Health Emergencies,” *Georgetown Law Journal* 96, no. 6 (2008): 1913-69.

20. Model State Emergency Health Powers Act § 608(b)(3) (2001).

21. See Model State Emergency Health Powers Act, State Legislative Activity, <http://www.publichealthlaw.net/MSEHPFA/MSEHPA%20Leg%20Activity.pdf>, accessed 4 November 2010. According to this source, Alabama, Arkansas, Arizona, California, Connecticut, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Idaho, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Virginia, Vermont, Utah, Washington, D.C., Washington State, Wisconsin, and Wyoming have all passed legislation modeling parts of MSEHPA.

22. Model State Emergency Health Powers Act § 804(b)(3).

23. Model State Emergency Health Powers Act § 804(b)(1)(4).

24. La. Rev. Stat. Ann. § 29:771(B)(2)(c); Me. Rev. Stat. Ann. tit. 22, § 816(1); Cal. Gov’t Code § 8659.

25. Federal Volunteer Protection Act, 42 U.S.C. § 14503.

26. 42 U.S.C. § 14503(d).

27. 42 U.S.C. § 14503(d).

28. Uniform Emergency Volunteer Health Practitioners Act § 11.

29. Colo. Rev. Stat. § 12-29.3-101 (2007); D.C. B18-0071 (2010) (Mendelson); 225 Ill. Comp. Stat. 140 (effective 1 Jan. 2011); Ind. Code § 10-14-3.5 (2009); Ky. Rev. Stat. Ann. § 39A.350 (2007); La. Rev. Stat. Ann. § 29:781 (2009); N.M. Stat. § 12-12A6 (2008); Okla. Stat. Ann. tit. 63 § 684.14 (2009); Tenn. Code Ann. § 52-8-201 (2007); Utah Code Ann. § 26-49-101 (2008). See also A. Walters, “UEVHPA: An Update,” *Bulletin of the American College of Surgeons* 29, no. 5 (May 2010): 28-9.

30. Ga. S.B. 315 (2010) (Smith); Miss. H.B. 561 (2010) (Moak).

31. Uniform Emergency Volunteer Health Practitioners Act § 11.

32. DHHS, Health Resources and Services Administration, *Emergency System for Advance Registration of Volunteer Health Professionals (ESAR-VHP)* (2008), [http://www.sccm.org/SiteCollectionDocuments/ESAR-VHP\\_Tise-2.pdf](http://www.sccm.org/SiteCollectionDocuments/ESAR-VHP_Tise-2.pdf), accessed 4 November 2010.

33. 745 Ill. Comp. Stat. Ann. 49/68; Nev. Rev. Stat. § 41.500.

34. S. Rosenbaum et al., “State Laws Extending Comprehensive Legal Liability Protections for Professional Health-Care Volunteers During Public Health Emergencies,” *Law and Public’s Health* 123, no. 2 (2008): 238-41.

35. Alaska Stat. § 09.65.090.

36. Ariz. Rev. Stat. Ann. §§ 9-500.02 & 48-818.

37. Ky. Rev. Stat. Ann. § 411.148.

38. LA. Rev. Stat. Ann. § 37:1731. However, Louisiana does include liability for protection for physicians who act in hospitals if the emergency is dire and the physician has no obligation to be there.

39. Ohio Rev. Code Ann. § 2305.23.

40. Ore. Rev. Stat. § 30.800.

41. Fla. Stat. § 768.13.

42. 745 Ill. Comp. Stat. Ann. 49/68.

43. Nev. Rev. Stat. § 41.500.

44. Okla. Stat. Ann. 76 § 5.1.

45. Vt. Stat. Ann. 12, § 519.

46. Vt. Stat. Ann. 12, § 519.

47. Furthermore, all of these statutes have exceptions for either willful misconduct or grossly negligent conduct.

48. See Rosenbaum et al., see note 12 above, p. 239.

49. This is also the approach taken in the Turning Point Model State Public Health Act § 6-105, [http://www.hss.state.ak.us/dph/improving/turning\\_point/PDFs/MSPHAWeb.pdf](http://www.hss.state.ak.us/dph/improving/turning_point/PDFs/MSPHAWeb.pdf), accessed 4 November 2010.

50. See Model Intrastate Mutual Aid Legislation, <http://www.emacweb.org/?150>, accessed 4 November 2010.

51. Ala. Code 1975 § 31-9-16.

52. Arizona Mutual Aid Compact, <http://www.dem.azdema.gov/logistics/spcprog/mutaid.html>, accessed 4 November 2010.

53. Ark. Code. Ann. § 12-75-103.

54. Conn. H.B. 7024 (2007) (Boukus).

55. Del. Code Ann. tit. 20 § 3201.

56. Ind. Code § 10-14-3-15.

57. Iowa Code § 29C.22.

58. Mississippi Statewide Mutual Aid Compact, <http://www.emacweb.org/?703>, accessed 4 November 2010.

59. Mont. Code Ann. § 10-3-1204.

60. N.D. Cent. Code § 37-17.1-01.

61. Ohio Rev. Code Ann. § 5502.41.

62. Okla. Stat. Ann. tit. 63 § 683.14.

63. Ore. H.B. 2049 (requested by governor) (2005) (failed).

64. Va. Code § 44-146.13.

65. 2003 Wis. Act 186.

66. Ark. Code. Ann. § 12-75-103.

67. National Emergency Management Association & National Public Safety Organizations, Model Intrastate Mutual Aid Legislation, Art. X 2004 <http://www.emacweb.org/?1546>, accessed 4 November 2010.

68. Model Intrastate Mutual Aid Legislation Art. V.

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70. Pub. L. No. 104-321 (1996); “Emergency Management Assistance Compact,” <http://www.emacweb.org>, accessed 4 November 2010.

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76. Model State Emergency Health Powers Act § 608(b)(3), § 804(b)(3), § 804(b)(1)(4).

77. National Emergency Management Association & National Public Safety Organizations, Model Intrastate Mutual Aid Legislation, Art. X, 2004, <http://www.emacweb.org/?1546>, accessed 4 November 2010.

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79. See C. Stroud et al., “Crisis Standards of Care: Summary of a Workshop Series,” 59 (2010), [http://www.nap.edu/openbook.php?record\\_id=12787&page=1](http://www.nap.edu/openbook.php?record_id=12787&page=1), accessed 4 November 2010; see also 42 U.S.C. 1320b-5 (2006).

80. 42 U.S.C. § 1320b-5 (2006). See also 42 C.F.R. § 489.24(a)(2)(2009) (outlining the responsibilities of Medicare during an emergency; the Public Health Security and Bioterrorism Preparedness and Response Act of 2002 Pub. L. No. (2002) (outlining the National Disaster Medical System).

81. 42 C.F.R. § 489.24 (2009).

82. *Ibid.*

83. 42 U.S.C. § 1320b-5 (2006).

84. See Stroud et al., note 79 above, p. 60.

85. 42 U.S.C. § 1320b-5.

86. Idaho has taken a liberal approach to licensing requirements during an emergency; it allows for emergency services to be rendered by a non-licensed individual, if under the supervision of a licensed physician. Idaho also allows physicians licensed out of state to practice in Idaho during an emergency. Idaho Code Ann. §§ 56-1011 to 56-1081B.

87. Model State Emergency Health Powers Act § 608(a).

88. Model State Emergency Health Powers Act § 608(b)(2).

89. Model State Emergency Health Powers Act

§ 804-a.

90. J. C. Ahronheim, "Service By Health Care Providers in a Public Health Emergency: the Physician's Duty and the Law," *Journal of Health Care Law & Policy* 12, no. 2 (2009): 195-234, 229. These states include Arizona, Delaware, Florida, Illinois, Louisiana, Maryland, Missouri, New Jersey, South Carolina, South Dakota, Utah, Washington, D.C., and Wisconsin. See also "The Model State Emergency Health Powers Act: Legislative Surveillance Table 1" (2006), <http://www.publichealthlaw.net/MSEHPA/MSEHPA%20Surveillance.pdf> (listing the states that have incorporated aspects of the model act), accessed 4 November 2010.

91. S.C. Code Ann. § 44-4-570.

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# Imagining the Unthinkable, Illuminating the Present

*Jeffrey T. Berger, Guest Editor*

## ABSTRACT

During a catastrophe that disables the health system, ethically charged situations will undoubtedly emerge that will challenge patients, relatives, clinicians, and others involved in health delivery. This second of two special sections of *The Journal of Clinical Ethics* includes discussions of the implications of a system collapse on particularly vulnerable member of society, children, pregnant women, and those who are socio-economically, culturally, and linguistically disempowered. Additionally, it offers insights into the processes used by committees to plan for catastrophic care.

This second of two special sections of *The Journal of Clinical Ethics* on ethics and health

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system catastrophe directs a measure of its attention to groups within our community who have specific vulnerabilities. Children, women who are pregnant, and these women's fetuses, raise particular issues in catastrophic scenarios that are worthy of anticipation. Patients' developmental age, state of gravidity, and fetuses' gestational age may add susceptibility to various biological, environmental, toxic, and other insults. Additionally, age and state of pregnancy can affect one's responsiveness to treatment. Children are vulnerable beyond physical or physiologic dimensions during a catastrophe, since they are dependent on parents and other adults for food, shelter, protection, accessing medical care, and emotional and spiritual support.

What are parental responsibilities during a health system collapse? How far should parents go in advocating for their children during a catastrophe? What would be obligatory and what would be permissible? What actions would be

disruptive and unfair to others in the community? How should issues regarding family bonds, fealty, and responsibility be honored? To what degree? With or without consideration for other similarly needy children who are worse-off for lack of parental or other advocates? To what extent should parents be expected to sacrifice for their children? Who will advocate for orphaned and abandoned children so that their care will not be inferior to that of other children?

How should persons (or systems, if they continue to function) make resource allocation decisions that involve minor children? Should decisions consider notions of fair opportunity to pursue life? How should fetuses be considered among priorities for care? Does the degree to which they are viable matter, and, if so, how? Should limited resources be apportioned to save only fetuses who are expected to survive with minimal or no medical supports? Should resources be expended for all fetuses deemed viable under a hypothetical state of health system normalcy? In a catastrophe, how should just-delivered babies compete with existing patients in a neonatal intensive care unit (NICU)? Do NICU babies who are decreasingly viable lose vent support to make way for more potentially viable babies, similar to recommendations for adult patients to be extubated as their prognostic scores become worse in the case of ventilator rationing?<sup>1</sup> How do the challenges inherent in prognostication in neonatal medicine confound the optimal use of NICU resources?

How should planning for catastrophe anticipate the likely amplification of existing health disparities during a crisis? Certainly, issues such as health literacy, general literacy, English language competence, and culturally based beliefs about disease and illness may pose barriers to accessing medical attention that do not exist for other segments of society. This special section includes an article that illuminates the concerns and perspectives of relatively disenfranchised segments of society as they pertain to anticipating pandemics.

Another particular vulnerability is that of the clinicians, whose otherwise average per-

sonal medical risks for harm in catastrophe are multiplied by their professional commitments. These persons may find themselves exposed to contagious diseases and perilous work environments as they fulfill their role-related obligations. What degree of personal risk is acceptable? What is reckless? What do hospital administrations and local, state, and federal governments owe these persons in terms of mitigating risk of harm? What do clinicians owe the populace by virtue of the specialized knowledge that they have acquired with public support? When should clinicians consider their own welfare, or their obligations to their families, above that of their patients?

Other questions that are raised in this special section pertain to physicians' ability to prognosticate during the throes of a catastrophe, particularly for illnesses that may be unfamiliar to many, if not most, clinicians. Data suggest that prognostication is poor when patients have more than two weeks to live.<sup>2</sup> Unfortunately, many victims of catastrophe will not fall into that category, such as those infected with anthrax, pandemic influenza, and ebola virus. Other data suggest that physicians' ability to render absolute prognostication is not good, but their relative prognoses are fairly good.<sup>3</sup> That is, the magnitude of error is consistent. This bodes well for prognosticating in some disasters, since triage depends more closely on relative survival, rather than on absolute survival. Other data suggest that physicians' ability to prognosticate vary widely by demographic characteristics and specialty,<sup>4</sup> which introduces a potential source of bias in triage that may need to be managed.

In this special section we are given a window into the process of deliberating about the ethics of catastrophe by a government commissioned committee. Deeply held presuppositions among various committee members gave way, after many face-to-face meetings, to a more shared appreciation of competing positions. Nevertheless, normative positions ultimately were staked out amid recognition of the dearth of empiric, descriptive research on how various constituencies in the public view the value judgments that are likely to be made in times of

health system collapse. In fact, the interface between professional value judgments and societal assessments of values are brought into sharp relief by catastrophe. In times of normalcy, we enjoy a slow process of continual modification and realignment between these domains. Catastrophe disallows such process. To the extent that foresight, planning, and preparedness are wanting, those in authority will have to act pragmatically based on moral intuition, rather than on strong, publicly endorsed, ethical assessments.

