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At the Bedside

A Different Approach to Patients and Loved Ones Who Request "Futile" Treatments

Edmund G. Howe

ABSTRACT

The author describes an alternative approach that careproviders may want to consider when caring for patients who request interventions that careproviders see as futile. This approach is based, in part, on findings of recent neuroimaging research. The author also provides several examples of seemingly justifiable "paternalistic omissions," taken from articles in this issue of *The Journal of Clinical Ethics* (*JCE*). The author suggests that while careproviders should always give patients and their loved ones all potentially relevant information regarding "futile" decisions, careproviders may wish to consider, paradoxically, not giving advice in these situations, when the advice is based mostly or wholly on their own moral views, based on this same, ethical rationale.

One of the most painful dilemmas that careproviders presently face is how to respond when a patient or a patient's loved one wants a treatment that the careprovider believes is "futile." Recent publications from the American Medical Association discuss *informed assent* and *selective paternalism* as possible approaches that careproviders could consider in these situations, which hints at the pain that all parties may feel in these situations. These publications suggest that many careproviders believe that, when necessary, they must be able to deny patients and loved ones such care.[1]

In this issue of *The Journal of Clinical Ethics* (*JCE*), I will present a different approach that careproviders may use, at least initially, that could be preferable for all parties. To support this approach, I will describe a just-published neuroimaging study—the first of its kind—and data regarding the use of this approach with real patients.

First, I will discuss three cases from articles that appear in this issue of *JCE*. All of the cases are characterized by careproviders and patients who feel particularly intense emotional turmoil. In the first case, a physician and nurse in Israel are performing a colonoscopy, and, during the procedure, the physician, nurse, and patient suddenly become subject to a rocket attack. In the second case, which occurred after the 2010 earthquake in Haiti, an emergency physician has to decide which of four patients she should try to save; all need oxygen, urgently, to save

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their lives, and all have air hunger. In the third case, a patient is dying and wants to go home, but there is no one there who can care for him. What should his careproviders do?

I will discuss important issues that each case raises, and a question that all of the cases pose, which has profound implications for how careproviders face questions involving futile treatment—and numerous other, similarly difficult ethical questions as well.

Finally, I will describe a different approach to futility. I will consider what is "state of the art" in this area, some early data on this different approach, and its underlying rationale. The core principle underlying this different approach is to start by considering what a patient or loved one is most likely to feel, and go from there. Intentionally or not, the careproviders in these three cases followed this approach.

THE "LESSON" INHERENT IN THESE THREE CASES

Should We Limit When We Ask Patients to Make Life-and-Death Decisions?

In "Endoscopy During a Missile Attack: A Military Dilemma for Physicians," Stephen Malnick, Orit Faraj, and Alan Jotkowitz relate how, during a colonoscopy, rockets began to rain all around them.[2] This raised the ethical question of what to do: Leave the patient unattended and try, in 90 seconds, to reach safety? Remove the endoscope from patient and then try to seek safety for all? We might propose, for example, that the careproviders should simply stay with the patient, although this would cause all of parties to be at higher risk.

The authors note that many civilian urban centers of the world may become a "battlefield," and that citizens in these areas may find themselves in "acute war situations" within "seconds." It could be imagined that both patients and careproviders in these situations may feel that the loss of only one life is better than the loss of several.[3] Malnick, Faraj, and Jotkowitz go beyond this. They ask, more generally, what greater measures careproviders can take to eliminate or diminish problems such as these that could be anticipated. They highlight two concerns that pertain to careproviders everywhere: that they are vulnerable to outside factors, such as, in this case, the stress created by trying to perform a procedure during a rocket attack, as well as "inside factors" such as fatigue, that may greatly impair their capacity to give patients optimal care. For example, when a careprovider performs a colonoscopy, she or he may do this better in the morning than in the afternoon.

There is a question in this case that the careproviders did not ask; they did not ask the patient what he or she would want done. We might wonder why not. Usually, not asking a patient about something like this might be seen as insufficiently respecting a competent patient's autonomy; after all, the patient's life was also at risk. But was "asking" warranted under these circumstances? And, of course, was there adequate time to ask?

It may be that, consistent with the authors' recommendation, once having had the experience of being subject to a rocket attack while performing a procedure, they could ask patients in advance what they would want to do in the future. On the other hand, this would hardly help to relieve any apprehension patients might feel. In this instance, we could imagine, the careproviders didn't ask this patient because they believed that it would be "too much," too overwhelming, if they did.

If these surmises are accurate, this case could be seen as illustrating *paternalism by omission,* that is, when a careprovider makes a choice, not maximize a patient's autonomy, but instead to spare the patient from real (or imagined) unjustifiable harm. This is what occurs legally, overtly, when a careprovider exercises therapeutic privilege and knowingly withholds information from a patient for the patient's own good. Whether a judgment was warranted can be contested in court. More covertly, this occurs when an institutional review board (IRB) precludes possible research participants from being able to subject themselves to certain kinds of research harms.[4]

My point is that the ethical considerations in this case of colonoscopy during missile attach begin, at least implicitly, from a conscious

(or unconscious) recognition of the patient's "human" (that is, emotional) limitations. Careproviders who confront ethical considerations in the delivery of futile treatment might also begin here, because patients may become overwhelmed by the same kinds of feelings when they fear that their careprovider will refuse to provide what the careprovider considers to be futile treatment.

Should We Limit What We Tell Patients about How Life-and-Death Decisions Are Made?

Michelle Daniel, in "Bedside Resource Stewardship in Disasters: A Provider's Dilemma Practicing in an Ethical Gap," in this issue of *JCE,* describes the anguish she experienced while in Haiti after the 2010 earthquake, trying to decide whose life, among four patients, she should try to save.[5] She was there as an emergency physician working night shifts, and relates she was "lucky" to sleep "three hours a day." (This echoes the previous authors' concerns regarding fatigue). Of course, her question is which of the four she should save.

As Jeffrey T. Berger points out in "Resource Stewardship in Disasters: Alone at the Bedside,"[6] in this issue of *JCE,* peer support can be "critical" when a careprovider feels agonizing moral distress due to having to make the kind of triage decisions alone that Daniel did. Daniel and others might find some comfort in knowing that there may be no "boiler-plate" rubric that is better than the rubric they construct on their own, because their rubric alone is tailored to their own unique context. There might be some comfort in knowing that even with the uncertainty they feel, they are heroic. Although all four of Daniel's patients that one night shift required oxygen, there was only one oxygen tank, and all of the patients had "air hunger."

Daniel raises concerns that she might have been overly influenced because one patient was a nurse—a careprovider like herself—or that she found another patient to be "heart-breakingly beautiful." She asks herself, unsparingly, if she is overly influenced by one of those factors, or both. Deeply hidden biases in our nature, she remarks, can lead even the best-intentioned individual astray.

She, as any of us, could be biased without our knowing it. In an attempt to prevent this, we could consciously shift too far in the other direction. For example, I routinely fear this when I have an opening in my outpatient psychiatry schedule. When I have an opening, I can choose to continue to see a new patient, or I can refer the new patient to another psychiatrist. I fret that I may do one or the other, not for the patient's good, but for my own good. That is, some patients are more "concrete" in their thinking than others—for instance, if you ask such a patient, "What does the phrase, 'People who live in glass houses shouldn't throw stones,' mean?" and the patient might answer, "Well, if you throw a stone, somebody might get hurt." For me, a patient who can be more "abstract" is more likely to be engaging and challenging. Thus, I fear that when making a decision to continue to see a patient or to refer, I may respond more to my own needs than to the patient's.

Likewise, I fear going "a step further" for other members of the careproviding profession. For example, I may consider prescribing a greater number of medications at one time to save a careprovider-patient from waiting as long in line at a pharmacy. This consideration is important. For example, Kay Redfield Jamison, an expert on bipolar illness who has the disorder herself, said, regarding a colleague's doing this for her after her husband died: "My colleague made it easy for me. Instead of my having to call one of my doctors and wait at a pharmacy . . . he took it into his own hands to get a prescription filled. It was a small act of kindness but enormously important."[7] But, on the other hand, such efforts would be important to any patient.

Daniel, the emergency physician-responder in Haiti, explains that she thought if she gave her patient who was a nurse the oxygen, that morally, if the nurse lived, he might be able to help others to a greater extent, since he was a careprovider. Daniel also thought that since the nurse was a careprovider, he might have, "in the line of duty," taken on more risks on behalf of others, and thus might more deserve to have a chance to live and continue serving others.

Each of her arguments, in and of itself, has ethical merit. But it is important to note that we may use arguments that are sound in themselves to rationalize how we want a situation to come out for other reasons, without knowing it.

Daniel also fears she may have overresponded to the patients' looks. This is a risk to which we are all prone, and it may be greater than we imagine. In one study, even though subjects were not given enough time to clearly see faces that were projected on a screen, their ability to "guess" regarding how they would rate the "attractiveness" of the faces was "surprisingly accurate." More importantly, once the subjects made judgments about the attractiveness of the faces, the subjects became "primed" to make more-positive subsequent judgments about other aspects of the people behind the faces whom they found attractive, even though there was no basis for the accuracy of their judgments. And, interestingly all of the subjects' subsequent judgments were made more quickly than their initial judgement.[8]

Such quickly based judgments may affect how a patient responds when he or she senses that a careprovider may withhold a treatment that the careprovider believes is futile. The human brain may be hard-wired to do this, some believe, because such "thin-slicing" may enable us to make snap judgments useful for survival. A brain that responds in this way may, for example, help us select healthier "mates" and avoid disease.[9]

To return to Daniel's emergency response experiences in Haiti, and to the medical team's analysis of the missile attack during a colonoscopy. What was it that did Daniel not say to her four patients? She didn't tell them that she was determining which one among the four of them would have a chance to live. And her reason is one that we can surmise.

Matthew Hunt, Christina Sinding, and Lisa Schwartz, in "Tragic Choices in Humanitarian Health Work," in this issue of *JCE,* suggest that it may seem "cruel" to people in a catastrophe when they learn that they had not been chosen to receive treatment.[10] Even so, when this kind of information is accurate and involves whether a patient lives or dies, a patient may want to know about it. Is it plausible that a patient might, in some way, understand a careprovider's plight, so that the patient could appreciate it when a careprovider shared this kind information?[11] Such candor might be something that a careprovider could offer to a patient under these most terrible circumstances.

Should a careprovider choose not to disclose this kind of information, it could "count" as a type of *paternalistic omission*—and an omission that is quite likely to be ethically justifiable. In Daniel's situation, she did not choose to prioritize treating her patients as persons by enhancing their autonomy, by telling them about her choice and how she made it. This suggests that optimal ethics may begin with acknowledging how we, as humans, are most likely to respond to these kinds of terrible situations.

Should We Tell Patients Why, When We Do Not Support Their Interests?

In this issue of *JCE,* in "When Negative Rights Become Positive Entitlements: Complicity, Conscience and Caregiving," Andrew G. Shuman, Adam A. Khan, Jeffrey S. Moyer, Mark E. Prince, and Joseph J. Fins discuss a patient who understands that his condition is terminal, but still wants to be able go home, where he will have no assistance, to die.[12] In the hospital, the patient required "near-constant nursing attention for wound care, positioning, airway/secretion management, hygiene/toileting, and pain control." Further, he couldn't speak. But once his careproviders understood what he wanted, they sought to find a way they could fulfill his wishes—thus providing the highest imaginable quality of care.

Such situations may require careproviders to imagine what a patient may most want, either because the patient won't say what that is, or perhaps the patient can't understand what that is, herself or himself. This is often the case with incompetent patients, but may be the case for even competent patients. For example, I think of a patient who wanted to leave the hospital against medical advice (AMA). Even though it is legal for a patient's doctor to sign a patient out of a hospital AMA, to help protect

the hospital legally, this patient's doctor refused to do so. He imagined that if he signed his patient out AMA, the patient would feel betrayed by him, and abandoned (even though it was the patient's wish to leave). On this basis, the doctor strove to maintain the alliance he had established with the patient—and still had—and refused to sign the patient out AMA, although this was the usual policy at the hospital. The patient left anyway, but the physician continued to provide care to the patient.

These kinds of choices may erode patient/careprovider relationships in other contexts, as well. Psychiatrists may have this kind of concern, for example, when they consider whether they should ask a suicidal patient to sign an anti-suicide contract. Even though the contract may or may not affect the likelihood that the patient will try to commit suicide, when a psychiatrist requests such a contract, it may negatively affect their prior patient/careprovider bond.[13]

The physicians in the case described by Shuman and colleagues, who did not want their patient to go home alone to die, were committed to the patient, and even courageous, as was the doctor of my experience who refused to sign his patient out of the hospital AMA. But what happens when careproviders are not this committed or courageous? Should they tell a patient that they aren't willing to go this far? Should they share that they won't do something that they believe is in the patient's best interest because they have concerns for themselves? To do so would, no doubt, be rare. But there still may be something to be said for this approach, although it would probably be one of the most difficult decisions a careprovider could make.[14]

In any event, it is not uncommon for careproviders to make decisions that are based on their own needs and fears. According to one study, the percentage of clinicians who acknowledged that they had, at some time in their practice, done what was best for themselves, despite believing that this wasn't what was best for a patient, was 85 percent.[15]

To repeat a point made above: careproviders may not respect a patient's autonomy to the greatest extent possible when they believe this is what is best for the patient, what I have called *paternalistic omission.* This same value priority, while it may tend to remain hidden, may be warranted, as when a patient or loved one wants a treatment that a careprovider considers "futile." Rather than prioritizing enhancing the patient's or loved one's autonomy in these situations, a careprovider may instead ask what will work best for the patient. We shall consider this now.

A DIFFERENT APPROACH

The three cases described above illustrate that there may be situations in which the usual, "logical" ethical priorities may not apply because most patients, as human beings, couldn't bear the result. Generally, our "lesson" in this, then, is that when careproviders face an ethical conflict, they might do well to always start with considering a patient's emotional, human limitations. They may base what they choose to do on their best estimate of what most patients could bear to hear. The alternative would be to ask a patient to hear what is "too much" to bear, which is most likely not going to "work," emotionally.[16] To consider a patient's or loved one's emotional limitations is an approach that careproviders might consider when a patient or a loved one wants an intervention that the careprovider sees as being futile.

Futility: The Present Practice

When a patient or loved one requests a futile treatment, careproviders commonly explain why they believe that the treatment requested is futile.[17] All too often, this approach fails. As I mentioned above, a stronger approach may be emerging, in which careproviders increasingly make decisions by themselves. The practice of *informed assent* is an example: using this approach, a careprovider might say, "Unless anyone disagrees, I'd like to write in her chart that if her heart stops, she not be resuscitated."[18] But, all too frequently, these new approaches also fail; although the futile treatment isn't provided, the patient or family may remain embittered.

Why might this happen? A recent study offers one possibility. Researchers studied how

participants' brains responded when they saw one person purposefully harm another, or accidentally harm another. The researchers found that exceptionally fast nerves within the brain automatically recorded the kind of action that the study participant observed (that is, purposeful harm or accidental harm). That the "early engagement" experienced by the study participants was evoked by their exceptionally fast perception suggests to the authors that "affective processes precede cognitive evaluative processes," or that "intentionality judgments both precede and guide moral cognition."[19]

A possible implication of these findings is that, once careproviders try to persuade a patient or loved one to accept their view regarding the futility of an intervention, a "warning bell" may go off somewhere in the patient or loved one's brain, and the resulting fear may prevent him or her from ever changing his or her mind. Is there yet another alternative?

Futility: A Different Approach

In a presentation at the 2012 annual meeting of the American Society of Bioethics and Humanities (ASBH), Erinn Nakahara, a counselor for an organization called Vital Decisions, presented what that organization sees as a "unique approach" for responding to patients with "advanced illness." Medical insurance companies contract with Vital Decisions, and insurers inform their insureds with advanced illness that a counselor working for Vital Decisions may call. When a person with this insurance has a medical condition and a counselor may help, a counselor calls. The counselor identifies him- or herself and makes clear that there is no agenda whatsoever, other than to give the patient more control over choices—if the patient wants this—by giving the patient, in an ongoing way, information that may be relevant, and the opportunity to discuss the information. The patient and the counselor can discuss, over the phone, over time, the patient's concerns, fears, and preferences. The result? Vital Decisions reports satisfied patients as well as economic savings.

After 15,000 consultations, the program reports a 9:1 return on program investment when costs were compared in the last three months of the patients' lives,[20] which is not surprising: if there were not demonstrated savings, the insurance companies would not contract with Vital Decisions for very long. As for patients' satisfaction—the main point of this discussion—the "primary driver" of the savings, Nakahara reported, is patients' increased selection of palliative/hospice care earlier in their disease, for longer periods.[21] The counselors that work for Vital Decisions relate three very important insights.

First, they assume that all individuals differ. They know that if a patient feels safe enough for a long enough time, the patient is likely to share her or his more idiosyncratic preferences, and her or his personal views.

Second, the counselors assume, and so inform the patient, that although the patient may have what he or she regards as a clear, static view at any one time, new preferences may continue to emerge over time. This second point is pricelessly made by Marc Tunzi in his article in this issue of *JCE,* "Incapacitated Patient Decision making: The Clinical Standard of Surrogate Empowerment."[22] He calls this, quoting Lachlan Forrow, "The Green Eggs and Ham Phenomena": until an individual has experienced a situation for some time, the person may not know what she or he really wants, and, thus, "an individual's initial response may not be that individual's ultimate response."

Third, and most important of all, the counselors discuss futile treatments, but do not try to influence the patient in any way—which is more difficult to do than it may appear. For example, Tunzi offers superb verbatim examples of how careproviders can speak with surrogate decision makers: "After all, you are the person [the patient] asked to make decisions for him/her [or: "After all, you are the person with the closest relationship to (the patient), so he/she must trust you a great deal]." But the use of the words "after all" could be seen as persuasive, and may trigger the alarm response that I describe above. The approach taken by Vital Decisions is, all in all, paradoxical, in that it moves the patient to not choose futile care, but not by *advising* that. Rather, the counselors

start wherever the patient is, and go wherever the patient wants to go.

Thaddeus Mason Pope and Melinda Hexum offer, in "Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment," in this issue of *JCE,* by far the best approach to advance directives, to date.[23] As they note, there remains "significant concern with abuse," as POLST may be implemented in "a coercive and manipulative manner," and they provide an example. Yet they also indicate that patients can complete POLST in any way they want, and that 23 percent of patients in one study chose "full treatment." When a patient chooses full treatment, and full treatment would be futile, careproviders could opt to implement the approach that Vital Decisions uses.

The initial success reported by Vital Decisions suggests that careproviders might want to approach "ethics" by attending first to where patients or their loved ones actually "are," even when this sometimes seems to be a place that is extremely irrational. There may be a reason for the irrationality; recent studies indicate that patients in intensive care units may be are very significantly traumatized by the experience.[24] Other studies indicate that patients who have had breast cancer may be—and stay—greatly traumatized, but may do much better after therapy.[25] Our task, then, would be to get patients who have been traumatized by an ICU visit into therapy. This might be done best by "starting" with patients right where they are, which is what Vital Decisions does.[26]

CONCLUSION

More than many may realize, careproviders make paternalistic decisions by omission for patients based on their beliefs or intuitions on what will do the patients the most good. Careproviders agonize over what to do when patients and loved ones want interventions that are futile. Most careproviders respect patients' autonomy by telling them that the preferred treatment is futile. There may be a case, though, for increased paternalistic omission. Careproviders may tell a patient what they feel the patient wants or needs to know, but stop short of giving the patient advice (although they may need to tell the patient what he or she should expect to experience up the line).

The cardinal principle, the general emotional, human paradox involved, has been known for some time. More than a decade ago, Elliott Aronson, an eminent psychologist, put it this way: " . . . very little can be gained if someone tells us how we are supposed to feel. How we are supposed to behave or what we are supposed to do with our lives . . . a great deal can be gained . . . if we understand the wide variety of options available to us."[27]

NOTES

1. Regarding informed assent, see J.R. Curtis, "ETHICS CASE/ The Use of Informed Assent in Withholding Cardiopulmonary Resuscitation in the ICU," *Virtual Mentor/ American Medical Association Journal of Ethics* 14, no. 7 (July 2012): 545-50, 546. Regarding selective paternalism, see B.C. Drolet and C.L. White, "Selective Paternalism," *Virtual Mentor/American Medical Association Journal of Ethics* 14, no. 7 (July 2012): 582-588, 583.

2. S. Malnick, O. Faraj, and A. Jotkowitz, "Endoscopy during a Missile Attack: A Military Dilemma for Physicians," in this issue of *JCE.*

3. Ethics during warfare, not infrequently, raises different ethical questions. A physician's primary loyalty to a military mission (howsoever that is defined) or to the tenets of the medical profession—if and when the two moral obligations conflict—may (like the duty of the doctor doing the colonoscopy) be seen as varying, depending on whether the country itself is under attack.

Michael Gross, a philosopher in Israel, for example, holds that when duties to the greater society and those of the medical profession conflict, careproviders should give priority to the needs of their country. He states that if one can substantiate a supremely important goal and is convinced that the state's interests are at risk, professional medical obligations emphasizing the priority of the patient should fall to collective survival. M.L. Gross, *Bioethics and Armed Conflict* (Cambridge, Mass.: MIT Press, 2006), 331.