Analyses of the health implications of upheaval in our society are important for preparedness planning, but also provide valuable insights into contemporary care. Are our health-care efforts adequate to empower the disempowered? How ought we assess palliative care among our health priorities? What does it mean to be a family member of a patient in terms of both rights *and* responsibilities? How inclusive and relevant are efforts to define normative ethical practices? How well do governmental and public bodies and health systems define, articulate, and integrate ethical values? What health-related responsibilities and entitlements attach to our respective memberships in society? We hope these special sections of *JCE* will stimulate much discourse both for planning for the unthinkable and for addressing the present.

## NOTES

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2. N.A. Christakis and E.B. Lamont, "Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study," *British Medical Journal* 320, no. 7233 (2000): 469-72.

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## How Can Careproviders Most Help Patients during a Disaster?

*Edmund G. Howe*

### ABSTRACT

This article reviews careproviders' most difficult emotional challenges during disasters and provides approaches for responding optimally to them. It describes key approaches that careproviders may pursue to best help patients and others during a catastrophe. It raises unanswered questions regarding when, if ever, careproviders should provide active euthanasia to patients who are incompetent, and when, if ever, careproviders should give their own food and water to patients or others who may otherwise soon die without them.

As we consider disasters in this issue of *JCE*, the earthquake and tsunami that recently occurred in Japan cannot help but weigh heavily on all of our minds. This issue of *JCE* includes the second of two special sections on ethical issues that may arise in a mass disaster, such as a hurricane, pandemic, or terrorist attack. Jeffrey T. Berger has been the guest editor of both sections. In the last issue of *JCE*, I discussed the possibility that society might triage people with

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severe disabilities on an equal basis with those without disability during disasters, on the basis of expected life years, even though this might require using more resources to meet the needs of those with severe disabilities, thus saving fewer lives.<sup>1</sup> Dorothy E. Vawter and colleagues report on the findings of a project team that sought feedback from a group consisting entirely of people with severe disabilities, most of whom required personal care attendants to assist with activities of daily living, in "Attending to Social Vulnerability When Rationing Pandemic Resources," in this issue of *JCE*.

In this column, I will discuss how careproviders can best help patients during disasters. Present evidence suggests that during disasters people have five basic emotional needs: to feel safe, calm, and connected; to feel a sense of efficacy; and to feel hope.<sup>2</sup> Careproviders may be able to meet these needs more effectively than others because they already have the trust of most patients. As Jay Katz said, "Vulnerable patients in their quest for relief of suffering may be readily inclined to place their trust in physicians."<sup>3</sup>

To best help patients, careproviders must first be able to deal satisfactorily with their own emotions, and I consider this first. Then, I will describe the three groups of patients most likely

to cause careproviders the greatest anguish during disasters, namely, those with severe disabilities, families, and children; the fears careproviders may have that come from within themselves, which typically are fears for their own family and themselves; and how careproviders can maximally help patients during a disaster.

### **THE THREE GROUPS LIKELY TO CAUSE CAREPROVIDERS THE MOST ANGUISH**

It is now unclear how we, as a society, will prioritize limited medical resources during a disaster—if we must. According to one source, there are nine different triage plans, already recognized, that we could adopt.<sup>4</sup> Triage is painful to imagine, much less carry out, especially during a disaster, since during a disaster such plans may involve placing people into categories that may make the difference between whether they will live or die.

As Frank Chervenak and Laurence McCullough note in “An Ethical Framework for the Responsible Management of Pregnant Patients in a Medical Disaster,” in this issue of *JCE*, “Triage results in categorization of patients. . . . As a consequence, the central ethical challenge for clinicians and organizational leaders in such disasters will be the preferential management of some patients with the expected consequence of increased morbidity and even mortality for other patients.” Margaret Moon, a pediatrician and ethics scholar at the Johns Hopkins Berman Institute of Bioethics, points out that such triage conditions may be particularly difficult for careproviders because they may not be able to treat patients whom they would treat under normal circumstances.<sup>5</sup> There are many reasons this may happen; for example, medical resources may be inadequate; resources may be available, but not where the patient is or resources may be available on a hospital ship, but the patient is not able to get necessary follow-up care once off the ship.

The role that society expects careproviders to fill during a disaster is not clear. Some disaster plans now recognize that the roles of careproviders who triage as well as treat patients may be in conflict, and so assign triage roles to

administrators. But, in actual practice, this solution may not be feasible. As J. Jaime Cairo and colleagues note in “Unaltered Ethical Standards for Individual Physicians in the Face of Drastically Reduced Resources Resulting from an Improvised Nuclear Device Event,” in this issue of *JCE*, “Although ideally an experienced triage officer is designated, it may fall to the individual clinician to make allocation decisions until order is restored.”<sup>6</sup>

Careproviders may find that if they participate in triage to any degree—whether it is planned, or comes about in practice—carrying out the responsibilities of these two roles may cause great stress. Even when careproviders are not making triage decisions, the awareness that members of vulnerable groups—people with severe disabilities, families, and children may not receive the care that they would receive under normal circumstances—can cause great stress. Careproviders must recognize and deal effectively with their emotions if they are to be able to help patients to the greatest extent possible.

### **People with Severe Disabilities**

*The stress caused by having a utilitarian, public-health-oriented view.* As I discussed in the last issue of *JCE*, careproviders may encounter people during disasters who have severe disabilities. I used the well-known physicist, Stephen Hawking, as an example. I will refer to him again later in this column. Saving patients with severe disabilities may require using additional, limited medical resources. Thus, treating patients in this group as “equally” as other persons may save fewer total lives. When careproviders treat—or do not treat—these patients equally in a triage situation following a disaster plan, they may find that their feelings are strongly affected. However, when patients with severe disabilities are triaged equally to others without disabilities, careproviders who have more-utilitarian moral views, who favor “the greater good” for “greater numbers,” may oppose and resent this. On the other hand, when the interests and survival of those with severe disabilities are not accorded an equal priority, careproviders, regardless of their own moral

views, may feel guilty. This may be because careproviders feel the same way toward patients with severe disabilities as they do toward other patients. Conversely, there is evidence that careproviders, in general, tend to underestimate the quality of the future lives of patients who have severe disabilities, whether the patients are young or old. Careproviders, in general, also tend to underestimate the quality life for the parents of children with severe disabilities.<sup>7</sup> As a result, some careproviders may unknowingly use these assumptions to help them deny and rationalize away any guilt or distress they may feel when patients with disabilities, as a result of triaging, receive care that is less than equal.<sup>8</sup> Even if careproviders have no role in triaging, engaging in denial and rationalization may affect them negatively: first, psychologically, their capacity to assist patients may be reduced; second, careproviders may be harmed by the experience, especially in the long run.

Careproviders' feelings of angst and the concerns just mentioned may extend beyond patients with severe disabilities, like Stephen Hawking. In the Winter 2010 issue of *JCE*, Adrian Furnham, Niroosha Loganathan, and Alastair McClelland reported in "Allocating Scarce Medical Resources to the Overweight" that people may discriminate against those who are overweight and against those who have emotional problems.<sup>9</sup> Careproviders may have the same feelings in response to patients with severe disabilities. When they do, they may discriminate "for" patients with disabilities, in an attempt to compensate or offset their negative feelings. This may benefit the patients, but this overcompensation may lead to discrimination against other patients with disabilities. It may also emotionally reduce careproviders' capacity to help patients to the greatest extent possible, and may be emotionally harmful to careproviders themselves.

Given this, it might be best for a triage plan to be decided by societal consensus. Still even with such a societally approved triage plan, some careproviders (as well as others) will not agree with it, and so the careproviders who will probably be involved in triaging should discuss and work through any disagreements they have

with whatever triage plan has been adopted, before a disaster occurs.

When careproviders understand the rationales for triage decisions, it may help them later on. If they understand how and why a triage plan was made by societal consensus, careproviders may feel less guilty or individually responsible for their actions during triage, or for what they may observe if they are not involved directly in triage discussions. Greater understanding will also help them educate and explain triage decisions to patients during a disaster. Careproviders should also seek an opportunity to imagine with others, before a disaster occurs, the worst-case scenarios they could confront. Such prior work has been shown empirically to provide careproviders who work in disasters some degree of stress "inoculation."<sup>10</sup>

*The stress caused by being uncomfortable with patients with disabilities.* As I discussed at some length in the Winter 2010 issue of *JCE*, some careproviders may feel uncomfortable emotions with people who have severe disabilities—as others may. These kinds of feelings are described nowhere better than by Rosemarie Garland-Thomas, describing people with severe facial disfigurement: "The atypical face is a failed face, perhaps an improperly human, irrationally organized face."<sup>11</sup> Other persons may stare, or, to avoid staring, look away; "This unethical stare," Garland-Thomas continues, is "looking without recognizing, a separated stare that refuses to move toward one's fellow human."<sup>12</sup> Another example is offered by a mother whose son has microcephaly (an exceptionally small head); she reports that many people felt "embarrassed" when they are in her son's company. "Others welled up with pity. Others withdrew reflexively, as if his disability was infectious."<sup>13</sup>

Of course careproviders are not "immune" from these kinds of responses, and their moral views may cause them to have exceptionally strong feelings when they respond to a person with a severe disability—or any disability—in this way. Thus, when these careproviders are associated with patients with severe disabilities who may be triaged, it may harm the care-

providers, and, in turn, harm patients. What can careproviders who respond in this way, and know it, do *before* a disaster occurs? First, they may try to get to know people with severe disabilities better. This could, in and of itself, result in their changing how they feel.<sup>14</sup> Second, careproviders can try to assess honestly within themselves whether or not they have these feelings. If they recognize that they have these feelings and try to oppose them, it may substantially help. This is the basis and mechanism of change in most kinds of cognitive therapy. People recognize that what they feel makes no sense, and that they do not want to feel what they feel.

Careproviders who try to change—by getting to know persons with severe disabilities or by trying to change how they feel—or both—may end up with a different feeling that may be a source of pain when they are exposed to triage. That is, if society does not accord a high priority to the interests of patients with disabilities, careproviders who have changed their feelings may find it more difficult to accept the decisions. They may find it harder to carry out triage procedures when they know the procedures discriminate in some way against members of this group.

Careproviders who do want to get to know these patients better may hesitate, for any number of reasons. For example, some careproviders say that when a person has a visible disability, they don't know where they should look.<sup>15</sup> Kristy L. Kirschner, a physician who has exceptional expertise in this area and has spent her career working with these patients, provides this rule-of-thumb: simply ask. She says that she might ask a patient, "Where would you want me to look?"<sup>16</sup> I would add two important points. First, patients may not know the answer to questions such as where they would want another person to look. Second, it may be that patients might not want others to ask.<sup>17</sup> Thus, careproviders who want to get to know these people better should know that, notwithstanding the wisdom Kirschner offers, there are no *sure* rules; rather, careproviders should be prepared to be flexible, sensitive, and understanding. As Garland-Thomson notes, "If an arc of empathy is

to leap across the breach . . . persistence and generosity must prevail on both sides."<sup>18</sup>

Careproviders who want to try to recognize uncomfortable feelings within themselves may find this painful. I recently experienced this at a conference on teaching about disability at the most recent American Society for Bioethics and Humanities (ASBH) Annual Meeting. It was at this conference that Kirschner and others shared the points above.<sup>19</sup> Presenters showed a film that depicted several people sitting, side by side, along the far side of a table, not unlike Jesus and his disciples depicted in da Vinci's *The Last Supper*. In the film, these people interacted with each other as they sat—one after the other, from one end of the table to the other. As I watched I tried to discern what the actors were trying to convey. I concentrated on it strongly, in part because I know I am generally not good at inferring underlying meanings in mime or art. I then learned that I had missed something else altogether: all of the actors had disabilities. Then the presenters showed the film a second time.

I experienced the film quite differently the second time. I couldn't experience it as I had initially. I couldn't experience it any longer as *art*. Rather, I was preoccupied with my new awareness that all of the actors had a disability. I could not stop asking myself, "How can each of them do what they are doing?" I asked myself this question over and over, despite my best effort, like a broken record. It was beyond my control, and I felt ashamed.

*The stress caused by a feeling that patients who have severe disabilities are more insightful.* There may be a third possible reason that careproviders feel stress with these patients. To my knowledge, this source of stress has not been noted elsewhere (and may or may not be valid). But since it may help careproviders, I will describe it in some detail. On average, people with a severe disability, due to their disability or due to experiences caused by or related to their disability, have greater insight and even wisdom than many others. Unconsciously, if not consciously, many people recognize this, and may resent it. The parents, children, and siblings of persons with severe disabilities may, in general, also have greater insight. For example, they may

have a deeper sense of what should count most in life.

Like others, careproviders may find this deeper perspective threatening, and, in response, they may, consciously or unconsciously, emotionally defend themselves. They may, for example, distance themselves from people with disabilities to preserve or restore their own self-esteem. Examples abound. I think of Stephen Hawking, confined to a wheelchair with only limited use of one hand and arm. He says, notwithstanding, “Being confined to a wheelchair doesn’t bother me as my mind is free to roam the universe. . . .”<sup>20</sup> I think too of people I know, for example, a father of a toddler who is severely impaired. The father told me, I think truthfully—he had no reason to be dishonest—that he lives, mostly, if not solely, for the times he sees his son smile. I think too of an older sibling of a child who had severe special needs. The child died in his early teens, and his older sister is pursuing medical school to be able to help children like her younger brother.