4. A. Wertheimer, "Is Payment a Benefit?" paper presented at the PRIM&R Advancing Ethical Research Conference, Gaylord National Harbor, Maryland, 1 December 2011.

5. M. Daniel, "Bedside Resource Stewardship in

Disasters: A Provider's Dilemma," in this issue of *JCE.*

6. J.T. Berger, "Resource Stewardship in Disasters: Alone at the Bedside," in this issue of *JCE.*

7. K.R. Jamison, *Nothing Was the Same* (New York: Vintage Books, 2009), 123.

8. I.R. Olson and C. Marshuetz, "Facial Attractiveness is Appraised in a Glance," *Emotion* 4, no. 4 (2005): 498-502.

9. J. Pincott, "What's in a Face?" *Psychology Today* 45, no. 6 (November/December 2012): 52, 55.

10. M. Hunt, C. Sinding, and L. Schwartz, "Tragic Choices in Humanitarian Health Work," in this issue of *JCE.*

11. S.H. Imbus and B.E. Zawacki, "Autonomy for Burned Patients When Survival Is Unprecedented," *New England Journal of Medicine* 297, no. 6 (11 August 1977): 308-11.

12. A.G. Shuman et al., "When Negative Rights Become Positive Entitlements: Complicity, Conscience, and Caregiving," in this issue of *JCE.*

13. M. Goodman, T. Roiff, A.H. Oakes, and J. Paris, "Suicidal Risk and Management in Borderline Personality Disorder," *Current Psychiatry Reports* 14 (2012): 79-85.

14. I know careproviders who have, for the interests of their patients, spent time in jail (for contempt).

15. R. Krawitz and M. Batcheler, "Borderline Personality Disorder: A Pilot Survey About Clinician Views on Defensive Practice," *Australas Psychiatry* 14 (2006): 320-2.

16. "Resistance . . . is often seen as a nuisance, a barrier to overcome, a culprit that allows one to blame others. . . . [It suggests, though] . . . a re-evaluation of the course of action and urges changes toward a sustainable project." G. Sammut and M.W. Bauer, "Social Influence: Modes and Modalities," in *The Social Psychology of Communication,* ed. D. Hook, B. Franks, and M.W. Bauer (New York: Palgrave Macmillan, 2011), 102-3.

17. D. Mukherjee, G.R. Spill, P. Tarsney, and J. Hauser, "Disability and Do-Not-Resuscitate: Teaching Difficult Conversations," Representing Bioethics," paper presented at the 14th Annual Meeting, of the American Society for Bioethics and Humanities, Washington, D.C., 19 October 2012.

18. "A few minutes later, the nurse who had been in the family meeting approached him. 'You didn't give the family a chance to choose,' she said angrily. 'You just decided for them. What if after CPR she bounces back? It's happened before.' " See note 1, above, p. 545. If this careprovider responded angrily after the family meeting, loved ones well might, too.

19. J. Decety and S. Cacioppo, "The Speed of Morality: A High-Density Electrical Neuroimaging Study," *Journal of Neurophysiology* 108 (2012): 3068-72, 3071-2.

20. E. Nakahara, "Representation for Advanced Illness Patients: An Innovative Approach to Improve Communication and Decision-Making Processes at End-of Life," paper presented at the 14th Annual Meeting, of the American Society for Bioethics and Humanities, Washington, D.C., 20 October 2012.

21. Ibid.

22. M. Tunzi, "A New Standard for Incapacitated Patient Decision Making: The Clinical Standard for Surrogate Empowerment," in this issue of *JCE.*

23. T.M. Pope and M. Hexum, "Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment," in this issue of *JCE.*

24. At follow up, 55 percent had psychological morbidity. D.M. Wade et al., "Investigating Risk Factors for Psychological Morbidity Three Months After Intensive Care: A Prospective Cohort Study," *Critical Care* 16, no. 5 (15 October 2012): PMID 23068129.

25. D. Von Ah et al., "Advanced Cognitive Training for Breast Cancer Survivors: A Randomized Clinical Trial," *Breast Cancer Research and Treatment* 135 (2012): 799-809. These patients' and other patients' responses to cancer is most likely difficult or impossible for those who haven't had this to accurately imagine. "Like health itself, the loss of such a thing [as one's voice] can't be imagined until it occurs." C. Hitchens, *Mortality* (New York: Twelve/Hacherre Book Group, 2012), 47. "On a much too regular basis, the disease [cancer] serves me up with a teasing flavor of the month. On the less good days, I feel like that wooden-legged piglet belonging to a sadistically sentimental family that could bear to eat him only a chunk at a time. Except that cancer isn't so . . . considerate." Ibid., 46.

26. K.A. Calderwood, "Adapting the Transtheoretical Model of Change to the Bereavement Process," *Social Work* 16, no. 2 (April 2011): 107-18.

27. E. Aronson, *The Social Animal,* 8th ed. (New York: Worth Publishers/W.H. Freeman and Company, 1999), 418.

Kayhan Parsi and Nina Hossa, "Complex Discharges and Undocumented Patients: Growing Ethical Concerns," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 299-307.

Features

Complex Discharges and Undocumented Patients: Growing Ethical Concerns

Kayhan Parsi and Nina Hossa

ABSTRACT

A growing number of discharges at acute-care hospitals involve patients who are undocumented and lack legal status. Because such patients are ineligible for public assistance, long-term care facilities will routinely deny them admission. These discharges become complex discharges because of such financial barriers. If local family support is unavailable, discharging such patients to a safe and suitable location becomes increasingly difficult. These complex discharges implicate a number of ethical principles. We describe such complex discharge cases, apply various ethical frameworks, and call for potential policy solutions to address this growing ethical concern.

INTRODUCTION

Case Study

A 22-year-old man was working in the construction industry as a roofer. He fell one day and was admitted to a nearby hospital. He experienced a neck injury that resulted in quadriplegia. He is now dependent upon a ventilator. His acute medical needs have been met at the hospital and he is ready for discharge. Unfortunately, he has no insurance and is an undocumented worker. He has no nearby family and is not eligible for any long-term care facilities because of his insurance status. How should his discharge be handled?[1]

Discharge planning, once relegated solely to the domain of the social worker, has begun to engage the interest of ethicists. Although most hospital discharges are relatively straightforward, an increasing number of them are becoming more complex. These complex discharges require a multi-disciplinary stakeholder approach. In this article, we plan to examine this increasingly prevalent phenomenon in the acute-hospital setting. We first define discharge planning, describe a complex or difficult discharge, identify relevant ethical principles and stakeholders, and examine the heightened burden such discharges place on hospitals, long-term care facilities, and communities. We focus specifically on the challenge of undocumented patients who are involved in difficult/complex discharge cases and the growing ethical concerns these kinds of discharges raise.

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Discharge planning is one of the main responsibilities of hospital social workers.[2] In planning for a discharge, social workers have to perform a number of tasks and ask a number of questions. First, they have to assess where the patient came from originally (home, nursing facility?). Second, they have to assess functionality and ask what are the patient's current care needs. Then, social workers have to determine whether the patient can go back to her or his previous setting. Still other questions need to be asked: Is it safe for the patient to go home alone? Does the patient have family/friends available to help with care upon discharge (transportation to medical appointments, physical assistance during recovery)? Does the patient have adequate insurance or private funding for recommended medical services upon discharge (prescriptions, further treatment)? Once a patient is deemed medically stable, the discharge plan needs to be arranged prior to the patient being able to leave the hospital. This can become a challenge when patients lack funding and family support, and are not able to receive necessary follow-up medical care for a variety of reasons.

A routine discharge becomes a difficult or complex one when there are barriers present to completing a safe discharge. These barriers may be financial—the patient lacks insurance coverage to provide care at a long-term care facility. The barrier may be familial—the patient lacks any kind of family support. The barrier may be one of safety—the team believes that discharging the patient may pose an unreasonable risk to the patient. An example of a simple discharge would be a patient returning home after hospitalization without further medical needs, other than outpatient follow-up appointments. An example of a complex discharge would be that of patients who are medically stable but who have limited options due to the barriers described above. The patients would not be able to return home due to an inability to care for themselves and would not be able to transfer to a lower level of care (for example, a skilled nursing facility) due to a lack of medical insurance or their undocumented status. For the purposes of this article, we will focus on complex discharges that entail substantial financial barriers.

The primary factor that categorizes an undocumented patient with long-term medical needs as a complex discharge is a lack of insurance. Such patients do not qualify for any public insurance, such as Medicare or Medicaid (although California and New York City do offer some moderate public benefits).[3] A non-U.S. citizen who is in the U.S. legally must remain in the country with legal documentation (green card, active visa, et cetera) for a minimum of five years prior to being able to apply for public insurance. The Emergency Medical Treatment and Active Labor Act (EMTALA) requires hospitals to accept and treat emergently ill patients regardless of their legal status or ability to pay.[4] This provision declares the necessity for hospitals to provide care, but it does not reimburse hospitals for emergent care, nor does it assist with patients' post-acute care needs. In these situations, while the law requires a hospital to stabilize an undocumented patient, it does not mandate that anyone care for a patient who requires continued non-acute care. The government does not assist hospitals or long-term care facilities to care for these patients. Moreover, once patients are deemed medically stable, there is no law or policy that intervenes or provides guidance on how a hospital is to proceed in discharging undocumented patients who have been left physically incapable of independently caring for themselves due to their medical condition.

APPLYING PRINCIPLE-BASED BIOETHICS

Traditional bioethics principles have been invoked when dealing with such complex discharge cases. Swidler, Seastrom, and Shelton applied principle-based bioethics when they examined this issue in a 2006 article in the *American Journal of Bioethics*.[5] The four principles of beneficence, nonmalificence, autonomy, and justice are all implicated in these kinds of cases. For instance, we want to honor beneficence and nonmalificence, but also ensure that principles of justice are upheld. Au-

tonomy plays a role when a patient is discharged without his or her consent. This occurred in the case featured at the beginning of this article. The hospital that was treating the patient decided to repatriate him to his country of origin. The patient, however, did not provide consent to be transferred to a facility in Mexico. This case generated a great deal of outcry in the local Mexican community in Chicago. Other cases of repatriation without consent have resulted in legal action, most notably the case of *Montejo Gaspar Montejo v. Martin Memorial Medical Center,* 874 So.2d 654 (Fla. Dist. Ct. App. 2004). Others have begun to explore the ethics of repatriation in the face of such difficult cases.[6] We will focus our discussion on some salient cases and argue that a more robust ethical framework is necessary to analyze and resolve such cases. In the absence of any uniform policy that provides for some kind of public assistance for the undocumented population in the U.S., such thorny cases will continue to emerge.