The special insight and responding resentment I am describing here are illustrated in a piece of fiction entitled *Firegirl*.<sup>21</sup> The main character, Jessica, is a young girl in grade school, whose face, hands, and body have been badly burned. Her teacher asks all of the students in Jessica’s class to hold hands. A boy who is next to Jessica is afraid to do this. “She extended her hand, crooked and red and bent open. . . . He pushed his balled-up fists into his pockets and didn’t hold anyone’s hand. ‘It’s okay,’ said Jessica, letting her hand drop.”<sup>22</sup> The comprehension described here illustrates the kind of exceptional understanding or insight I have in mind. Later in the story, Jessica gets to know another boy in her class, and says to him, “‘Do you want to touch my face?’” To me, this is another illustration of this kind of special insight.<sup>23</sup> Jessica says to the boy, “‘Every time I go in the hospital, I find out all over again about what really matters. . . .’”<sup>24</sup> She conveys one possible source of the insight about which I am speaking, when the boy says to her, “‘people are scared of you’ . . .” she replies, “‘Sure I hate them. You don’t even know. But there are always some people who won’t be that afraid.’”<sup>25</sup>

The friend, rightly or wrongly suspecting Jessica’s insight, resents it. Exulting in the glamour of a flashy car, he tells her, “‘It’s a sports car.’” He then tells the reader, “‘She looked at me. . . . Suddenly, [I] felt stupid. . . . Does everything have to be about being burned?’”<sup>26</sup> This fiction may mirror reality.

Lucy Grealy, who as a young teen lost half of her jaw fighting Ewing’s sarcoma, wrote in *Autobiography of a Face*, that she “was disgusted by peers who avoided their fears by putting their energy into things as insubstantial as fashion and boyfriends and gossip.”<sup>27</sup> She states that she also “discovered what it was to love people. . . . It required . . . always seeing them for themselves and not as I wished them to be, of always striving to see the truth of them.”<sup>28</sup>

### Families

During disasters, members of families often feel terror; they may particularly fear being separated from their loved ones, possibly forever, by death. Careproviders may help patients bear this terror by helping them to find their family members or at least by providing information that may help them find other family members. To help maximally during a disaster, careproviders must avoid overreacting, no matter how others respond. It may help to understand why people respond as they do. As I mentioned in the Winter 2010 issue of *JCE*, some people choose to stay in their homes with a loved one during a hurricane, when their loved one couldn’t be moved. They stay, even though they know they could be rescued, and that they may die if they stay. Others choose to stay with pets. The percentages of people who stay with a loved one or a pet, is, according to one source, 10 and 7 percent.<sup>29</sup>

Domestic violence anecdotes abound regarding spouses who stop fighting when the police arrive, and join forces to attack the police *together*.<sup>30</sup> Similarly, during the stress of a disaster, families may band together against those they perceive to be in authority. For example, during Katrina, the adult children of an elderly woman who was stranded at a flooded hospital arrived in a small boat to rescue her. After they were sent away without the patient by hospital

authorities, they returned—with the families of other trapped patients, in many additional small boats, and dared the authorities to stop them from rescuing their loved ones.<sup>30</sup>

In the next section, I will give frightening instances of families' behavior that occurred little more than a decade ago around an outbreak of Ebola.<sup>31</sup>

Despite this, careproviders must find a way to cope emotionally even with these responses, if they can. Froma Walsh recently reviewed studies of families during disasters. In this review, Walsh focuses in on how careproviders can most help patients. She points out how important it is for careproviders to be able to accept families' highly divergent reactions, so that careproviders can support them. Some families, she reports, will "anxiously cling" to each other, while other family members will distance themselves from one another to limit their pain.<sup>32</sup> Experts reported on the violence in the Belgian Congo (formerly Zaire) in response to fears of acquiring Ebola: "Patients may see careproviders as the enemy. . . . It is important for medical personnel to see these reactions for what they are: misguided but self-protective behaviors. . . . If not, medical staff . . . may become hostile and experience a breakdown of their own protective denial (Why should some individuals place themselves at risk when they are being viewed as the enemy?)." <sup>33</sup> If careproviders can manage their own emotional responses, they may be able to help patients maximally—both during and after a disaster.

During and after a disaster, family members almost invariably ask, "Why?" "Why us?" Each must find their own answer. Careproviders can assist them in finding enough meaning in the answer to these questions that family members can go on with their lives, in a way that has significance for them. When family members are unable to find personal meaning, later on they may still find a way to live, feeling that their lives have some significance.

When a child is harmed in a disaster, parents may need help to "reframe" their experience and overcome the guilt they may feel, so that they can go on and find meaning in their lives. In the next section on children, I will in-

clude an example of what careproviders can do to help parents in this situation. To close this section on families, I offer an illustration of how important it is for those who have experienced a disaster to be able to find and feel meaning and significance in their lives. During Hurricane Katrina, a man lost hold of his wife's hand in the midst of the flooding. Later, he was asked how he'd been able to go on with his life. He said that, as his wife lost hold of his hand, she said, "Take care of the kids and grandkids." This gave him the "courage and determination" to live.<sup>34</sup>

### Children

Of all of the feelings that family members may experience, parents' feelings for a child may be the most intense. Some parents would choose to die during a disaster if, for example, it would "free up" a careprovider or another medical resource and make it possible for their child to be treated for pain. Later in this article, I will discuss careproviders' dilemma when a child is in extreme pain during a disaster and there is no way to relieve it. I will focus now on how careproviders can help parents to reframe—to see things they may feel guilty about that happened during or after a disaster, in a less-painful way. As Walsh says, "Clinicians can help families gain factual information and examine beliefs that foster blame, shame, and guilt."<sup>35</sup> This strategy is one among many approaches found to be effective by empirical research that careproviders can use to help parents and others to cope and find meaning during and after a disaster, so that they can better, and with meaning, go on.

Parents may be exceptionally likely to feel guilty when something bad happens to their child in any context. They almost always say to themselves, "If only I had done *this!*"<sup>36</sup> Real-life examples are as boundless as they are poignant. An example from "normal" times is that of a mother from my experience, whose son was born with hydrocephalus (extra fluid in his skull, outside his brain). Surgery was performed after his birth, but he continued to have severe special needs. Years later, a careprovider asked her, regarding her son: "Did you consider, then,

doing anything *else*?” This mother didn’t know exactly what the careprovider meant at the time (and still doesn’t, years afterwards), but still she “obsesses” painfully every day. She said to me, “Perhaps there *was* something else I should have done.” Her experience illustrates, in general, how parents may feel guilty if, in conversation, careproviders leave open *any* ambiguity that may suggest that the parents have harmed their child. Because of this possibility, careproviders should try to anticipate when this might be possible, and, if it seems at all likely, they should try to clarify what they mean.

Such guilt may be felt by women when they are pregnant, regarding their fetus. A woman of my acquaintance became pregnant and asked her doctor if she should continue taking antidepressant medication. Her careprovider said she should, based on the severity of her prior depression. Wanting to ensure that the patient was adequately informed, however, the careprovider told her of the risks to the fetus that *research with animals* had reported. As a consequence, the patient obsessed throughout her pregnancy. And, because some of the reported side-effects in animals continued after birth, the patient continued to obsess. This indicates how any specific information that careproviders give to parents (and other patients) may be harmful. Thus, careproviders might often ask patients whether they want specific information that might subsequently “haunt” them. These examples show how, even in normal contexts, parents may be especially prone to experiencing guilt and to obsessing. The guilt may repeatedly occur, like a broken record, throughout the rest of their lives. Input from careproviders may possibly change this broken record.

I will end this section on children with a no-less-painful example. This real case illustrates how the meanings people may see in an event may wholly alter their life. During Hurricane Katrina, as a 12-year-old boy and his father approached their home, they saw the boy’s mother being carried away by the flood surge. The father yelled to the boy to swim out and save his mother, but the boy stood frozen in place as his father yelled at him, and his mother was swept away. The boy ran away, too ashamed

to tell his father that he couldn’t swim, and he wouldn’t return home later, but instead slept in the streets of a nearby town. His uncle heard what happened, took the boy to his own home, and worked to reunite the boy and his father. The uncle told the boy that the floodwaters that day were too strong even for a good swimmer to rescue anyone. The uncle also told the boy that the boy’s father couldn’t swim, which is why he had spoken so strongly to his son about saving his mother. The boy was slowly reconciled with his father.<sup>37</sup>

### FEARS THAT EMERGE FROM WITHIN

During a disaster, careproviders may also be vulnerable to fears from within themselves. They may fear for their families or for themselves. To help others, they must be able to adequately cope with their feelings. During a disaster such as Katrina, these kinds of fears may not be a great problem; for example, one hospital became stranded, without electricity or water but the careproviders there knew it was only a matter of time before they were rescued.<sup>38</sup> But even when careproviders are free of fear for themselves, others may lack food and water, and die, and the ethical problem careproviders may experience, if and when this occurs, will be considered at the end of this article.

Careproviders had profound fears for their families and themselves during pandemics in the last decade involving severe acute respiratory syndrome (SARS). Thus, in discussing these kinds of fears, I will begin the discussion with this example.

### SARS

SARS outbreaks occurred throughout the world between November 2002 and July 2003. There was relatively little exposure to SARS in the U.S., since there were “only” eight documented cases here and no deaths.<sup>39</sup> SARS was the first pandemic of the 21st century. Worldwide, there were 8,098 cases and 7,774 deaths. Initially the world did not even know what the SARS virus *was*, and there is still no vaccine available to specifically treat or prevent it. It was, in fact, a “new virus,” and more lethal than

others that are known and related to it, because it “houses” itself in the lower parts of the lung where it is harder to treat, rather than in the upper parts of the lung, where other viruses stay.

The main ways that careproviders could detect that a patient might have SARS was from the patient’s having a cough, a fever, and/or a history of exposure. More definitive lab tests (blood, nasal, or throat cultures) were available, but took too long. Since patients could have a fever due to another cause—for example, an increased temperature after an operation—careproviders had to try to determine whether the patient’s fever was due to surgery or SARS. If the careproviders were wrong, a case of SARS might go unidentified and spread, and cause the loss of several lives. Therefore, careproviders had to screen numerous people likely to have been exposed, daily, to separate those who might have SARS from those who did not, so SARS wouldn’t spread. Careproviders feared that they might acquire SARS, and inadvertently spread it to their families. (SARS could be acquired within six feet of an infected person by respiratory droplets.) In one SARS ward in Toronto, for example, approximately 90 percent of the ward nursing staff became infected. In one hospital in China, 17 medical students acquired SARS from doing physical exams on infected patients. Seven physicians who treated patients with SARS in Toronto later issued a list of 10 lessons that they had learned, for other careproviders. It is no wonder, based on what careproviders everywhere experienced, that the ninth of the lessons is: Mental health resources should be provided for *patients and staff*.<sup>40</sup>

The fears of others, for example those of family members and especially parents, may “spill over” and become an additional source of fear for careproviders in regard to the health of their families and themselves. A worst-case scenario of this happened in response to the Ebola virus.

### **Ebola**

Careproviders’ fears for their families and themselves was much worse when people feared getting Ebola in 1995 in the Democratic Republic of the Congo (then Zaire). Neighbors

of careproviders feared that the careproviders and their families might be infected with Ebola. Reportedly for this reason, neighbors “at times” “stoned” careproviders and their families, and burned their homes. Researchers studied the feelings of careproviders who became infected, and the findings illustrate how strong careproviders’ fears can become: all felt fear: 55 percent feared having pain and suffering; 53 percent feared a horrible death; 41 percent feared being separated from their loved ones, and 23 percent feared being abandoned.<sup>41</sup> World-renowned experts on disasters recently reported: “Disasters challenge every aspect of human adaptation at both societal and individual levels. . . . They call forth strength, cohesiveness, and courageous altruism, . . . and savage destructiveness in the fight for competitive advantage for survival. . . .”<sup>42</sup>

The example of Ebola illustrates the courageous altruism shown by careproviders as well as the “savage destructiveness” that the fear of contagion brought about. It is hard to imagine how careproviders could continue to strive to help patients, but they did. In most disaster settings, careproviders’ primary task may be to avoid emotionally distancing themselves from their patients. Some distancing may be necessary and adaptive, to enable careproviders to help patients as much as they can. Necessary distancing may be a challenge in both disaster and non-disaster contexts. As this is the case, I will next consider necessary distancing on the part of careproviders when they are involved in triaging patients during a disaster, or observing triaging during a disaster, or even as part of “managed care.”

### **Managed Care**

Experts recognized more than a half century ago that careproviders need to avoid distancing themselves unduly during a disaster. Drayer and colleagues stated then, “There are occasions . . . when even very stable people are so overwhelmed by an event, that they are unable to recover a semblance of emotional balance . . . and may require help from someone else.”<sup>43</sup> At these times, persons (including careproviders) may feel panic or “blind fright”; become

“numb” or slowed down; become “frantic” or, generally, overactive; and have bodily reactions such as nausea and vomiting. Bodily reactions may even include conversion symptoms, such as patients who suddenly lose the ability to walk. When patients have conversion symptoms, it may *appear* that they are “faking.”<sup>44</sup>

These authors used this example of a conversion reaction to illustrate how careproviders could become angry at the patients during a disaster. Careproviders might become angry at seeing a patient who seemed to be faking an illness. Thus, this is a useful, paradigmatic example of the kind of response careproviders should most try to avoid during a disaster. Writing five-plus decades ago, Drayer and colleagues noted, “During training, your annoyances . . . at imperfections in disasters should be fully worked through so that in times of crises you do not find yourself overwhelmed by a flood of resentment at the ‘authorities, . . . .”<sup>45</sup>

This is the same point I made above: when careproviders disagree with the accepted triage plan, they should present these disagreements before the plan is needed. Drayer and colleagues addressed how careproviders should best respond to feelings such as anger at a patient who appears to be faking a disability, which is the main point that I wish to convey. They say careproviders must “at all costs guard against a very common tendency . . . [to] easily begin to resent intangible disabilities in those around you.”<sup>46</sup> Clearly, when careproviders do feel resentment toward a patient who appears to be faking a disability, they cannot give the patient the support she or he needs.

I felt this way myself years ago, and still feel ashamed. A patient, feeling stressed, started to fall. Like the 12-year-old boy who couldn’t swim (but without the boy’s good reasons), I froze. I recall telling myself that my patient had to learn to take more responsibility for herself, but, more simply, I was blaming the victim, which is the very thing that Drayer and colleagues were trying to warn careproviders like myself to avoid. Fortunately, the patient did not fall far, and was not injured.

Two psychiatrists, Bursztajn and Brodsky, studied more recently how careproviders tend

to respond emotionally when patients are being triaged in the context of managed care. Their findings are most instructive and illuminating, in that they seem to apply as well to the emotions that careproviders may experience when, during triage, patients are denied care they would receive in normal conditions. This may be, as Moon says, the worst situation that careproviders may experience during a disaster.

Bursztajn and Brodsky state that such circumstances may “amplify the patient’s transference reactions” (by which they mean that patients may experience their careproviders as though they were people, such as their parents, who were previously a part of the patients’ lives). Bursztajn and Brodsky state that these transference responses can “amplify the physician’s defensive counter transference reactions” as well.<sup>47</sup> (While there may be differing views of the use of how the word counter transference should be used in this and other contexts, here it is used to refer to any response that is not justified by the current situation.)

Chief among these reactions, Bursztajn and Brodsky suggest, is a “human tendency to forget, to look but not see, to deceive or anesthetize oneself.” The reactions may serve to “bypass the hard work of communication needed.” Careproviders who have these reactions may feel “conflicted” that “their primary allegiance is to the patient,” and they may, in response, “inadvertently abandon their fiduciary duties,” which may “undermine the doctor-patient alliance.” Most importantly, the doctor-patient alliance can be “a protective factor in the bearing of uncertainty and grief.”<sup>48</sup> It is possible that careproviders can “gag themselves” into silence in interacting with patients, rationalizing that they don’t want to raise patients’ expectations.<sup>49</sup> Careproviders may distort their own reality through counter transference. Bursztajn and Brodsky state that common expressions of counter transference may be seen in statements such as “That’s not my problem,” “My hands are clean,” and “I’m only following orders.”<sup>50</sup> They write, “These defensive maneuvers stand in the way of forming a working alliance. . . .”<sup>51</sup>

Drayer and colleagues summarized and extended these insights: “Health care profession-

als need to understand the patients' mind-sets during a viral outbreak, as well as their own potential stress reactions. Physicians need to realize that their patients will be frightened and may potentially lie about symptoms and exposure risk."<sup>52</sup> When such "lying" endangers others, it may evoke careproviders' rage. Patients may lie in these contexts to protect their family members—they may want to protect family members and themselves from any number of possible repercussions, from avoiding stigma to avoiding death. People may lie to alter the treatment that they or others will receive as a result of being triaged. For example, they may have a respiratory virus, but will be placed on an artificial respirator, which may "save" them, only if they have had the virus for less than, let us say, 48 hours.

When it is a child who is sick, parents may learn about this guideline "through the grapevine," and thus learn what time line they must use to give their child the best chance of being saved. Thus, parents may lie about how long they or a loved one has been infected, in the hope that this will save their child's life.<sup>53</sup> These kinds of circumstances may deeply test careproviders' capacity to understand. Their anger may be increased when patients' lies put others at increased risk. Patients may lie during a disaster because, as discussed above, they are afraid.

### WHAT SHOULD I DO DURING TRIAGE?

Several optimal approaches for careproviders to take during a disaster are based on empirical data. One is to separate patients who do not need emergency care, early on, from patients who do, to reduce "chaos" and improve "patient flow."<sup>54</sup> Guidance entitled "Psychological First Aid" is now available at <http://www.ptsd.va.gov/professional/manuals/psych-first-aid.asp>. Other approaches include careproviders' asking "children, adults, families, and survivors to rate their level of current distress," and asking parents and children, later, to provide a "time line of their disaster-related experiences to promote a shared understanding of both overlap and differences in their objective and sub-

jective experiences and responses."<sup>55</sup> These optimal responses are available through other sources as well.<sup>56</sup>

Here I will discuss three initiatives by careproviders that involve ethical issues. (1) Careproviders can try to protect themselves by avoiding being too courageous. (2) When they can, careproviders can avoid both doing triage and treating patients, to avoid having mixed loyalties. (3) In addition to meeting patients' most basic needs, careproviders go further, to help patients have some form of hope—even a new or different sort of hope—when patients know, or believe, that they may die.

### Being Too Courageous

I have emphasized how important it is for careproviders to take care of themselves, before anything else. After doing this, careproviders can adequately help meet patients' physical needs and help patients to cope with their feelings. Experts point out that physical needs for warmth, food, and protection from further danger should be met first.<sup>57</sup> Ethically, careproviders can prepare to help during a disaster by pre-considering and pre-discussing any disagreements they may have with the disaster plan, and they should seek opportunities, especially when a disaster occurs, to pre-imagine worst-case scenarios they may encounter.<sup>58</sup>

Another primary suggestion is that careproviders not try to be heroes. Courage is a most admirable virtue, but, paradoxically, during a disaster, it can prevent careproviders from doing all they can for patients. Experts say that during "nearly every disaster," careproviders are an "often overlooked, highly stressed group." During a disaster, careproviders "are expected to carry the burden of idealization placed on them by the community. They are required to be away from their homes and families, always to be good, and . . . are rarely allowed to express their own despair, worry, and fear. . . ."<sup>59</sup>

In a time of disaster, careproviders may feel it is "the right thing to do," and only right thing to do, to help patients as much as they can.<sup>60</sup> They may help patients more, though, when they take the time they need for sleep, food, and respite.

Experts recommend that, during a disaster, careproviders have a “buddy,” so that a colleague, by purpose someone who is most attuned to them, can suggest—strongly, when necessary—that they “halt” and get the sleep, food, and respite that they need. Experts add that the buddy should recognize that asking a team member to take time out may cause him or her to feel devalued, but that, in any case, it “may be necessary.”<sup>61</sup>

### **Avoiding “Mixed Agency”**

Careproviders should be careful to not accept mixed obligations to conduct or participate in triaging, in any way, while they are treating patients. If they accept this mixed agency, patients may perceive it, and careproviders may lose the patients’ trust. The need to separate these potentially mutually exclusive roles is widely understood, but, as Cairo and colleagues state at the beginning of their article, such “firewalls” may break down.

The potential emotional effects of mixed agency are often underestimated in other contexts. For example, two daughters brought their quite elderly father to the hospital for care. He had early dementia. His careproviders feared that the daughters were living illegally off their father’s Social Security. The careproviders considered contacting the authorities to investigate their suspicions, but chose not to, because even if their suspicions proved to be correct, the outcome for the patient could be dire: it could destroy his life as he knew it, and his reason for wanting to be alive. His daughters might go to jail, and, without them, he might have leave home for an institution, and remain there for the rest of his life.

The careproviders decided to treat the patient and send him home with his daughters, because their fears were based also, and more subtly, on how the daughters might respond to an investigation. Even if the daughters were found innocent of violating the law, they could lose trust in “the system,” and they might not continue to bring their father to the hospital right away when he needed care.

There may be a number of reasons that patients acquire distrust during a disaster. Patients

may know that their careproviders have food and water when they lack it. *This* knowledge could undermine their trust. Careproviders may feel a greater degree of comfort in this regard, as patients routinely can (and do) accept some differences in circumstances between themselves and their careproviders, especially patients who know that they must accept this for careproviders to be able to continue to treat them. Patients in prison, for example, accept that careproviders go home.

The mixed agency of careproviders who participate in triage decisions during a disaster, however, may not be sufficiently the same. Patients may know that the careproviders who are treating them are, at the same time, determining whether they live or die. What, then, should careproviders do when a triage plan requires them to triage and treat patients at the same time? If they can’t accept the triage, based on principle, they should probably make that clear ahead of time so that others people, including patients, won’t rely on them to be present and serve during a disaster.

Analogously, if careproviders anticipate that they may choose to stay with their family during a disaster, they should let the appropriate parties know this, in advance—although the adverse consequences to themselves and their families may be considerable. But what if careproviders aren’t given time in advance to decide not to participate? What if they have no time to make a decision, and are “put on the spot” by a disaster? Two different authors raised similar questions in the last issue of *JCE*.<sup>62</sup> They asked what careproviders should do if a patient has severe pain that can’t be relieved and the patient asks for active euthanasia. Both of the authors supported some acceptance that careproviders do what they feel they must do in this event. But what if the patients have seemingly unbearable pain, and aren’t competent? What if they are children? What if, in addition, their parents are present and plead with careproviders to relieve their child’s pain?

The first arguments likely to be raised here are self-evident. On one side, some may argue that patients who are incompetent and are in extreme pain should be treated equally to oth-

ers—even—or especially—when they are children. Others may oppose this, because life is sacred and/or because these patients lack autonomy. A consideration that is possibly also relevant is how much moral weight, if any, should be placed on these patients' not understanding why they are, and are being left in, such extreme pain.

This lack of understanding could, perhaps, to some extent be beneficial, because these patients would not know that their pain, short of death, might not be soon resolved. Yet, an inability to understand might, on the other hand, make the pain worse: for example, these patients may feel abandoned. Might it be, then, possibly, in this situation, that the "burden" might be placed on those people arguing that such patients should *not* be relieved by active euthanasia from unbearable pain?

### **Patients Who Fear They Might Die in a Disaster**

I have described several ways that careproviders can help people emotionally, to the maximum extent, during a disaster. Here is yet another example. A leader who says out loud, "We need help!" may allow others to say, "I need help." A leader who scorns people who ask for help, on the other hand, may prohibit them from being able to say they need care.<sup>63</sup> Careproviders may benefit patients by asking them about their concerns. Giving people even a couple of minutes to talk freely about their experiences during a disaster may relieve "remarkably" some of their "feelings of despair and helplessness."<sup>64</sup>

How far should careproviders' help go, however, during a disaster? Can careproviders, for instance, help patients find meaning in their lives, when they know, or believe, that they will die? Hospice workers and others do this, under normal circumstances, every day. Perhaps the best example that careproviders *can* help patients in this way during a disaster was provided by the psychiatrist Victor Frankl, who lived with people who found hope while in concentration camps during World War II. Frankl himself believed that he had only one chance in 20 of sur-

iving. He describes how he and others coped, sharing, even in this context, their sense of humor. He says, "We knew that we had nothing to lose except our ridiculously naked lives. When the showers started to run, we all tried very hard to make fun both about ourselves and about each other. After all, real water did flow from the sprays."<sup>65</sup>

An ethical question that remains, though, is how far careproviders should go during a disaster to retain their own hope. Philosophers emphasize that one source of hope for humans, regardless of their circumstances, is having the capacity to choose. One choice facing careproviders during a disaster may arise when they have food and water to meet their own needs, while patients and other persons lack food and water, and without them may soon die.

Such conflicts are real. One careprovider who just returned from treating patients in Haiti told me, for instance, that this was the most painful ethical conflict he experienced while he was there. I know of another careprovider who gave away a considerable portion of the food and water given to her for her own use, in similar circumstances. Should careproviders who are serving patients during a disaster go this far to help patients to have hope, and model for their patients the benefits of the capacity to choose?

### **CONCLUSION**

I have discussed how careproviders may most help patients during a disaster. First, above all else, careproviders must try to manage their own feelings effectively. I have suggested that careproviders should resist the temptation to be heroes, should try not to have mixed obligations, and should try to help patients to have hope, even when patients believe that they may die. I raised, finally, some unanswered questions: whether, during a disaster, careproviders should ever perform active euthanasia for patients with unbearable pain who are incompetent, and whether careproviders should give food and water that has been reserved for them to patients who will soon die without it.