Utilizing traditional bioethics frameworks offers only limited solutions in such cases. The principle of beneficence suggests that the healthcare team is obligated to do only what is of benefit to the patient. Everyone involved in the direct care of a patient is striving to meet this obligation during a patient's stay at an acute-care hospital. Once, however, a patient no longer has acute-care needs, what does the principle of beneficence mean? For the social worker, this would suggest finding a safe place for discharge, along with ensuring that the patient's post-discharge medical care needs are met. This also meets the obligation of nonmalificence. In terms of the case discussed above, a discharge plan that would be in unity with the principles of beneficence and nonmalificence would include either a long-term care facility that continues to provide ventilator care, or sending the patient home with a home ventilator after adequate training is provided to family/caretakers on how to properly manage a ventilator. Yet, these cases pose serious challenges when there are no family members who are either willing or able to house patients with significant long-term care needs. Without the support of some kind of public assistance (for example, Medicaid), long-term care facilities will routinely decline to accept such patients.

With regard to honoring a patient's autonomy, we traditionally think of such an obligation as respecting a patient's wishes and values regarding his or her care. In classic cases, autonomy is honored when the healthcare team respects a patient's (or his or her surrogate's) refusal of some kind of medical treatment. What does autonomy mean when a patient (or surrogate) demands certain care beyond the walls of the hospital? Autonomy rights seem limited in such situations. As Swidler and colleagues stated: "put simply, autonomy supports a capable patient's right to leave the hospital despite his or her need for care—but it does not support a capable patient's right to remain in the hospital beyond that need."[7] Respecting autonomy does not necessarily include a patient's choosing placement that is inappropriate due to medical necessity or financial constraints.

This occurred in a case when an undocumented patient was admitted with lower extremity weakness. The patient was eventually stabilized and started to receive dialysis for kidney failure. The medical team recommended that the patient receive dialysis indefinitely on an out-patient basis as treatment for chronic kidney disease. Without regular dialysis, the patient was not expected to live much longer than weeks to months. The patient continued to be physically weak once he was stabilized and not able to ambulate out of bed and into a wheelchair without assistance. The patient lacked any family support nearby, was without health insurance, and also lacked legal status in the U.S. Without insurance or funding, the patient would not be able to receive the needed dialysis once out of the hospital. The patient's acute-care needs were long met, and the patient eventually stayed on the general medicine floor for several months. Such a stay incurred hundreds of thousands of dollars in expenses. Social work staff attempted to work with family members living abroad as well as the local consulate, but to no avail. This case resulted in an extended

set of discussions in the complex discharge committee meeting.

The principle that is most often invoked in such cases is the principle of justice. What is a just way to discharge such patients? Do these patients possess any basic rights to healthcare? Is the hospital obligated to keep a patient if they do not have the means to obtain necessary medical care post-discharge? Is it the hospital's responsibility to attempt repatriation of a patient to her or his country of origin, or should this be handled by the U.S. Immigration and Naturalization Service? At what point does this stop being a medical matter, but instead an immigration case? Hospitals typically do not have a set protocol to handle such cases, but rather are reactive on a case-by-case basis. This is primarily due to the lack of available resources that can be used for assistance in resolving such cases. A hospital's mission is to medically treat patients coming in for emergent care, regardless of where the patient came from or his or her ability to pay for treatment. However, with such complex cases, the hospital also becomes a residence for patients who, once stable, are now not able to safely return home and who are not accepted to lower level care facilities. The hospital is also transformed from a place for acute medical care to one that houses a medically stable patient for weeks and even months, while contemplating financial, political, and social decisions that can literally change the course of the patient's life.

REPATRIATION AND THE MORAL STATUS OF THE UNDOCUMENTED

Much attention has been placed on hospitals that repatriate patients to their country of origin. Repatriation is a process in which hospitals work with transportation firms to transport undocumented patients to their country of origin.[8] If a patient is deemed medically stable for discharge to home, the hospital staff (typically the social worker) takes on the role of finding family members in the country of origin who agree to take the patient into their home for further care. If the patient still requires substantial medical attention, the U.S. hospital will transport the patient directly to an accepting hospital in the country of origin. Both forms of repatriation require permission from the government of the country of origin to allow the patient back into the country. These repatriations ideally occur with the patient's consent, although not always. Some critics state that whether or not patients give consent is not the primary issue; rather, a hospital should simply not have such power over a person's life. The process raises ethical concerns, as it is assumed that patients returning back to their country of origin will not receive the healthcare needed to treat their illness. Arguments in favor of repatriating patients to their country of origin note that the U.S. struggles to provide healthcare to all documented citizens and therefore does not have an obligation to care for undocumented individuals, nor should U.S. hospitals be held ethically responsible to keep patients because there is a lack of medical care available in other countries. If a hospital does decide to repatriate a patient to his or her country of origin, the hospital typically takes on the financial responsibility for the transportation of a medically fragile patient, typically via air ambulance. Kuczewski has argued that repatriation can be done ethically, so long that the patient gives full and informed consent.[9] This is a serious challenge, in that many patients may refuse to give consent if they believe they will be repatriated to their country of origin, which may have very limited resources available for long-term care, which may result in the provision of suboptimal care.

During President Obama's address to Congress in September 2009, he adamantly stated that those who are in the U.S. illegally would not be eligible for any healthcare coverage under his proposed legislation. To this assertion, Congressman Joe Wilson uttered his famous "you lie" retort to the president. The exchange highlighted how hot the tension is regarding the rights of the undocumented to healthcare. Who "counts" in our moral community will influence who "counts" in our law and policy decisions. If undocumented patients are viewed as simply "illegal aliens" who usurp jobs and resources, then our moral sentiments (and le-

gal policies) will be shaped in a harsh and punitive way. On the other hand, as Kuczewski has argued, if the undocumented are considered a part of our community who work, produce, and contribute, then such participation in the community merits an appropriate moral status.[10] The National Association of Social Workers Code of Ethics speaks directly to the moral status of the undocumented in two provisions; for instance, section 4.02 proscribes social workers from condoning or facilitating any form of discrimination on the basis of immigration status. Moreover, section 6.04 encourages social workers to "promote policies that safeguard the rights of and confirm equity and social justice for all people."[11] Unfortunately, these aspirational professional obligations of social workers are routinely thwarted when there are policies that undermine the moral status of the undocumented.

APPLYING OTHER CLINICAL ETHICS APPROACHES

There are other venerable clinical ethics frameworks at our disposal in trying to resolve such cases. The Jonsen, Siegler, Winslade model would have us look at the facts of the case, the patient's preferences, quality of life issues, and then other contextual features.[12] Recall our opening case. Here, we have a young man who is working in this country as an undocumented worker. He suffers a catastrophic injury and is treated at a hospital. Once his critical injuries have been treated and he is ready to be discharged, how does this model help us? We have a good grasp of the facts. The patient is undocumented, has no family locally, and no local long-term care facility is willing or able to take him. The patient's preferences are to be cared for locally. It's not clear what his quality of life would be if he was repatriated to his country of origin. If the patient is someone who is culturally American but who lacks legal status, such a repatriation could be emotionally traumatic. The contextual features seem to garner the most attention. A patient who lacks insurance but does have legal status may benefit from public assistance. Such assistance simply does not exist for patients who are undocumented. This kind of clinical ethics approach helps us dissect the case in a careful way, but does not offer any clear solutions. Such complex discharge cases require other ethical frameworks to help us better achieve reasonable solutions.

AN ORGANIZATIONAL ETHICS APPROACH

Because of the inherent complexity of these cases, there are a number of parties who are involved. Patients, family members, healthcare professionals, administrators, long-term care facilities, government agencies, and local, state, and national governments are all involved. Each party has its own interests and each has its own set of obligations. The healthcare professionals who care for patients in acute-care settings have typically fulfilled their ethical obligations to patients once their acute-care needs have been met. When faced with a difficult discharge situation, social workers may find themselves working with a larger committee that is dedicated to placement of such patients. At our institution, a multi-disciplinary team will gather to discuss the facts of a given case and try to determine a reasonable solution. The social worker's obligation is primarily to the patient, in trying to achieve a safe and feasible discharge. The administrators also wish to see a safe discharge, but are also acutely aware of the expenses incurred by patients who are undocumented and uninsured. Long-term care facilities will typically deny admission to patients who lack any kind of private insurance or public assistance. The ethicist involved in such cases tries to mediate between the differing interests at the table. When a patient lacks insurance coverage for discharge placement, such problems seem intractable. This is especially the case with the undocumented, who are typically ineligible for any Medicaid coverage.

Can an organizational ethics approach help us address these kinds of cases? Organizational ethics utilizes a stakeholder theory approach: it attempts to balance the interests of these various stakeholders while remaining committed to issues such as stewardship, integrity, and

mission. Each institution has a mission statement. At our institution, we explicitly state the following:

> Loyola University Health System is committed to excellence in patient care and the education of health professionals. We believe that our Catholic heritage and Jesuit traditions of ethical behavior, academic distinction, and scientific research lead to new knowledge and advance our healing mission in the communities we serve. We believe that thoughtful stewardship, learning and constant reflection on experience improve all we do as we strive to provide the highest quality healthcare.
>
> We believe in God's presence in all our work. Through our care, concern, respect and cooperation, we demonstrate this belief to our patients and families, our students and each other. To fulfill our mission we foster an environment that encourages innovation, embraces diversity, respects life, and values human dignity.
>
> We are committed to going beyond the treatment of disease. We also treat the human spirit.

What can we glean from this statement? Values such as stewardship, care, concern, respect, and cooperation are all highlighted. Human dignity is valued. Moving beyond the disease process, the mission statement adds that we also treat the human spirit. How does this statement shape how we go about making the difficult decisions in cases involving undocumented patients? It appears that we need to balance being good stewards of scarce resources while also ensuring that individuals' dignity is respected and preserved. Yet, the onus is mainly upon the hospital that treats patients acutely, and not upon the myriad of long-term care facilities that are being sought for placement for such patients. This creates a stark discrepancy between the legal and ethical obligations of hospitals and long-term care facilities. The former are obligated to treat emergently ill patients. They may even have a mission that creates an ethical obligation toward the poor and underserved. Unfortunately, long-term care facilities have no legal mandate to accept patients, and unless they have some special mission (faith-based or otherwise), they lack any ethical obligation to accommodate the needs of the undocumented.

While many hospitals provide charity care to uninsured and undocumented patients, these hospitals must balance this free medical care with financially sound decisions that will allow them to remain open and serve the greater community. The question, "how much medical care does the hospital owe a patient?" is difficult to answer in these cases. The cases previously discussed involved individuals who were essentially bed bound and not able to physically care for themselves. Nevertheless, cases can also be complex for undocumented individuals who are physically independent upon returning home. For example, a hospital performed a surgery, via charity, that ended in a complication that left the patient needing expensive intravenous medication for the remainder of the patient's life. The patient was known to be a charity case prior to the surgery. However, the patient's undocumented status was not known to the hospital until after the surgery. (Which prompts us to ask, Should this be asked or discussed?) The complication was unexpected and irreversible. The cost of the medication needed was too high for the patient to afford. While the surgery was openly done through charity care, the cost of the medication needed afterwards was not considered, and increased the cost of the charity surgery. This opened up discussion as to whether the hospital was morally obligated to pay for the costly medication, as it was a complication of the surgery. The case highlighted the question of whether an extensive amount of charity resources should be provided to one patient or should be preserved to treat as many patients as possible. Moreover, the question as to whether such charitable offers should be time limited was also raised.