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64. Ursano, Fullerton, and Norwood, see note 60 above.
65. V. Frankl, *Man's Search for Meaning*, 3rd ed. (New York: Touchstone, 1984). Bursztajn and Brodsky relate that Frankl's work testifies "to his ability to help others find meaning, perspective, and humor . . . amid [this] world of tragedies." Bursztajn and Brodsky, see note 47 above, p. 246.

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# An Ethical Framework for the Responsible Management of Pregnant Patients in a Medical Disaster

*Frank A. Chervenak and Laurence B. McCullough*

## ABSTRACT

The ethics of managing obstetric patients in medical disasters poses ethical challenges that are unique in comparison to other disaster patients, because the medical needs of two patients—the pregnant patient and the fetal patient—must be considered. We provide an ethical framework for doing so. We base the framework on the justice-based prevention of exploitation of populations of patients, both obstetric and non-obstetric, in medical disasters. We use the concept of exploitation to identify a spectrum from ethically acceptable, to ethically challenging, to ethically unacceptable, management of obstetric patients in medical disasters. We also address the ethics of the care of obstetric and neonatal patients when the resources of a hospital are completely overwhelmed in a large-scale medical disaster.

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## INTRODUCTION

The ethical challenges of managing pregnant patients in medical disasters are not an abstraction. On the morning of 11 September 2001, the New York Presbyterian Hospital (NYPH) went on emergency status in response to the terrorist attacks on the World Trade Center, in which four NYPH Emergency Medical Services personnel lost their lives in attempts to rescue victims. The emergency plan required one of us (FAC), as obstetrician and gynecologist in chief, to discharge all elective obstetric and gynecologic admissions, to free-up beds for expected casualties. Tragically, they never came, causing the enormity of the loss in lower Manhattan to become a stark reality throughout our medical center. One indelible memory is the scores of photographs of missing family members in the halls of NYPH.

The obstetric service of NYPH on that horrible day did not have to address the full ethical dimensions of a large-scale medical disaster. The purpose of this article is to provide an ethical framework to guide organizational policy and its implementation for the respon-

sible management of obstetric patients in a medical disaster.

### ETHICAL FRAMEWORK

In large-scale medical disasters, there will not be sufficient resources to meet the medical needs of every patient. As a consequence, the central ethical challenge for clinicians and organizational leaders in such disasters will be preferential management of some patients, with the expected consequence of increased risk of morbidity, and even mortality, for other patients.

Triage results in categorization of patients, and their individuality drops away. As a result, clinical judgments become population-based, not clinical judgments about each individual patient and her clinical needs. The ethical principle of beneficence is therefore supplanted by the ethical principle of justice. In the clinical setting, the ethical principle of justice requires the prevention of exploitation. *Exploitation*, as we use the term here, occurs when a population of patients is treated unjustly: they are managed in ways that expose them to risk of ethically significant disease-related or iatrogenic harm, for the benefit of another patient population, without the exposed population of patients having the opportunity to experience off-setting clinical benefit. “Ethically significant disease-related and iatrogenic harm” means that there are risks of mortality and of serious, far-reaching, and irreversible morbidity and lost functional status of pregnant, fetal, and disaster patients. Exploitation becomes an ethically urgent concern when the patient population that is put at risk is vulnerable, in the sense of lacking decision-making capacity or otherwise being unable to protect himself or herself. Notice that this analysis of exploitation is not equivalent simply to using one population of patients for the benefit of another population, because such use does not necessarily involve the loss of opportunity for off-setting clinical benefit for the used population. For example, cesarean delivery for well-documented complete placenta previa in the intrapartum period uses pregnant women for the benefit of fetuses, by essentially eliminating the risk of fetal mortality, but also

benefits pregnant women, by dramatically reducing their risks of mortality and morbidity by means of effective and safe surgical delivery. Elsewhere, we have deployed a justice-based account of prevention of exploitation to provide ethical frameworks for the clinical management of peri-viability and for research on pregnant women for fetal and/or maternal benefit.<sup>1</sup>

Obstetrics ethical analysis of exploitation for hospitalized pregnant patients (all of which are viable pregnancies), requires consideration of ethical obligations to both the pregnant patient and the fetal patient, because the viable fetus, when a pregnant woman presents for clinical care, is a patient.<sup>2</sup> Viability means the ability of the fetus to exist ex utero, even with full neonatal intensive care and other support, and in the absence of major anomalies, and usually occurs at approximately 24 weeks of gestation, based on reliable ultrasound dating.<sup>3</sup> If not done previously, an ultrasound examination can readily be performed on a newly admitted pregnant patient. The fetus is obviously a vulnerable patient. Pregnant women, as a rule, should not be regarded as vulnerable with respect to having the capacity for autonomous decision making and exercising that capacity, because pregnancy usually does not adversely affect decision-making capacity or the ability of the pregnant woman to protect herself through the informed consent process. Women may become physically vulnerable during obstetric emergencies such as severe pre-eclampsia, requiring immediate delivery.

The reality of two patients makes the ethics of the management of pregnant patients in medical disasters ethically unique. When both pregnant and fetal patients experience only clinical risk with no offsetting clinical benefit, they then meet the justice-based criterion for exploitation. The application of the concept of exploitation in the management of pregnant patients should focus on increased risk of both mortality and morbidity. This is because, in obstetric practice, the risks of mortality and morbidity for the pregnant and fetal patient are usually intertwined.

One end of the spectrum is defined by unequivocal exploitation of pregnant and fetal

patients: denying access to immediate surgical obstetric services when such denial is known to markedly increase the risk of mortality or the risk of serious, far-reaching, and irreversible morbidity for either or both of the pregnant and fetal patients. Such risk can be eliminated or significantly reduced by immediate intervention. As noted above, cesarean delivery for well-documented complete placenta previa for a woman in labor essentially eliminates the risks of mortality, and such morbidity for both the pregnant and fetal patients. In addition, cesarean delivery for acute fetal distress significantly reduces the risk of anoxic injury to the fetal brain, which can result in permanent neurologic damage and loss of function.

The other end of the spectrum is defined by using pregnant and fetal patients for the benefit of other populations of patients when such use involves low or manageable risk: elective intervention that can be postponed with less-than-marked increased risk of mortality or morbidity. Elective repeat cesarean delivery at 39 weeks of gestation can be safely postponed, provided that there is adequate monitoring until after the medical disaster has subsided. Such monitoring can be accomplished by fetal surveillance using an external fetal heart-rate monitor, which can be done on an outpatient basis. The use of out-patient fetal monitoring does not deny access to hospitalized patients to any intervention that they may require. Non-obstetric patients are not denied any clinical benefit, meaning that exploitation of non-obstetric disaster patients does not occur.

The ethical analysis of the types of cases in the middle of the spectrum will be matters of clinical judgment. These should take into account evidence-based clinical judgments about the increased risks of mortality and of serious, far-reaching, and irreversible morbidity and lost functional status of pregnant, fetal, and disaster patients. Put another way, the goal should be to avoid outcomes in which one population experiences disproportionate clinical benefit with little risk, while another population experiences clinical risks without the opportunity for offsetting clinical benefit.

### CLINICAL APPLICATION OF THE ETHICAL FRAMEWORK

The first step in applying this ethical framework to obstetric patients in a hospital's response to a large-scale medical disaster should be to identify patients for whom immediate discharge from the hospital and for whom postponed scheduled admission does not result in exploitation. Because these patients will experience either no unacceptable increased risk of mortality or morbidity, or increased risk that is manageable on an out-patient basis, the criterion for exploitation is not satisfied. Careful planning should be made for hospital-based delivery, given the unacceptable increased perinatal risks of planned home birth, especially from the transport of women in labor in response to obstetric emergencies.<sup>4</sup> Failure to prevent such risks would subject fetal and neonatal patients to iatrogenic burdens without sufficient off-setting benefit. Hospital-based labor and delivery should be managed as described below. An explanation of this ethical analysis should be provided to this patient population. Pregnant women in these patient populations who insist on staying in the hospital, or on admission, should be informed that implementing their request will result in exploitation of other pregnant patients or disaster victims who have more urgent medical needs and that their requests will not be accommodated. The urgency of undertaking this first step may increase as a medical disaster unfolds, depending on the number of admissions to the hospital's emergency department and the severity of treatable injuries and diseases. The goal should be the prevention of exploitation of other populations of patients.

A distinctive clinical aspect of obstetric management is flexibility about the physical location of the management of labor. If an obstetric hospital room is needed for an emergency intervention for effective treatment of a disaster patient, the laboring woman should be moved from her hospital room to the hall or another space, provided that there is adequate fetal monitoring and clinical supervision. The

obvious loss of privacy is nontrivial in its psychosocial dimensions, but is not far-reaching and irreversible. Moreover, the prevention of mortality or of serious morbidity of a disaster victim by providing effective treatment is of greater justice-based significance in a population than the psychosocial risks of compromised privacy. While loss of privacy occurs, clinical management can be adequately provided. Therefore, no exploitation occurs by relocating laboring patients under this condition.

A related ethical concern is the physical location for the performance of cesarean delivery. A unique aspect of the ethics of disaster management and obstetrics is that triage to prevent mortality must take into account the fact that there will be situations in which cesarean delivery is lifesaving, for both the pregnant and the fetal patient. If an obstetric operating room is needed simultaneously for both an obstetric patient and a non-obstetric disaster patient, the justice-based prevention of exploitation requires priority be given to the obstetric patient: two lives will be saved rather than one. One of those patients, the fetus, is wholly vulnerable and therefore deserves special protection. This ethical analysis has direct bearing on the triage of disaster victims in the hospital's emergency department: among disaster patients, pregnant women at-term with obstetric or non-obstetric conditions or injuries that are life-threatening, for either the pregnant or fetal patient, should be given surgical priority over all other disaster victims who have life-threatening injuries, to prevent exploitation of such pregnant or fetal patients.

Existing ethical standards should be applied to decisions about resuscitation of premature infants. Based on the above account of viability, we have argued elsewhere<sup>5</sup> that resuscitation of infants born at 22 weeks' gestation, as determined by reliable obstetric ultrasound dating, should not be offered or recommended. For infants at 24 weeks', who do not have prenatally diagnosed major fetal anomalies, resuscitation should be performed, and therefore should be recommended. For infants born at 23 weeks' gestation, resuscitation should be a mat-

ter of informed parental choice. Premature infants for whom resuscitation achieves its physiological outcome, restoration of spontaneous circulation, are, with very rare exceptions, intubated and placed on a ventilator. They should be transferred to the neonatal intensive care unit (NICU). Prematurely born infants in the NICU are, perhaps, the most physically vulnerable patients in a modern hospital and are not able to protect themselves from exploitation. If personnel or equipment in the NICU are needed for adult patients in other hospital units, decisions about their allocation should be based on the ethical guidance for which one of us (LBM) has argued in a previous issue of the *JCE*.<sup>6</sup>

There is one remaining, grim scenario: the scale of the medical disaster is so large that a hospital's resources to meet the standard of care for its patients—disaster and non-disaster alike—are completely overwhelmed. In such terrible circumstances, as one of us (LBM) has argued in the *JCE*, clinicians and hospitals should be held prospectively and retrospectively to a simple ethical standard: doing the best that one can.<sup>7</sup> For example, if the only physical space to perform an emergency cesarean delivery is the patient's room in non-sterile conditions, when all of the hospital's operating rooms are in use for other patients, a resulting surgical infection is an acceptable outcome. The pregnant patient should be informed that this is a risk that must be taken, and that every effort will be made to minimize that risk, as well as to monitor for and treat subsequent infection. In a rationally ordered universe, no liability should be incurred because one met the applicable standard: doing the best that one can.

## CONCLUSION

The ethics of managing obstetric patients in medical disasters should focus on justice-based prevention of exploitation in the population of both obstetric and disaster patients. That is, triage priorities should be based on preventing risks of mortality and of serious, far-reaching, and irreversible morbidity and lost function status of pregnant, fetal, and disaster patients. The

unique ethical feature of our proposed ethical framework is that clinicians' fiduciary obligations to both pregnant and fetal patients must be considered. The medical needs of two patients, not just one, and one of them who is wholly vulnerable, count ethically, and sometimes justifiably take priority over the needs of other patients in a medical disaster.

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# Non-Pharmaceutical Interventions to Limit the Transmission of a Pandemic Virus: The Need for Complementary Programs to Address Children's Diverse Needs

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## ABSTRACT

Non-pharmaceutical interventions, including social distancing, quarantine, and isolation, are a potentially attractive means to limit the transmission of a pandemic virus. Many of these interventions are directed at children given children's disproportionate role in amplifying epidemics. The ethics of non-pharmaceutical interventions can be analyzed using Nancy Kass' ethics framework for public health. Such an analysis highlights the limited data supporting these interventions' effectiveness. It also suggests the framework itself needs to be expanded to consider harms other than constraints on liberty and to consider affirmative programs to mitigate these broader harms.

Recent events, including 9/11, Hurricanes Katrina and Rita, and the novel H1N1 influenza pandemic, have focused attention on disaster

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preparedness. While some topics in this field have received significant attention, others have not. This article will focus on two relatively neglected subjects: non-pharmaceutical interventions to mitigate pandemics and pediatrics. We will use Nancy E. Kass's framework for public health ethics to examine the potential effects of social distancing, quarantine, and isolation on children.<sup>1</sup> We will argue that the debate needs to be broadened to examine harms other than constraining liberty and affirmative programs to minimize these wider harms.

In this article, we will analyze non-pharmaceutical measures to mitigate pandemics. Non-pharmaceutical measures include social distancing, quarantine, and isolation. *Social distancing* is a range of methods to decrease interpersonal contact, from avoiding handshaking to closing schools or prohibiting large social gatherings.<sup>2</sup> *Quarantine* is the sequestering of individuals exposed to the infection, while *isolation* is the sequestering of individuals who have contracted the infection.<sup>3</sup> The various non-pharmaceutical interventions are intended to be used in combination.<sup>4</sup> It is not clear, for example, what effect school closure will have on children's and adolescents' behavior outside of school, and this measure may need to be ac-

accompanied by the closure of other sites where they congregate.<sup>5</sup> Non-pharmaceutical measures can be distinguished from pharmaceutical measures, such as vaccination and drug treatment.

Non-pharmaceutical strategies are potentially attractive because a well-matched pandemic strain vaccine is unlikely to be available or in sufficient supply at the pandemic's start, and antiviral medications may be in short supply or ineffective. In addition, if they are effective, non-pharmaceutical measures will diminish the peak demand for medical services.<sup>6</sup> There are very limited data, however, on the effectiveness or unintended consequences of these measures, and little has been written about their ethical implications. In contrast, the ethics of allocating critical care resources has received much more attention.<sup>7</sup>

Our discussion will also focus on children. Although they are a vulnerable population, the needs of children have been relatively neglected in the discussion of disaster preparation.<sup>8</sup> In addition, children play an important role in the implementation of non-pharmaceutical measures, especially school closure and quarantine, because of their particular contributions to the transmission of influenza.

### FRAMEWORK FOR PUBLIC HEALTH ETHICS

Our analysis will be primarily ethical. We will use the perspective of public health ethics rather than bioethics. Bioethics has historically focused on the ethical issues related to medical care and research involving human subjects. The issues that led to its development have resulted in an emphasis on autonomy. In contrast, public health seeks to improve communities' health as well as reduce social inequities related to health outcomes through social action. The ethical framework for analyzing such interventions necessarily differs from the bioethical framework for analyzing clinical care and research. Kass proposes a framework that includes six questions:

1. What are the public health goals of the proposed intervention, policy, or program?
2. How effective is the intervention, policy, or

program in achieving its stated goals?

3. What are the known or potential burdens of the program?
4. How can burdens be minimized? Are there alternative approaches to achieve the same goals?
5. Is the program implemented fairly?
6. How can the public health benefits and the accompanying burdens be balanced? What procedures will best allow for fair consideration of differing views?<sup>9</sup>

We will use these questions to analyze non-pharmaceutical interventions effecting children. In the process, we will suggest modifications of the framework. Specifically, we will argue that the emphasis on the burden of constraining liberty is inordinate, especially when children are the subject, and that the consideration of minimizing burdens needs to expand beyond the intervention itself, to consideration of supplemental programs.

#### 1. What Are the Public Health Goals of the Program?

Appropriately, the goals of non-pharmaceutical interventions are to reduce morbidity and mortality. The focus is on the region in which interventions are implemented, although other regions may also benefit. Non-pharmaceutical interventions will accomplish this goal directly and indirectly.<sup>10</sup> (Consideration of other means to achieve this goal, such as travel restrictions, is beyond the scope of this article.) The Centers for Disease Control and Prevention (CDC) and the U.S. Department of Health and Human Services (DHHS) have identified three major goals for non-pharmaceutical interventions:

1. Delay the exponential growth in incident cases and shift the epidemic curve to the right, in order to "buy time" for production and distribution of a well-matched pandemic strain vaccine,
2. Decrease the epidemic peak, and
3. Reduce the total number of incident cases.<sup>11</sup>

Reducing the total number of incident cases directly reduces morbidity and mortality. Altering the growth of the epidemic indirectly re-

duces morbidity and mortality by buying time for the development of a vaccine that can then be used to prevent individuals from becoming infected. Decreasing the epidemic peak also indirectly decreases morbidity and mortality. In many pandemic scenarios, there will be inadequate clinical surge capacity to meet the needs of all individuals seeking treatment. The discrepancy between resources and demand may be most problematic in critical care. Decreasing the epidemic peak will decrease the number of individuals who will require treatment at a single time, and thereby decrease the potential unmet demand for treatment.<sup>12</sup>

Non-pharmaceutical interventions also have other types of potential benefits. They may help maintain the social infrastructure and/or decrease the economic losses.<sup>13</sup> These additional benefits are not, however, the programs' primary goal(s).<sup>14</sup>

## **2. How Effective Is the Program in Achieving its Stated Goals?**

Evidence for the efficacy of social distancing comes from a variety of sources, including historical analyses, mathematical models, and experience with seasonal influenza and influenza epidemics. The CDC and DHHS conclude, "Taken together, these strands of evidence are consistent with the hypothesis that there may be a benefit in limiting or slowing the community transmission of a pandemic virus by the use of combinations of partially effective [non-pharmaceutical interventions]. At the present time, this hypothesis remains unproven. . . ."<sup>15</sup> The CDC has, therefore, called for additional research.<sup>16</sup>

One of the fundamental issues that must be addressed is what would constitute sufficient evidence of effectiveness, given the nature of the evidence and its limited generalizability.<sup>17</sup> Because of their reliance on underlying assumptions, mathematical models can only play an ancillary role.<sup>18</sup> The other data regarding non-pharmaceutical interventions are largely observational. Within clinical medicine, observational studies are considered a lower level of evidence than randomized controlled trials or meta-analyses. It is not clear whether random-

ized controlled trials would be feasible or ethical. For example, what type of intervention, if any, would investigators be obligated to provide the control group? The issue of generalizability is twofold. Many of the observational studies analyze historical data from time periods with different social structures and healthcare resources. There are few methodologically sound modern observational studies. In addition, new epidemics may have unknown or different characteristics. It may not be clear at the time interventions must be implemented whether the results of the existing research are applicable to the new situation.

## **3. What Are the Known or Potential Burdens of the Program?**

Kass identifies three broad types of risks and argues that different public health activities are associated with different types of burdens. The three types of risks Kass describes are:

1. Risks to privacy and confidentiality,
2. Risks to liberty and self-determination, and
3. Risks to justice.

Kass nonetheless recognizes that some public health interventions pose physical risks or risks to health. In her illustrative comments on avian influenza, she emphasizes risks to liberty, noting their psychological and financial consequences.<sup>19</sup>

Kass implicitly focuses on adults and neglects the harms that are more relevant to children. Children only develop the capacity for autonomous action over time. Parents are the primary decision makers for their infants and children. While pediatric ethics emphasizes that the development of children's autonomy should be promoted and older children's and adolescents' autonomous decisions respected, it focuses primarily on beneficence—promoting children's well-being. It is important to acknowledge that children's well-being has multiple dimensions that develop over time. It involves not only their physical well-being, but also their social, emotional, and spiritual needs. The focus on children's needs has important implications for both biomedical and public health ethics.

Social distancing measures directed at children may have multiple harms beyond risks to liberty. School closure, for example, may have several orders of effects. Schools' primary goal is to educate students. They also have a number of secondary goals, including, but not limited to, providing students adequate nutrition.<sup>20</sup> Closure inhibits both types of goals. School closure may also have second- and third-order effects. Workplace absenteeism to provide child care threatens the loss of personal income or employment and could impair the delivery of goods and services.<sup>21</sup> Within the family system, the loss of parental income or employment has significant negative consequences for children. Women with dependent children represent an important proportion of the healthcare work force. Their absence could undermine the delivery of healthcare services at a time of increased demand.<sup>22</sup> Alternatively, if parents continue working, children may be placed at risk due to inadequate supervision.<sup>23</sup> Other higher order effects might include loss of public trust in government and stigmatization of affected groups.<sup>24</sup>

Contemporary planning emphasizes quarantine in homes rather than in designated facilities. Exposed individuals are instructed to take various measures to prevent transmission to other household members, should they develop an infection. Home quarantine of children or their parent(s) is more likely to meet children's needs by keeping families intact and children in familiar settings. Nonetheless, potential burdens include difficulty obtaining food, medication, and personal care items. As with school closure, the loss of parental income or employment and its indirect effects on children is a major concern. In their study of Toronto's severe acute respiratory syndrome (SARS) quarantine, DiGiovanni and colleagues, for example, report that fear of loss of income was the most common reason given for noncompliance. There is also evidence of negative psychological effects. During the SARS outbreak, fear, anxiety, isolation, loneliness, depression, boredom, and stigmatization were significant issues.<sup>25</sup>

Isolation may have significant negative effects on children. Isolation is the sequestering

of individuals with confirmed or probable infections and may occur in the home or hospital, depending on the type of medical treatment required. Isolation measures depend on the infection's mode of transmission. Excluding parents from hospitals, for example, interferes with their legitimate role as decision makers for their children. Isolation may also have negative effects on children's emotional and psychological well-being. In Koller and colleagues' qualitative study of children hospitalized in Toronto with SARS, children, parents, and healthcare providers reported sadness, loneliness, worry, and fear. Wearing personal protective equipment, such as tight-fitting masks that cover the mouth and nose, may exacerbate these responses by inhibiting communication.<sup>26</sup> Parental isolation for their own treatment may also intensify these burdens.<sup>27</sup>

#### **4. How Can Burdens Be Minimized? Are there Alternative Approaches to Achieve the Same Goals?**

Other authors frame this consideration in terms of requiring the least restrictive or least intrusive alternative. For example, voluntary interventions are generally preferred over mandatory ones. There are deontological and consequentialist reasons supporting this prioritization.<sup>28</sup> Experience in Taiwan during the SARS epidemic, for example, suggests that the aggressive use of quarantine contributed to panic and undermined the quarantine's intended goals.<sup>29</sup>

The CDC's *Planning Guidance* does not discuss less-restrictive means of social distancing for children, such as symptom screening at schools or modification of the school environment. It primarily focuses on implementing effective programs for the shortest duration necessary. For example, to be effective, social distancing should not be implemented before there is evidence of community transmission and not after it is too widespread.<sup>30</sup> The CDC and DHHS also recommend matching the intensity of the intervention to the severity of the pandemic. They argue it is reasonable to use a single criterion and support the use of the case fatality ratio, which is available early in a pandemic.<sup>31</sup> They recommend planning for short-term im-

plementation (less than four weeks) of child social distancing in moderate pandemics and prolonged implementation (one to three months) in severe ones.<sup>32</sup> (Early in the 2009 novel H1N1 influenza pandemic, however, when decisions about school closure needed to be made, data on severity and case fatality ratio were not available.)

In a similar way, the duration of quarantine should be related to the incubation period of the agent. The CDC and DHHS recommend a quarantine period of seven days following symptom onset, which should be extended, if other family members become ill, to seven days from the time that the last family member became ill.<sup>33</sup> If coercive measures are needed to enforce quarantine, they might vary in severity from monitoring, to fines, and finally to imprisonment.<sup>34</sup>

Isolation measures can also be graded to limit burdens. During the SARS outbreak, Hong Kong's Prince of Wales Hospital stratified its infection-control procedures based on how likely a sick child was to have SARS. The likelihood of SARS infection, for example, determined the types of eye protection, face mask, and personal protective clothing that staff, patients, and visitors were required to wear. Visitation also varied according to risk. Parental visitation was prohibited in the SARS isolation ward; parents were contacted by the medical staff daily. Parental visitation was permitted for two hours per day in the other wards.<sup>35</sup>

Insufficient attention, however, has been paid to additional programs to mitigate the burdens. Berkman, for example, uses the language of "proactive strategies for mitigating or minimizing potential adverse consequences."<sup>36</sup> There may be alternative ways, for example, for schools to advance their goals. While schools are "closed," faculty and staff may be able to provide instruction through means such as television and the internet. Cauchemez and colleagues, for example, report that France plans to provide educational continuity through lessons broadcast on television and radio, and teacher-student interactions via telephone or the internet.<sup>37</sup> This would both maintain learning and alleviate boredom.<sup>38</sup> In terms of schools'

non-educational goals, Berkman reports that while there have been efforts to improve food distribution following disasters, more work is needed to address the specific challenges of distributing food during a pandemic.<sup>39</sup>