POTENTIAL POLICY SOLUTIONS

The current U.S. policy stance that excludes undocumented patients for healthcare coverage

does little to help hospitals across the U.S. when providing millions of dollars in unreimbursed treatment to such patients. It is estimated that approximately 30 million non-U.S. citizens are living in the U.S., and 11.6 million of these individuals are undocumented.[13] The topic of undocumented patients who are difficult to discharge from hospitals has drawn much attention in the last few years, as a struggling economy has placed increased political and media focus on the growing cost of healthcare, along with the lack of affordable healthcare for many American citizens. Despite the passage of the Affordable Care Act, nothing in the act provides for coverage of undocumented patients. Without a national strategy on how to discharge medically complex undocumented patients from a hospital, each hospital with such a case is left to deal with each patient on a case-by-case basis.

Recent cases examined by the media have prompted attention to the court-created designation "Permanent Resident under Color of Law (PRUCOL)." This court-created category is not considered an immigration status, but rather a public benefits eligibility category.[14] In order to be in this category, the U.S. Citizenship and Immigration Services (USCIS) must be aware that such a person is in the U.S. illegally, and must formally acknowledge the individual with a letter stating there are no current plans to deport said person. Being deemed a PRUCOL allows an individual to be eligible for public assistance benefits without being allowed to apply for U.S. citizenship. This category is without national guidelines for application or for approval; instead, the process of application and award has been left to individual cities and states.

Some hospitals in the U.S. have begun the process of attempting to have undocumented patients qualify for this category as a means to receive reimbursement and to place patients in post-acute-care facilities. This process may bring about another set of ethical concerns for the autonomy of patients. Individuals must declare themselves as being undocumented and residing in the U.S. Many undocumented individuals may not declare themselves, for fear of being deported. The issue then becomes, can a hospital force patients to apply for PRUCOL status, knowing that it will prevent them from being able to apply for citizenship? Most likely not, as a hospital does not have the authority to command patients to report their undocumented status to the government. On the other hand, even if patients do comply with applying for PRUCOL, attention may shift onto the financial benefits provided to individuals who are not paying taxes to the government. Should undocumented patients be allowed to qualify for public welfare? Should the financial benefits of this category be time limited? Should the USCIS limit what forms of healthcare are covered by such a provision?

Such questions inevitably raise ethical questions regarding the moral status of undocumented workers in this country. Some communitarian thinkers have argued that these individuals are part of our moral community, and therefore deserve the same level of rights and privileges as individuals who possess legal status.[15] Others have a more punitive approach—such individuals do not deserve the same moral status because they have circumvented the rules in establishing residence in the U.S. The law may like bright lines, but ethics is more nuanced. One could argue that individuals who have been in the U.S. since childhood and lack legal status are nevertheless American, both linguistically and culturally.

Without a national policy involving funding and adequate resources to aid such patients and complex discharges, there is not a clear solution for hospitals facing difficult discharges. For this reason, there is a need for increased open conversation regarding the topic on the micro and the macro level. Communities may need to examine what outpatient care and housing resources can be made available for undocumented patients. Hospitals may benefit from examining their policies for charity cases and developing a proactive plan that identifies undocumented patients prior to or immediately upon admission. This may include creating a permanent committee that meets to plan for such complex discharges. Some hospitals may have *ad hoc* committees that emerge once a

complex discharge is identified. Having a permanent group may benefit these cases, as the identified staff members would have worked on previous similar cases, giving them experience with options, resources, and possible outcomes. Lastly, some hospitals may consider helping to pay for patients' long-term care needs, at least for a certain period of time, as these costs are still considerably less than housing patients in acute-care settings.

Even with hospitals becoming more aware of such patients and cases early on in the admission process, it is clear that without adequate financial resources or government aid and involvement, such complex discharges will continue to heavily burden hospitals all over the U.S. The government may soon not be able to avoid becoming involved in such cases, due to the increased media coverage on the financial strain of the cases on the healthcare system. Hospitals may consider convening, on a macro level, with other healthcare institutions to bring further attention to the growing problem and to attempt to petition for government assistance to create a national policy.

With EMTALA ensuring that hospitals will continue to provide care regardless of legal status or ability to pay, policy changes to assist difficult discharges would be most effective when focused on reimbursement and availability of healthcare resources outside of hospitals. Some have called for EMTALA to become a funded mandate.[16] Many hospitals have charity care programs that allow them to receive some reimbursement for the emergent care they provide. How this is filed and reimbursed differs between states. Expanding policies and programs that mimic charity care into the community to healthcare clinics and to skilled nursing facilities would not only relieve hospitals of the burden to care for such patients, but the overall cost of undocumented patients' healthcare would be less expensive for that particular state. Rather than a state reimbursing a hospital several hundred thousands (or in many cases, millions) of dollars in charity care for a prolonged in-patient stay, the state would reimburse a great deal less to lower levels of care that are much less expensive.

Public hospitals do provide care to all patients, regardless of their legal status and ability to pay. However, often these hospitals are few and far between. Patients are unlikely to travel long distances for regular medical appointments and maintenance healthcare. Having more outpatient healthcare clinics providing care to undocumented individuals can assist in providing proactive care, and, in turn, reducing the emergent hospital visits that often lead to admission followed by complex discharge. While increasing the number of public healthcare hospitals and clinics could be effective, it would come at a large cost that many states simply cannot cover. Many public hospitals and clinics are currently reducing services and have long wait lists for clinic visits, due to lack of funding and continuing increases in healthcare costs.

Because the Affordable Care Act excludes undocumented immigrants, some commentators have called upon the states to create coverage programs for this population. In examining vulnerable populations in the U.S., we have historically provided charity to those we deem vulnerable (for example, the "deserving poor"). Orphans and widows were the traditional beneficiaries of such charitable care. With the creation of Medicaid in the mid-1960s, our commitment to the poor was formalized through legislation. Nonetheless, we have limited our obligations to certain individuals who meet very rigid definitions of poverty. Unlike Medicare, which is an entitlement largely determined by acquiring work credits throughout one's life, Medicaid utilizes means-testing (both financial and medical need) to determine who is eligible. Because Medicaid is a program that is administered through the states, commentators have called for the states to be creative in addressing the needs of the undocumented. Unfortunately, in the current economic crisis facing the states, there is little political appetite to argue for greater coverage of this population. Ultimately, we call for undocumented individuals to be able to participate in insurance exchanges that will provide some modicum of insurance coverage, and hopefully avert at least some of the worst-case scenarios we have discussed. Roman

Catholic healthcare argues that we have an obligation to care for all individuals, regardless of legal status.[17] Such a view should inform our public policy. As Martin Luther King, Jr., said, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane."[18]

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MASKING OF THE CASES

The case at the beginning of this article was published in the *Chicago Tribune* on 6 February 2011, and so is part of the public record. Details regarding the persons in the second and third case examples in this article have been masked to protect the patients' privacy.

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When Negative Rights Become Positive Entitlements: Complicity, Conscience, and Caregiving

Andrew G. Shuman, Adam A. Khan, Jeffrey S. Moyer, Mark E. Prince, and Joseph J. Fins

ABSTRACT

Clinicians have an obligation to ensure that patients with adequate capacity can make autonomous decisions. Thus, patients who choose to forego treatment and leave hospitals "against medical advice" are typically allowed to do so. But what happens when they require clinicians' assistance to physically leave? Is it incumbent upon clinicians to not only respect and fulfill patients' requests with which they disagree, but to physically assist in their fulfillment? We attempt to develop an ethical framework wherein clinicians can honor patients' wishes without necessarily sacrificing their own moral position.

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INTRODUCTION

Autonomy is one of the *prima facie* principles of conventional medical ethics; at its core, clinicians have an obligation to respect patients' informed decisions, including preferences to forego care or leave the hospital against medical advice. A unique ethical dilemma arises when patients need to rely upon medical staff to facilitate such wishes. What is the scope of a patient's right to refuse care? To what extent, if any, do clinicians need to actively participate in facilitating requests that are not consonant with their own values or professional judgment?

To delve into these novel and difficult questions, we must consider the confluence of and conflict between multiple virtues: patients' safety, nonmaleficence, non-abandonment, equality, voluntariness, and the right of conscientious objection. Only once these competing forces are dissected may we formulate a nu-

anced approach to resolving problems that juxtaposition patients against professionals' obligations to service and professionals' own moral compass. Using a challenging case example, we seek to elucidate a working framework to address this impasse that relies upon existing ethical methodology, respects competing interests, and encourages cooperative mediation.

CASE PRESENTATION

A middle-aged man with extensively recurrent squamous cell carcinoma of the larynx was admitted to the hospital with a malignant fistula. Despite heroic interventions, his condition could not be stabilized, and he suffered a carotid rupture and subsequent stroke after hemostasis was achieved. Neurological deficits compounded his underlying weak and frail state, leaving him hemiparetic and bed-bound, requiring continuous nursing care. He is unable to speak due to his tumor, and communicates by writing and gestures. Despite remaining alert, awake, and cognitively intact, his prognosis is extremely poor.

The patient understands that his condition is terminal, and he expresses his desire to die at home. He has a do-not-resuscitate (DNR) order. He is partially estranged from his family and has limited financial resources. The patient's relatives are unable to provide the level of care he requires, and he has no insurance coverage for home hospice or other form of nursing care at his residence. He likewise refuses transfer to either inpatient hospice or a skilled nursing facility. His desire to die at home supersedes all other concerns; he understands that he may be left alone in that setting, and is willing to sign out against medical advice (AMA). Palliative care and ethics representatives have been consulted.

Given that his current medical condition precludes his physical ability to leave the hospital without assistance and that he will be unable to care for himself at home, his care-providers are uncomfortable honoring his wishes.

FRAMING THE DEBATE

This case example illustrates the limitations of utilizing a strictly principle-based approach to solve ethical dilemmas, as autonomy diametrically conflicts with nonmaleficence, which also emphasizes a clinician's obligation not to abandon a patient in need. To address these concerns, more information is needed. Why does the patient feel compelled to go home? Is there something specific that he needs to obtain or accomplish in doing so that might otherwise be facilitated? What is the degree and etiology of the familial estrangement, and could it be mitigated in his time of need? Are other potential social support structures or individuals available? Is his emotional response to the dying process coloring his judgment? Might dedicated psychosocial support be helpful? What is preventing the patient from receiving care at home; might a financial and/or institutional compromise be reached? While these factors were each considered, unfortunately they could not be resolved in a manner that facilitated an easy or timely solution.