Potential interventions to address second-order effects of non-pharmaceutical interventions include providing income replacement and ensuring job security.<sup>40</sup> Proactive strategies are important because existing mechanisms may be inapplicable or insufficient.<sup>41</sup> The Family and Medical Leave Act (FMLA), for example, is only applicable to a subset of individuals: employees with at least 12 months of service and 1,250 hours of work in the preceding year, and employers with 50 or more employees and state and local governments. Furthermore, leave is only granted for certain conditions: childbirth, adoption, or a "serious health condition." While FMLA may apply to individuals caring for an infected family member, it is unlikely to apply in cases of school dismissal or quarantine. Finally, while FMLA provides job security for 12 weeks, it does not provide income replacement.<sup>42</sup>

Programs to provide income replacement and guarantee job security are nonetheless feasible. Countries affected by the SARS epidemic enacted a variety of programs.<sup>43</sup> Ontario's SARS Assistance and Recovery Strategy Act of 2003, for example, provided an unpaid leave of absence for employees in a variety of situations, including those under quarantine or isolation and those caring for a family member.<sup>44</sup>

Other proactive programs to reduce burdens may include directing public education and communication, including information about infection-control measures during quarantine,<sup>45</sup> specifically at children and adolescents;<sup>46</sup> providing food and supplies to those under quarantine and non-hospital isolation;<sup>47</sup> supporting appropriate parental visitation in hospitals;<sup>48</sup> providing alternative modes of communication for those under isolation, both between children and their families and between families and their children's healthcare providers;<sup>49</sup> providing emotional and psychological support;<sup>50</sup> and ameliorating fear, stigmatization, and discrimination.<sup>51</sup>

### **5. Is the Program Implemented Fairly?**

Both the burdens and the benefits must be distributed fairly.<sup>52</sup> Focusing social distancing on children is justified because of their disproportionate role in epidemic amplification. Children play an important role in disease transmission, due both to their own characteristics and the nature of their environment. Children, in comparison to adults, are more susceptible to viruses, shed more virus, shed virus for a longer period, and are less skilled in handling their secretions. In addition, preschools, schools, public transportation, and school buses are socially dense environments that promote transmission. For example, preschool classrooms have 35 to 50 square feet per child, compared to office buildings and large retail buildings with 390 to 470 square feet per person. Children, therefore, are appropriate targets of intervention. Potential means of social distancing for adults should not, however, be neglected. Methods include canceling large community gatherings and altering workplace environments and schedules to decrease social density.<sup>53</sup> Employees could also be permitted to work at home or telecommute.

Within interventions, children's needs should be met fairly. This will require studying isolation measures in home environments and designing personal protective equipment for children.<sup>54</sup>

While this analysis has focused on children per se, the effects on children as members of low-income and minority populations should also be considered.<sup>55</sup> Individuals with low incomes may, for example, be less able to stay home from work. In addition to being less able to afford the loss of income, they may not have sick leave or the type of work that permits working at home. They may be more reliant on communal child care, increasing their children's risk of exposure. Income replacement and job security measures may, therefore, be particularly important for low-income families.<sup>56</sup> Some authors have argued that compensation programs are justified not only on the basis of increasing compliance, but also on the basis of reciprocity or fairness.<sup>57</sup>

### **6. How Can the Public Health Benefits and the Accompanying Burdens Be Balanced? What Procedures Will Best Allow for Fair Consideration of Differing Views?**

Finally, a decision must be made. Acknowledging our morally pluralistic society, Kass emphasizes fair procedures to permit the expression of minority views and dissent.<sup>58</sup> The emphasis on participation exceeds narrower claims regarding transparency or public justification.<sup>59</sup> There have been efforts to encourage public participation as part of pandemic planning.<sup>60</sup> To the extent that children and adolescents are able to meaningfully participate, they should be included. Otherwise mechanisms should be developed to assure that their interests are considered.

## **CONCLUSIONS**

Given the limited ability to produce a well-matched pandemic-strain vaccine rapidly, to stockpile enough effective antiviral medications, and to create sufficient surge capacity, non-pharmaceutical mitigation strategies are potentially attractive. Such discussion should include analysis of ethical issues and children's needs. Children's emotional and developmental needs must be met in addition to protecting adolescents and adults' liberty. The ethical framework for public health should be broadened to include not only the minimization of direct burdens of an intervention, but also additional interventions to reduce these burdens.

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# Attending to Social Vulnerability When Rationing Pandemic Resources

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## ABSTRACT

Pandemic plans are increasingly attending to groups experiencing health disparities and other social vulnerabilities. Although some pandemic guidance is silent on the issue, guidance that attends to socially vulnerable groups ranges widely, some procedural (often calling for public engagement), and some substantive. Public engagement objectives vary from merely educational to seeking reflective input into the ethical commitments that should guide pandemic planning and response. Some plans that concern rationing during a severe pandemic recommend ways to protect socially vulnerable groups without prioritizing access to scarce resources based on social vulnerability per se. The Minnesota Pandemic Ethics Project (MPEP), a public engagement project on rationing scarce health resources dur-

ing a severe influenza pandemic, agrees and recommends an integrated set of ways to attend to the needs of socially vulnerable people and avoid exacerbation of health disparities during a severe influenza pandemic. Among other things, MPEP recommends:

1. Engaging socially vulnerable populations to clarify unique needs and effective strategies;
2. Engaging socially vulnerable populations to elicit ethical values and perspectives on rationing;
3. Rejecting rationing based on race, socioeconomic class, citizenship, quality of life, length of life-extension and first-come, first-served;
4. Prioritizing those in the general population for access to resources based on combinations of risk (of death or severe complications from influenza, exposure to influenza, transmitting influenza to vulnerable groups) and

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the likelihood of responding well to the resource in question;

5. Protecting critical infrastructures on which vulnerable populations and the general public rely;
6. Identifying and removing access barriers during pandemic planning and response; and
7. Collecting and promptly analyzing data during the pandemic to identify groups at disproportionate risk of influenza-related mortality and serious morbidity and to optimize the distribution of resources.

## INTRODUCTION

Groups suffering social vulnerabilities may suffer disproportionately from a severe influenza pandemic.<sup>1</sup> Several such groups, for instance, experienced disparately high hospitalization and death rates from H1N1 pandemic influenza.<sup>2</sup> Discussions about whether, when, and how socially vulnerable groups should be attended to in pandemic planning and rationing of scarce resources are receiving increasing attention. Nevertheless, key questions about fairness continue to be unsettled, and guidance on how social vulnerability ought to factor into rationing decisions remains scant and contradictory.

In this article we review trends in pandemic guidance on socially vulnerable groups, describe the Minnesota Pandemic Ethics Project's (MPEP's) work on the topic, and signal where MPEP's recommendations fit in the array of guidance currently available.

We use the term "socially vulnerable" because that was the term embraced in MPEP. MPEP uses social vulnerability to refer to:<sup>3</sup>

... groups that suffer health disparities due to factors such as race, ethnicity, low income, poor education, geography (e.g., live in high density urban centers or live in isolated areas far from access to critical care resources), disability or sexual orientation.<sup>4</sup> Vulnerability may stem from many factors, including poor access to health care resources, inability to stockpile resources recommended by public health authorities and differences in exposure, susceptibility, resiliency and treatment.<sup>5</sup> Groups with compounded social vulnerabilities may have

particularly low resiliency during a severe pandemic and be at heightened risk of flu-related complications.<sup>6</sup>

## ATTENDING TO VULNERABILITY

State and national pandemic plans provide little guidance about how scarce resources should be allocated to groups suffering social vulnerabilities.<sup>7</sup> Federal guidance on prioritizing groups to receive influenza vaccine and antivirals is silent on these questions, as is much other pandemic planning literature.<sup>8</sup> The little guidance that mentions socially vulnerable groups often consists of a sole recommendation of the following sort: distribute resources to vulnerable populations equitably; inform vulnerable groups of their priority to receive resources; ensure fair access to resources; or remove barriers to access.

There is, however, growing attention in the literature on pandemic planning to socially vulnerable groups, and a spectrum of recommendations about responding to their special needs and interests is emerging.<sup>9</sup> Table 1 outlines six general types of recommendations, as well as a broad spectrum of specific recommendations (columns 1 and 2).

The range of rationing recommendations pertaining to socially vulnerable groups in a pandemic is striking. At one end of the spectrum, pandemic rationing guidance takes no account of social vulnerability. At the other extreme, some ethicists assert that the needs of vulnerable populations should be prioritized before any other group, including other groups at high risk.<sup>10</sup> Kaposy argues that when multiple people with equal clinical need compete for the same mechanical ventilator, it is appropriate to prioritize among them based on differences in social vulnerability.<sup>11</sup> The World Health Organization's ethics guidance mentions prioritizing vulnerable groups as an option for pandemic planners to consider, without elaborating whether to prioritize these groups simultaneously with, or before, other groups.<sup>12</sup> Many members of the public participating in public engagement activities about whether to prioritize access to resources based on differences in

social vulnerabilities (including most participants in MPEP) tend to prefer prioritizing according to other criteria.<sup>13</sup>

Some guidelines state that it is important to educate vulnerable groups about pandemic influenza so as to build their trust and willing-

ness to comply with pandemic response plans and to build their capacity to fulfill their role as citizens.<sup>14</sup> Other recommendations focus on the importance of collecting data and learning more about specific groups with health disparities.<sup>15</sup> Some of these recommendations include calls

**Table 1.** Ways to Attend to Socially Vulnerable Groups (SVGs) when Planning for Severe Pandemic

Type of Recommendation	Specific Recommendation	MPEP* Recommends	MPEP Rejects
Status quo	No special attention		+
Educate	Educate to increase trust and compliance	+	
	Educate to reduce barriers and increase access	+	
	Educate to empower SVGs	+	
Data collection	Collect/analyze data re: SVGs to identify risk of flu-related complications	+	
	Track and adjust the distribution of resources to avoid exacerbating health disparities	+	
Remove barriers	Remove cost barriers to access	+	
Public engagement	Conduct public engagement without special inclusion of SVGs		+
	Engage to identify barriers	+	
	Engage to identify strategies to reduce barriers	+	
	Engage to identify key worker groups	+	
	Engage to protect against compounding stigma and marginalization	+	
	Engage and elicit input re: which ethical objective(s) to guide rationing	+	
	Engage and elicit value preferences re: how to prioritize various groups including SVGs, key workers, high risk, etc.	+	
Rationing			
Discrimination	Don't ration based on socio-economic class, race, citizenship	+	
	Don't ration based on quality of life	+	
	Don't ration based on projected years of life saved	+	
	Don't systematically de-prioritize any group	+	
Prioritization	Permission to consider prioritizing SVGs without guidance about how		+
	Assume all SVGs are at high risk and prioritize together with other high-risk groups		+
	Among persons at comparable risk, differences in social vulnerability should be a secondary consideration meriting prioritization		+
	When rationing, prioritize SVGs before other groups		+
Health disparities	When rationing, don't exacerbate health disparities	+	
Compensatory	When rationing, reduce/eliminate health disparities		+
	Prioritize SVGs to rectify historical injustices		+

\* Minnesota Pandemic Ethics Project

to strengthen the infrastructure for collecting and analyzing mortality/morbidity data so that public health officials have the capacity to attend to such social characteristics as differences in race and ethnicity, income, and zip code.<sup>16</sup> Pandemic plans sometimes recommend removing access barriers only very generally, or focus narrowly on removing a single barrier. For example, Massachusetts and New Mexico propose providing services for free or at low cost, and making reasonable efforts to ensure that economically underprivileged groups receive resources.<sup>17</sup>

A final type of recommendation for attending to socially vulnerable groups calls for actively engaging members of such groups in pandemic planning. Although calls for public engagement are increasingly common, many who have issued such calls have yet to engage socially vulnerable groups.<sup>18</sup> Moreover, the objectives of the engagement activities vary.<sup>19</sup> Few authors specifically call for engaging with vulnerable groups about ethical issues in pandemic planning, including:

- What ethical objective(s) should guide rationing?
- What ethical considerations should be used to prioritize different groups for access to diverse types of resources?
- When is it appropriate to prioritize access based on non-clinical considerations, and might differences in social vulnerability be an ethically acceptable type of non-clinical consideration for prioritizing groups' access to resources?

MPEP is one of a small number of initiatives that designed and conducted public engagement activities so that rationing guidance would be informed by the ethical commitments and preferences of socially vulnerable members of the public, among others.<sup>20</sup>

### THE MINNESOTA PANDEMIC ETHICS PROJECT

The phrase “public engagement” is used variably in the literature, sometimes encompassing those with professional stakes in the out-

comes and sometimes encompassing only the general public. Although MPEP gleaned input from both stakeholders and laypersons, here we will focus on input from the general public.

Public engagement was a core commitment in MPEP. Among other things, it offered a procedural way of treating socially vulnerable groups fairly. Rationing scarce health-related resources involves high-stakes decision making, likely affects some community members more than others, and little was known about the range of ethical perspectives held by diverse Minnesotans.<sup>21</sup>

MPEP involved several public engagement activities, and more detail about methodology and results is published elsewhere.<sup>22</sup> First, the project team and the Minnesota Department of Health (MDH) recruited the panel that was ultimately responsible for recommending to MDH ethical frameworks for statewide rationing of scarce health-related resources in a severe influenza pandemic. The panel comprised approximately 45 Minnesotans representing a broad range of interests, expertise, and experience. It was not limited to pandemic experts, but included lay members of the public, as well as representatives of socially vulnerable groups (for example, representatives from neighborhood organizations and advocates for people with disabilities, seniors, and children).