Principlism, casuistry, and virtue ethics, among other constructs, have proven to be trusted methods of resolving moral problems, and are by no means mutually exclusive. Both moral theory and clinical circumstances steer all morally weighty decisions, just as underlying cancer biology and the physical location of a tumor dictate choices among oncologists. As such, clinical pragmatism seems to provide a convenient way to consider this dilemma.[1] In this model, ethical principles are not fixed; rather, they are proportional to perceived risks and benefits and are heavily dependent upon clinical context, practical reality, and the overarching goals of care.[2] That said, pragmatism is an eclectic approach that is open to the contributions of other methods if they can contribute instrumentally to resolving this quandary. Thus, our focus will remain vested in the content, rather than the process, involved in considering this dilemma.

CLINICAL CONTEXT

Prior to engaging in discussion specifically regarding this ethical dilemma, components of the clinical picture deserve clarification. Patients with terminal cancer present formidable challenges to providing compassionate medical and nursing care. Our patient's fierce independence and challenging social situation created barriers to providing adequate care—which occurs with some frequency in this patient population.[3]

From a practical standpoint, the patient requires near-constant nursing attention for wound care, positioning, airway/secretion management, hygiene/toileting, and pain control. If he were allowed to return home without assistance, he physically could not manage any basic functions or even summon assistance, given his inability to speak. Thus, adequate palliation would not be possible without some form of assistance. Palliative care team involvement in managing patients with terminal head and neck cancer is beneficial.[4] Data suggest that the end-of-life experience in head and neck cancer is improved when death occurs outside of the hospital.[5] Thus, the importance and value of hospice services in this case cannot be overstated.[6] That said, patients have the right to forego even interventions that have proven effective, and neither families nor clinicians should impose their values upon patients who are capable of making decisions.[7]

One distinguishing feature of this case is that the outcome is known; the patient has terminal cancer and will succumb to his disease in the very near future, regardless of his location or circumstance. This makes extrapolating other ethical discussions of "harm" challenging. What would make a situation unsafe or potentially injurious when death is already imminent? Of course, his demise may be a foregone inevitability, but its context is not. Palliation is the overriding goal, to facilitate a dying process in which pain is treated, other symptoms are addressed, dignity is maintained, and emotional support is provided. The patient and all other involved parties must then weigh competing interests with regard to this process in considering whether the preferred location of death might not override the sacrifices that it would require.

AUTONOMY AND CAPACITY IN CONTEXT

In accordance with the principle of autonomy, patients with decision-making capacity can refuse recommended treatments. Clinicians need only ensure that patients have adequate capacity, are sufficiently informed of the rationale for medical recommendations, and can recognize the consequences of their choices; this is typically described as the right to informed refusal.[8] This universal right applies equally to dying patients in intensive care units.[9] That said, a patient's preference is not absolute, and consideration of a patient's welfare should not be ignored in an effort to preserve independence at all costs. Rather, Pellegrino and Thomasma argue that clinicians have an equal (or even greater) commitment to act virtuously to improve and maintain patients' welfare, and they outline a new principle that they dub "beneficence in trust."[10] The obvious danger of such a construct is that it may degrade into paternalism, although this is mitigated by their concept of open communication and reciprocal conviction to a productive, professional relationship.

Autonomy is dependent upon a patient's ability to effectively and clearly communicate his/her decision and its potential consequences. Our patient's inability to speak may complicate effective dialogue and formal assessment of capacity, but it certainly does not obviate it.[11] In such situations, communication is paramount.[12] First and foremost, it is critical for the patient to understand his options, and to engage the multidisciplinary care team in efforts to attempt to provide adequate palliation while honoring his wishes. Thus, there is a need for forthright communication about what clinicians are worried about, and why it might be unwise for the patient to go home alone.[13] With considerable deliberation and patience, he was able to clearly communicate his wishes by writing, augmented with facial expressions and hand signals. The repercussions of expected inadequate palliation at home were discussed openly and frankly, and he demonstrated understanding thereof.

The concept of a sliding scale of capacity deserves attention, as decision-making capacity is neither all-or-none, nor absolute. A higher standard for capacity is required when decisions are more critical and have potentially dire consequences.[14] In the case at hand, in the opinion of his clinicians, the patient met the appropriate standard for decision-making capacity to leave the hospital. Given his condition, it is highly likely that he would lose capacity at some point, related to delirium.[15] However, as-

suming his wishes had remained consistent to that point, his surrogate decision makers and caregivers would be obligated to honor his wishes in accordance with the concept of substituted judgment, even if he became incapacitated.

This patient defines vulnerability; he is dying, unable to speak, unable to ambulate, and is estranged from those who know him best. While the patient met strictly defined criteria for capacity, was he truly free to act autonomously? Probably not. Not only was he physically confined to bed, institutionally limited due to inadequate social services, and medically condemned by a terminal disease, he was also at the mercy of decisions made by his clinicians, who remained in a position of relative power, even when working under the rubric of his freedom of choice. Thus, every effort needs to be made to avoid paternalistic impulses, which requires engaging him in the decision-making process and empowering him to have some control over those decisions that remain potentially within his purview.

Patients at risk for self-harm may be not granted the right to make autonomous decisions, even if they otherwise demonstrate capacity. As discussed, "harm" is relative when considering the plight of a patient with terminal cancer, although unnecessary suffering certainly qualifies as such. However, physical suffering from inadequately managed symptoms may be judged as the lesser evil when compared to the patient's anguish from not being able to die at home. As such, making a decision based upon the "lesser harm" remains contentious. Nevertheless, there is no doubt that there is a high likelihood for unintentional self-harm (or at least inadequate palliation), due to his inability to care for himself, assuming that he is able to go home. There also exists the possibility that the patient (and clinicians) may not be able to accurately anticipate his disease progression and the type or severity of symptoms he might experience on his own at home. Once he has been made aware of the risks, both direct and indirect, of leaving, as well as the potential for other unanticipated harms, his decision should be respected if he still decides to go.

AGAINST MEDICAL ADVICE: COMPLICITY VERSUS RESPECT

Is there a significant difference between passively respecting a patient's autonomous decision and assisting in carrying it out? Typically, a person can make an autonomous decision to leave the hospital AMA, and medical practitioners are not actively involved in facilitating what they believe is not in the best interest of the patient. In this case, clinicians' refusal to assist would be, by default, in conflict with the patient's autonomous request. If the medical team assists the patient in carrying out his decision (in this case, by physically carrying him out), would that be tantamount to endorsing his decision?

Most discussions of the principle of nonmaleficence revolve around potential harm from therapeutic interventions, and these conflicts often focus upon patients' cultural, religious, or personal mores that lead them to forego recommended therapies.[16] A clinician's active involvement in achieving a potential harm differentiates this case. When direct action is needed—as opposed to passive acceptance—the burden is greater. Autonomous decisions are no longer independent, as the involvement of others complicates this privilege and merits re-examination.

We contend that in this particular case, the medical team's assistance in carrying out a patient's autonomous decision to forego further care would be acceptable. The patient's decision to go home is an informed, capacitated choice, and facilitation thereof does not transfer the burden of its consequences upon his clinicians. Of course, while autonomy is an affirmative right, it does not erase a clinician's affirmative obligation to help. As such, clinical professionals should respect patients' choices to decline medical recommendations, but within a context in which the door remains open for future care. Once this door closes, we have essentially abandoned our patient, which is a development with dire professional and emotional consequences, to be explored in further detail shortly. In addition, it is difficult to define how far this obligation should extend.

Escorting a wheelchair-bound patient to an awaiting ambulance may be expected, but clinicians would not be obligated to drive this man home in their own personal vehicle and tuck him into bed. We admit that it is difficult to know where to draw this line.

In essence, just as ambulatory patients with sufficient capacity cannot be locked in a hospital ward over their objection, bed-bound patients cannot be kept against their will by refusal to physically assist them in leaving. While the latter action may not meet legal criteria for involuntary imprisonment, in our opinion, this line remains unacceptably thin.

ABANDONMENT

One of clinicians' fundamental obligations is to remain available to patients in need. As such, abandonment is perceived as an ultimate violation of professionalism. An early discussion of medical abandonment defines the practice as a physician-initiated, unilateral termination of the doctor-patient relationship with neither the patient's consent nor adequate opportunity to procure an alternate provider.[17] Surely, our case does not meet these strict criteria. A more flexible concept in which patients and clinicians maintain an "open-ended, long-term, caring commitment to joint problem-solving" more aptly describes the principles behind the need to avoid perceived or actual abandonment.[18]

The need to support patients during the dying process is, arguably, as important as the maintenance of partnerships with curative intent; experiences at the end of life require both physical and emotional support provided by individuals with whom patients have an established relationship.[19] As such, the need to avoid abandoning terminal patients is among the strongest imperatives in medicine. In a qualitative study of dying patients, their families, and doctors, the concept of non-abandonment comprised two distinct elements: providing continuity and facilitating closure of the therapeutic relationship.[20]

In our case, the patient's desire to die at home would likely prevent his clinicians from assisting him, and his inability to communicate verbally might potentially preclude him from summoning help even if he were to change his mind. Of course, consideration of practical solutions is warranted, such as a call button system that might alert emergency medical services, thereby keeping the proverbial door open for future care. However, the patient's request would nevertheless fundamentally limit his clinicians' availability. We must be mindful that patients' autonomy may supersede other conflicting professional obligations. Clinicians must then balance these incompatible values, preferably with some sort of compromise, to allow a patient's rights to be respected without sacrificing a major ethos of professional medical care.

CONSCIENTIOUS OBJECTION

While autonomy is an ethos of professionalism, it is not the only such factor. Since we have argued that autonomy is not a blanket that obscures all other considerations, physicians are not obligated to directly violate their own moral or professional values or existing laws when acquiescing to patients' requests.[21] Patients' refusal to facilitate or allow routine (or "ordinary") nursing care seems fundamentally different than refusal of "extraordinary" measures, such as chemotherapy or resuscitation.[22] Ignoring elemental human needs such as hygiene may be considered socially taboo, and caregivers may rightfully experience moral distress if they perceive that they are contributing to such "wrongs."[23] Failure to address such basic needs, particularly when considering vulnerable populations, may put clinicians at risk for accusations of professional or legal misconduct under the rubric of patient neglect.[24] As discussed, abandonment falls within the same moral purview.

Refusing to honor a patient's request on moral grounds requires professional diligence to ensure that the patient continues to receive care until another clinician who is willing to provide care is available. In addition, such cases require a critical reassessment of one's position to determine if there is truly an irreconcilable

disagreement, or whether cooperative mediation may yield a satisfactory answer.[25] Without such safeguards, the caregiver's conscience is satisfied only at the expense of the patient's.[26] Our case does not involve one caregiver's moral objection, but rather a collective (and admittedly paternalistic) professional opinion that honoring the patient's request would simply be a wrong that would be difficult to accept, even at the risk of shirking duties to preserve the patient's autonomy. The absolute categorization of this as a "wrong," we fully recognize, is as nebulous as knowledge of the "right" thing to do for this poor man.

In cases involving refusals of nursing care, another suggested solution involves "negotiated reliance," which "recognizes the reliance of the patient on her care providers . . . combines empowerment and dependence . . . presupposes a relationship of care and intimacy . . . [and] allows for more therapeutic and reciprocal responses."[27] This concept forces clinicians to do their best to avoid limiting patients' autonomy while encouraging patients to make concessions, and also asks clinicians to make allowances that may extend beyond standard professional practice. Essentially, it is based upon the principle that patients and clinicians "are in this together," and that mutual compromises and trade-offs are obligatory in pursuit of common goals. This idealized model allows clinicians and patients to shoulder the burden of their decisions together, in a partnership. The application of negotiated reliance to our case might involve discourse such as, "I know you want to go home, but I cannot abandon you . . . so let's see what we can arrange."

CONCLUSION

Members of the clinical team, ethics consultation service, and family discussed the case and their positions with the patient extensively. He remained adamant in his desire to go home, regardless of all other potential risks and clinical realities. Attempts were made to secure in-home assistance, including exploring options in which the cost of home services would be absorbed by the hospital. The next day, while such arrangements were still in development, the patient suffered a recurrent stroke and died peacefully in the intensive care unit.

In some measure, the clinical outcome is reassuring. The patient died tranquilly with adequate palliation. His clinicians did not overtly violate his wishes by refusing transfer to his home, nor did they act in direct opposition to their own morals. However, this is also a tragedy. A dying man's wish to return home was not honored, at least partially due to clinicians' refusing to acquiesce to his request in a timely manner; he was in effect held against his will, on someone else's terms. In retrospect, deliberation and delay were in fact decisive.

This case also highlights the inherent inequalities within our healthcare delivery system, since the ideal solution for all involved parties would involve dedicated home hospice services, which are cost-effective, clinically proven, and frequently covered by both private and public health insurance plans. While clinicians are bound by institutional and financial practicalities, we cannot simply shrug our shoulders without encouraging political advocacy and fighting for our patients' rights not only at the bedside, but also on a meta-level.

If our patient had not died so quickly, we would have been obligated to honor to his wish to go home. While the hospital is not compelled to assume these costs, such institutional decisions are based upon a permutation of financial, practical, and moral reasoning. Ideally, a plan would have been implemented involving some form of in-house services, although discharge should have been facilitated even if such an arrangement proved impossible. In essence, morally weighty decisions should not be made in a different context based purely upon physical ability. Assuming that an ambulatory patient in a similar situation would not be physically prevented from leaving the hospital, it is problematic to refuse to allow a bed-bound individual to make the same choices. In other words, it is hard to distinguish between passively enabling medical decisions that we cannot condone from actively participating in equivalent processes. A similar argument has been employed in condemning physicians' complicity

with euthanasia.[28] In such cases, the onus rests with the clinical team to achieve a workable solution that merges competing interests with clinical realities.

Healthcare providers have a fundamental, fiduciary responsibility to respect patients' autonomous decisions. That said, it is challenging to do so when a decision is perceived to be "wrong." Assuming that an informed choice is made by a capacitated individual, clinicians' disagreement with a decision should not adversely affect their willingness to assist their patient. In most cases, cooperative mediation will facilitate outcomes that honor patients' autonomy, but also provide safeguards that address clinicians' concerns. That said, the clinical obligation to respect "bad" decisions, both in word and action, remains a fundamental part of our professional duty.

MASKING OF THE CASE

The identity of the patient in this case has been masked to protect his/her privacy.

DISCLOSURE

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A New Standard for Incapacitated Patient Decision Making: The Clinical Standard of Surrogate Empowerment

Marc Tunzi

ABSTRACT

Founded upon the primacy of the principle of respect for autonomy, three methods of surrogate decision making traditionally have been promoted to help the family and friends of incapacitated patients. Unfortunately, the standards of advance directives, substituted judgment, and best interests are often inadequate in practice. Studies report that few patients have formal, written advance directives; that patients often change their minds about treatment over time; that many patients are simply not ready or willing to plan ahead—in part, because some patients and families simply don't believe in autonomy; that those patients who do plan ahead often do not communicate their plans; and that while some patients want their directives followed strictly, many prefer that their surrogates use judgment in making decisions. After reviewing articles describing a variety of alternative approaches, a new clinical standard of surrogate empowerment is proposed to reconcile and integrate these observations and concepts. The "procedure" for this clinical standard is presented.

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INTRODUCTION

People are different. We are different sizes, shapes, and colors. We espouse different values, beliefs, customs, cultures, and religions. We exhibit different personalities. We have different experiences of health, wellness, and illness.

And yet we throw patients and their surrogates all together into one big box, giving them only a couple of choices to facilitate complex medical decision making. It is time for a new standard to help widely diverse patients and families make these difficult, often life-and-death determinations: the clinical standard of surrogate empowerment.

Founded upon the primacy of the principle of respect for autonomy, three methods of surrogate decision making traditionally have been promoted to help family and friends evaluate medical options for patients who become inca-

pacitated.[1] The standard of advance directives states that surrogates should follow the previously documented, clearly written wishes of individual patients. This standard is usually viewed as a subset of the standard of substituted judgment, which states that surrogates should make choices in the same way the patient would make them if the patient were not incapacitated. The standard of best interests states that when a patient has not previously documented clear wishes, and when the surrogate does not know what the patient would decide under the current circumstances, the surrogate should make decisions that he or she believes are in the patient's best interests.

There are two very significant general problems with these standards. First, not every patient and family endorse the primacy of the principle of respect for autonomy, but may instead prefer to balance autonomy with beneficence, nonmaleficence, and justice, based on the family and community consequences of the decisions to be made. Second, even when patients and families do endorse the primacy of autonomy, it is not clear that these standards always support autonomous decisions in practice, relying instead on guesses or on opinions expressed in the past.

This article will examine the shortcomings of the standards of advance directives, substituted judgment, and best interests. It will then review the alternative decision-making methods of substituted interests, therapeutic interests, narrative, and covenants, and the process of shared decision making. Finally, it will suggest a clinical standard of *surrogate empowerment*, a model that better reflects the diversity of the patients and families we serve and the diversity of medical decisions we ask them to make in real life.

THE INADEQUACIES OF THE STANDARDS OF ADVANCE DIRECTIVES, SUBSTITUTED JUDGMENT, AND BEST INTERESTS

The growth of contemporary bioethics over the last 50 years has been based largely on the principle of respect for autonomy.[2] People have the right to control their own bodies and to make their own medical decisions. Advance care planning and advance directives (ADs) were developed to provide individuals the capability to make future healthcare decisions in the event they were to lose real-time decision-making capacity. The 1990 Patient Self-Determination Act endorsed the notion of future autonomy by promoting advance directive documents through legislation. The well-publicized cases of Karen Ann Quinlan and Nancy Cruzan highlighted the need for patients and families to have control over themselves and their loved ones if they wished to avoid the false beneficence of continuing life-sustaining treatment when there is no chance of meaningful recovery.

Bioethicists have encouraged the development and implementation of ADs as the most practical way to honor the two standards of surrogate decision making that best support autonomy—the standard of advance directives and the standard of substituted judgment.[3] The annotated durable power of attorney for healthcare has been promoted as the best of these AD documents. This type of AD does two things:

1. They respect autonomy by honoring a patient's carefully considered and clearly documented wishes regarding prospective medical care, noting particular treatments and interventions that the patient will accept or decline, and
2. They enable a patient to appoint a specific surrogate agent or proxy to make future medical decisions in the event the patient were to lose medical decision-making capacity—hopefully, a surrogate who will make decisions in the same manner that the patient would for him- or herself, based on discussions of the patient's clinical condition, medical values, and thinking processes that the patient and surrogate had together before the patient's incapacitation.

Unfortunately, despite their theoretical appeal, the standard of advance directives and the standard of substituted judgment are often inadequate in practice.[4] The standard of advance directives suffers from three problems:

1. Only a few U.S. adults have ADs,
2. Over time, many people change their minds

about their advance planning decisions, and

3. Many individuals who do clearly document their wishes about specific interventions actually prefer that their surrogates use judgment in making future medical decisions, rather than follow their previously documented directives strictly.

Studies of the rates at which advance directives are completed suggest that 18 percent to 36 percent of all Americans have an AD.[5] The large, national SUPPORT study performed at academic medical centers demonstrated a 21 percent AD rate.[6] A more recent, smaller study at four community hospitals in California, however, indicated that only 7 percent of patients had completed an AD, varying from <1 percent at a public county hospital to 12 percent at an urban community hospital.[7] Both the SUPPORT and California studies suggest that patients with ADs don't use them to their fullest potential, and that ADs do little to specifically guide hospital treatment.

Studies of the stability of patients' life-sustaining treatment preferences indicate that somewhere between 15 percent and 50 percent of patients change their minds about future medical decisions.[8] Stability varies by individual, by changes in patients' health status, and by clinical scenario. Some people exhibit more stability in medical decisions, overall, than others. Both positive and negative changes in health, illness, and disability are associated with changes in decision making that are difficult to predict, with better or worse states of future health influencing decisions in different ways for different people. And some clinical scenarios are more stable than others. Generally, initial decisions to decline care are more stable than initial decisions to accept care, and decisions related to the most serious and least serious conditions are more stable than decisions related to intermediate clinical scenarios. Patients with ADs exhibit more stability than patients without ADs—although this is probably related to the fact that more people with ADs decline aggressive future treatment than people without ADs. No groups of patients are completely stable, however: patients with and without ADs, patients who initially accept or decline care, and patients who are healthy, ill, or disabled all change their minds.

One reason people change their minds about medical decisions over time is due to what Lachlan Forrow calls "The Green Eggs and Ham Phenomena": until an individual has thought about a situation at some length—or better yet, has experienced it—that individual can't make a truly informed decision.[9] Thus, an individual's initial response may not be that individual's ultimate response. The nameless Seussian fellow in the book tells Sam-I-Am, "I do not like green eggs and ham"—until, of course, he finally tries them.

These phenomena may also explain why several studies report that many people who have previously expressed specific preferences about life-sustaining treatment prefer that their surrogates use judgment in making future decisions, rather than to follow their previously expressed preferences strictly.[10] These studies do not analyze the differences between those patients who want their preferences followed strictly and those who want their surrogates to use judgment, however. They simply group patients into two broad categories and note that patients who want their surrogates to use judgment in medical decision making cite *trust* as their primary reason for doing so.