The panel focused on scenarios involving different types of resources:

- Prevention (vaccines, antivirals, N95 respirators, and surgical masks),
- Primary care treatment (antivirals), and
- Critical care treatment (mechanical ventilators).

As a tool to aid the panel's ethical deliberation, the project team drafted several “single-goal” ethical frameworks for rationing each resource. Examples of such goals included ensuring equal access, saving the most lives possible, and protecting long-term social and economic stability. One such discursive framework invited panel members to outline the objectives, strategies, and implications if rationing were designed solely to redress historical and current injustices suffered by socially vulnerable groups.

Although redressing health disparities is a laudable fairness goal, the panel felt that it is neither the only nor the most important public health goal in a severe pandemic. Panel members observed that a severe pandemic is not the appropriate time to seek to redress historical injustices in the healthcare system and society at large. Although the panel decided to recommend that Minnesota not ration based on a single-minded focus on redressing historical injustices, it embraced a related, but more modest, fairness objective. It recommended that protecting against exacerbation of health disparities be included among several components of the fairness objective, which it balanced with two public health objectives, namely; protecting the population's health and protecting public safety and social order.

The panel rejected rationing strategies that are discriminatory or exacerbate health disparities, such as rationing based on race/ethnicity; income; geography; first-come, first-served; and so on. It also rejected prioritizing based on differences in social vulnerability. However, if implemented properly, its recommendation to consider various combinations of relative risks (mortality and serious morbidity, exposure and transmission) should accord priority to many people who suffer social vulnerabilities. The panel felt this was a fairer and more effective way of protecting the health of the population—including the health of vulnerable groups—than to assume that everyone who is socially vulnerable is at the same heightened risk of influenza-related complications, regardless of the specific strain of virus in circulation.

Second, the project team convened community forums and small discussion groups around the state, which were diverse in a number of respects. The two large, 100-person community forums were generally representative of the small cities where they were held. Nine small discussion groups were targeted to particular subpopulations. Some discussion groups had a high proportion of participants who were homeless, unemployed, or of low economic status. Groups were diverse with respect to race and ethnicity, with some groups being predominantly American Indian, African American, or

Latino. One group was entirely comprised of people living with severe disabilities, most requiring personal care attendants to assist with activities of daily living. In all, approximately 600 people weighed in on how Minnesota ought to fairly ration scarce resources in a severe pandemic.

Many of the socially vulnerable participants in the forums and small group discussions preferred not to be accorded higher priority. They thought resources would be better allocated if they were first directed to critical infrastructures on which they heavily relied, and they were concerned about being stigmatized. MPEP ultimately recommended an expansive set of intersecting strategies for attending to the needs, interests, and ethical perspectives of socially vulnerable groups in state planning for a severe influenza pandemic (see table 1, column 3).

#### **PUBLIC ENGAGEMENT WITH SOCIALLY VULNERABLE GROUPS: PURPOSE**

MPEP underscored five reasons, based on commitments to substantive fairness, why states should include members of socially vulnerable groups in public engagement activities when preparing for a severe influenza pandemic:

##### **Identifying and Removing Barriers**

To identify access barriers (financial/social/geographic/communication) and strategies for the removal of those barriers, taking into account differences in language, culture, and access to various types of media; to offer strategies that are feasible and not counterproductive.

##### **Defining Key Workers**

To help identify types of workers/students/volunteers on whom socially vulnerable groups depend, who should be included in the list of key workers prioritized, to various degrees, for access to scarce resources.

##### **Avoiding Increased Marginalization and Stigma**

To improve access to resources in a severe pandemic in ways that protect against stigma, further marginalization, and exacerbation of

health disparities within vulnerable populations.

### **Identifying Core Ethical Objective(s) to Guide Rationing**

To elicit input regarding which ethical objective(s) ought to guide statewide rationing of various types of resources during a severe pandemic.

### **Prioritizing Groups**

To elicit value preferences of socially vulnerable people about whether and how to prioritize access to health resources, based on differences in social vulnerability relative to other considerations, such as high risk of flu-related complications and key worker status.

## **ACCESS BARRIERS**

The community forums and small group discussions identified access barriers and strategized means of removing them.<sup>23</sup> For example, participants emphasized the need for special plans about where persons who use wheelchairs can safely and effectively access resources, since wheelchairs do not function well in crowds or in snow. Participants also noted that Medicaid restrictions prohibit recipients from acting on federal guidance to individuals and families about how to prepare for and protect oneself during a pandemic. They recommended policy changes so that Medicaid recipients would have more opportunities to stockpile basic resources, including food, water, and pharmaceuticals. They also recommended that government officials credibly ensure that immigration authorities would not be present in clinics providing immigrant communities access to vaccines, antivirals, and other pandemic-related resources. Most MPEP participants agreed that resources should not be limited to citizens or documented persons.

Access barriers must be identified and addressed during the planning process, as well as during the pandemic itself. They are best understood with the groups who experience them, hence, the value of public engagement with members of these groups to identify and strate-

gize about reducing access barriers and to avoid inadvertently stigmatizing or further marginalizing any groups.<sup>24</sup> The panel strongly recommended steps to remove social, economic, language, and geographic barriers to accessing resources.<sup>25</sup>

## **MPEP'S RECOMMENDATIONS REGARDING RATIONING AND SOCIALLY VULNERABLE GROUPS**

When particular socially vulnerable groups are at heightened risk of influenza-related mortality and serious morbidity, members of that group will be prioritized for access, together with other groups at similar risk. This underscores the value of timely data collection and analyses, which are sensitive to the potential impact of social vulnerability on clinical risk and effectiveness.

The ethics recommendations stemming from MPEP's public engagement helped to ensure that the rationing frameworks protect against exacerbating social vulnerabilities:

- Include and empower socially vulnerable groups;
- Take care not to compound stigma for groups that already suffer discrimination;
- Define critical infrastructures and key workers with care, for example, according priority to personal care attendants on whom persons with disabilities rely for lifesaving services;<sup>26</sup>
- Neither over- nor under-prioritize key workers, and protect against unfair relaxation/expansion of the criteria for identifying individual key workers. Although it is not always in one's self-interest to be prioritized before key workers, every time key workers are prioritized to receive resources, there are fewer resources for members of high-risk groups in the general population;
- To preserve trust, be accountable for and transparent about rationing decisions (including deciding which key workers to prioritize);
- Track and adjust the distribution of scarce resources so as to avoid exacerbating health disparities; and

- Take care not to systematically de-prioritize any group from protection and benefits.

The panel agreed with many others that some considerations are unfair bases for rationing, such as ability to pay, social or economic status, political power, race, citizenship, and gender. The panel also expressly rejected rationing based on judgments about differences in quality of life and life expectancy. It discussed the appropriateness of de-prioritizing people who would be unaware of any benefit they might receive from a scarce resource, such as people suffering from advanced dementia.<sup>27</sup> Ultimately, though, the panel rejected this criterion because of reluctance to consider the very subjective notion of quality of life and in order to protect against bias and systematic unfairness.

The panel concluded that it is unfair to prioritize access to resources based on differences in anticipated life span (such as likelihood of extending life by five years versus 15 years<sup>28</sup>), except for the very narrow circumstance of de-prioritizing individuals with an underlying condition that makes it relatively certain that they will die within a couple of weeks or months. It rejected considering differences in years of life saved because:

1. In a severe pandemic it would be infeasible to access the individual health records necessary to apply the principle fairly, and
2. It would exacerbate health disparities. This concern arises because the life expectancy of some groups (like affluent White women) is significantly higher than the life expectancy for others (like Native American men). The panel rejected considering life expectancy, because it would result in prioritizing privileged groups simply because they are more likely to live longer.<sup>29</sup>

Finally, the panel advised against relying on first-come, first-served as a proxy for randomization, in order to avoid inadvertently reinforcing social and geographic inequities in access to health resources.

The panel considered prioritizing vulnerable groups to receive health resources before all others, but ultimately decided against it for

several reasons. First of all, public health disasters are not the time to rectify long-standing historical patterns of injustices. Moreover, prioritizing socially vulnerable groups in this way is not the optimal way to protect such groups, or Minnesotans generally. Routinely prioritizing socially vulnerable groups before other groups, including key workers and groups at high risk, is inefficient, often is counterproductive and less protective of vulnerable groups, can increase social injustices to vulnerable groups in the form of increased stigma and marginalization, and is unfair to people who are at higher risk but denied resources.

The panel's comprehensive recommendations regarding when, how, and why to attend to the special interests, needs, and perspectives of socially vulnerable groups are consistent with its more extensive set of ethical recommendations regarding rationing (see table 2). Further detail about MPEP's ethical frameworks for rationing antivirals, vaccines, mechanical ventilators, N95 respirators, and surgical masks is available elsewhere.<sup>30</sup>

## CONCLUSION

MPEP has contributed to the recent trend in pandemic and disaster planning that calls for special attention to the needs, interests, and perspectives of socially vulnerable groups, without necessarily also calling for their prioritized access to health resources. Prioritization is neither the only, nor always the best, way to fairly and effectively attend to each group in a public health emergency. MPEP recommends that socially vulnerable groups be an important focus of data collection and efforts to remove access barriers. They should also be at the table to assist with identifying pandemic-related critical infrastructures, key workers, and the ethical values used to guide rationing decisions. The absence of social vulnerability in the panel's lists of prioritization criteria should not be misunderstood as signaling a lack of attention to the needs and interests of socially vulnerable groups. Quite the contrary: the design and fair implementation of MPEP's ethical frameworks for rationing seek to be attentive throughout,

**Table 2.** Ethical Frameworks for Rationing Health Resources in Minnesota in a Severe Influenza Pandemic: At-a-Glance

Ethical commitments for pandemic planning and response

Pursue Minnesotans' common good in ways that:

- Are accountable, transparent, and worthy of trust;
- Promote solidarity and mutual responsibility;
- Respond to needs fairly, effectively, and efficiently.

Ethical objectives for rationing resources in a severe pandemic

Steward scarce resources to promote Minnesotans' common good by balancing three equally important and overlapping ethical objectives.

- Protect the population's health by:
  - Reducing mortality and serious morbidity from influenza and its complications;
  - Reducing mortality and serious morbidity from disruption to basic health care, public health, public safety and other critical infrastructures.
- Protect public safety and civil order by:
  - Reducing disruption to basic health care, public health, public safety and other critical infrastructures;
  - Promoting public understanding about and confidence in resource distribution.
- Strive for fairness and protect against systematic unfairness by:
  - Reducing significant group differences in mortality and serious morbidity;
  - Making reasonable efforts to remove barriers to access;
  - Making reasonable efforts to reciprocate to groups accepting high risk in the service of others;
  - Rejecting strategies that are discriminatory or exacerbate health disparities;
  - Using fair random processes for those similarly prioritized.

General strategies

- Consider and adjust strategies as part of a comprehensive pandemic response plan.
- Revise strategies in light of new information about a specific pandemic.
- Extend supplies and conserve resources before rationing; ration only as a last resort.
- Scale rationing strategies to different levels of scarcity.
- Do not ration based on:
  - First-come, first-served;
  - Judgments that some people have greater quality of life than others;
  - Predictions that some people's lives can be extended more than others (except for people who are imminently and irreversibly dying);
  - Race, gender, religion or citizenship;
  - Judgments that some people have greater "social value" than others.
- Generally, de-prioritize people who are unlikely to benefit from the resource.
- Generally, prioritize key workers on a separate track in parallel with a track for the general public, recognizing that in limited circumstances a two-track approach might not be justified.
- Ration different resources based on varying combinations of the following considerations (rather than resort to random processes from the start).
  - For the general public:
    - Risk of flu-related mortality and serious morbidity;
    - Good or acceptable response to resource;
    - Risk of exposure to flu;
    - Risk of transmitting flu.
  - When appropriate to prioritize key workers separately from the general public, consider:
    - Risk of occupational exposure to flu;
    - Risk of flu-related mortality and serious morbidity;
    - Irreplaceability in the critical infrastructure work force;

*Table 2 continued next page.*

Table 2, Continued from previous page

- Risk of transmitting flu;
- Good or acceptable response to resource.
- When the supply is inadequate to serve all similarly prioritized people then use a fair random process. Note: Under limited circumstances and if feasible, before resorting to randomization among the general public in any given tier, consider prioritizing children. Then depending on the resource and its supply consider prioritizing younger adults before older (either after children or simultaneously with them, as the supply allows).

Source: D.E. Vawter et al., *For the Good of Us All: Ethically Rationing Health Resources in Minnesota in a Severe Influenza Pandemic* (St. Paul, Minn.: Minnesota Center for Health Care Ethics and University of Minnesota Center for Bioethics, 2010), <http://www.health.state.mn.us/divs/idepc/ethics/>, accessed 17 March 2011.

procedurally and substantively, to the perspectives and values of socially vulnerable groups.

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