The standard of substituted judgment suffers even more from a lack of clinical utility. Studies suggest that agreement among what most people would consider to be the best patient-surrogate pairs (a surrogate appointed via a power of attorney; a longtime spouse) is only about 66 percent when they are presented choices for care in various clinical scenarios.[11] Indeed, evidence suggests that agreement between patients and surrogates is not necessarily influenced by patient appointment, in contrast to "default" surrogates,[12] or by whether patients and surrogates have engaged in prior discussion about future decisions.[13] Studies have not assessed whether differences in patient-surrogate agreement vary by the patient appointment process (that is, do some appointments result in more agreement than others?) or by the quality of prior discussions between

patients and surrogates (that is, is agreement better if a specific set of issues and topics is covered?).

In practice, future medical scenarios are difficult to predict, and personal values and thought processes are difficult to discuss. Further, since individual patient's choices regarding complex treatment preferences often change over time, it is not surprising that surrogate decisions are also imperfect.

Moreover, not all patients and families believe in planning ahead or in picking one specific surrogate.[14] In fact, not all patients and families believe in the primacy of the principle of respect for autonomy. Some people simply don't plan: it's not their personality, it's too stressful, or they are too uncertain about their situation and their choices to think about any kind of medical issue in advance.[15] Others simply realize that once they lose capacity it won't be their problem. Many patients and families from minority cultural and ethnic groups do not believe in picking one surrogate.[16] Instead, they believe that all of life's complex decisions—especially medical decisions—are family decisions that can only be made in the context of family consensus. Because the outcomes of these decisions affect everyone in the family, individual autonomy makes no sense to them. Decision making must balance autonomy with beneficence, nonmaleficence, and justice in the family context, honoring the patient's role as a member of a larger, loving family community. Outcomes, too, can only be evaluated in the family context—outcomes that are necessarily influenced by the ongoing care patients receive from family members.

One family issue that often influences end-of-life decision making is that of family burden.[17] Patients often make decisions based on a personal value of wishing not to burden their families. And yet it is their families who will ultimately determine whether the consequences of a decision are burdensome to them or not, not the patient. Autonomy, beneficence, nonmaleficence, and justice: who decides?

This question of "who decides?" is also the basis for the practical inutility of the standard of best interests.[18] "Best" according to whom, using what criteria, under what circumstances? In practice, "best" usually means beneficence, and "doing good" usually means doing more, as if every unknown situation requires the default, emergency response of providing treatment unless it is clear that an individual would not accept it or should not receive it. Applying this line of thinking to advanced chronic illness and end-of-life care makes no sense. Very often, patients are provided more care than they would likely choose and accept for themselves. Elsewhere in medicine, physicians are admonished to "first, do no harm," honoring the principle of nonmaleficence. Somehow, this admonition is forgotten with incapacitated patients who, as attested to by their very incapacity, are the patients most in need of our compassion and practical wisdom to know when to quit and not be held hostage by misguided beneficence.

Surrogates who do not have the benefit of clearly expressed prior patient wishes, and who do not know a patient well enough to make decisions in the same manner that the patient would make them, are forced to make decisions based on their best guess of the right thing to do. Unfortunately, the four great goals of medicine—to prevent disease, to cure illness, to ameliorate pain, and to prolong life—are often in conflict with each other.[19] Surrogates often have an impossible choice—a choice that leads to uncertainly, anxiety, guilt, and personal distress.[20] And it is often a choice that provides no guarantee that the right decision has actually been made.

ALTERNATIVE CONCEPTS AND ADJUNCT RECOMMENDATIONS

A number of authors have presented alternative approaches to surrogate decision making, offering various insights into the process of preparing for, supporting, and fulfilling that difficult role. Several have written about the general process of shared decision making.[21] Some have described surrogacy as the process of continuing an individual's narrative when that person can no longer do so him- or herself.[22] Fins and colleagues have suggested that the role of a surrogate is to fulfill a covenant

with the patient.[23] Sulmasy believes that the concept of "substituted interests" is more helpful than that of substituted judgment.[24] Kapp recommends decision making based on "therapeutic interests" rather than best interests.[25]

"Shared decision making" refers to the process of negotiating how large a role patients or their agents play in making medical decisions. Kon describes a five-point continuum of participation, ranging from a 100 percent patient-driven process at one end, to a 100 percent physician-driven process at the other, with three steps in between.[26] Because surrogates are often unable to apply the standards of advance directives and substituted judgment, and because they are able to apply the standard of best interests only with difficulty, sharing the process of decision making with the clinical team is necessary in practice.[27] A study by Johnson and colleagues suggests that surrogates vary in their desire to participate in decision making, but tend to prefer more authority in value-sensitive decisions, such as those involving futility or quality of life, than in technical-medical decisions, such as those involving which specific interventions to accept or decline.[28] Clinical practice guidelines written by the American College of Critical Care Medicine endorse a partnership model of medical decision making in the intensive care unit, assisted by early and frequent family meetings to review the patient's and the family's understanding of the clinical situation, assess emotional needs, and provide information and support, as needed.[29]

The process of narrative has also been promoted as a means of directing surrogate decision making.[30] Narrative advocates assert that what surrogates are called to do is to help patients live/write/tell the next part of their personal story at a time when they cannot do it for themselves. Surrogates are advised to honor the personal identity of the patient and to make choices that "fit" or "hang together" with the choices that the patient previously made and the manner with which the patient has conducted his/her life. Indeed, such an approach can be helpful even when the patient's specific medical preferences and medical values are not known. The surrogate's task is simply to continue the patient's story to the best of her or his ability to do so.

Fins and colleagues believe that the traditional *contractual* standard of surrogate decision making should be replaced by a *covenantal* patient-proxy relationship.[31] In this model, a surrogate is not simply "a sterile instrument who accurately conveys patient preferences,"[32] but someone who can think "inductively and contextually" on the patient's behalf.[33] That is, a surrogate is someone who is responsible for faithfully representing the patient to the healthcare team by means of being an active and committed interpreter of the patient's interests and wishes. According to Fins and colleagues, patients and proxies favor a judgment-based covenantal approach over strictly following a patient's instructions—with one exception: negative instructions to withhold care are expected to be followed closely.

This notion of interpreting the patient's interests is also the basis of Sulmasy's approach to surrogate decision making.[34] Indeed, Sulmasy labels his approach "substituted interests," to emphasize that what surrogates are asked to do is to apply what is known about the patient's specific preferences to what the surrogate knows generally about the patient's values and interests, in order to make decisions for that person. For Sulmasy, the principle of *authenticity* is more important than the principle of *autonomy,* and the right question for surrogates is not "What would the patient choose if he or she could tell us?" (a theoretical question that is not usually answerable), but "What can you, the surrogate, tell us about the patient—about his or her values, beliefs, moral commitments—and how you can use that knowledge to make the right decision now?"

Kapp labels his approach to surrogate decision making "therapeutic interests," seeking the best action by balancing what is possible for patients with what is therapeutically indicated under the current clinical circumstances.[35] In effect, Kapp re-introduces the primacy of "do no harm" into clinical decision making—emphasizing the avoidance of unnecessary, painful interventions in order to determine what should be done.

All of these alternative surrogate decision-making approaches start by noting that the traditional standards are inadequate in many situations. Kapp, for example, specifically promotes "therapeutic interests" rather than "best interests" to balance beneficence with nonmaleficence and prevent futility. Kuczewski and the other narrative authors, Fins and colleagues, and Sulmasy all seek more practical alternatives to substituted judgment. In clinical practice, narrative, covenant, and substituted interests appear quite similar: all seek to engage surrogates in a way that builds on their relationship with the patient, rather than their knowledge of specific treatment directives by the patient, or their knowledge of the patient's specific views about clinical treatments.

In addition to these authors who have presented alternative concepts and philosophical approaches to surrogate decision making, others have discussed a wide variety of adjunct recommendations to augment and better inform all surrogate processes. For example, Emanuel and Emanuel have long advocated that patients and their surrogates discuss possible future medical scenarios and the kinds of treatment decisions that might be associated with them.[36] According to this recommendation, which directly supports the standard of substituted judgment by enabling surrogates to make the same treatment choices that patients would make in specific clinical situations, the more detailed the discussions patients and surrogates have together, the better. However, evidence that scenario-driven discussions make a significant impact in practice is weak: they do not address the issue of patients changing their minds over time, and they cannot possibly cover all future medical events.[37] One recent study, however, does suggest that disease-specific scenario discussions are helpful for patients with advanced illness.[38]

Doukas has proposed that detailed discussions of medical and personal values are more helpful than discussing a set of theoretical clinical scenarios.[39] This recommendation also directly supports the standard of substituted judgment—the more a surrogate knows about a patient's values, the better he/she can think like the patient regarding treatment decisions—but it also informs other approaches. Like scenario-based discussions, however, these discussions do not address how a patient's values may evolve over time, nor do they necessarily account for the harsh reality of care in the intensive care unit or care at the end of life. Indeed, some values develop only in the face of real-life choices. For example, a patient who values mental alertness over pain control or values "fighting until the end" over "quality of life" might have never considered what it's like to experience accelerating cancer pain or long-term ventilator support.

Some authors, most notably Pearlman and colleagues at the Veterans Administration, have attempted to combine scenario- and values-based discussion planning to help patients plan more broadly.[40] They have also encouraged other kinds of end-of-life preparations, such as organ donation, funeral arrangements, financial planning, and so on. Unfortunately, their monograph, *Your Life, Your Choices*, is no longer available from the VA.

The "5 Wishes" document, available from the organization Aging with Dignity, is another means to integrate scenario- and values-based planning.[41] This document asks individuals to consider:

1. The person they wish to be their surrogate decision maker,
2. The kind of medical treatment they want or don't want,
3. How comfortable they wish to be,
4. How they wish for others to treat them, and
5. What they wish their loved ones to know.

A menu of examples and choices for all five wishes is listed for consideration within the document.

Smucker and Houts and colleagues propose a non-patient-centered means of assisting surrogate decision making.[42] Based on a study of geriatric outpatients and their self-selected surrogates, these authors believe that an actuarial model of decision making using statistical analysis is just as accurate as surrogate decision making in predicting what patients would choose for care. Modal preferences are also just

as stable over time as surrogate decisions. Whether most patients would be comfortable with this kind of decision making is not clear, but community standards can certainly inform surrogate decision making. Such a process is consistent with concepts of community morality and the reflective consensus of communitarian ethics proposed by Kuczewski as the best approach to highly complex public medical policy issues.[43] It may also meet Dresser's quest for a "community mission" to address what she views as the "social problem of medical decision making for incompetent patients."[44]

Still, in the absence of alternative preparatory activities, reviewing scenarios, discussing values, and having an advance directive are better than nothing. After all, even community modal preferences must be based on *something.* Indeed, Silveira and colleagues have empirically demonstrated that patients with ADs receive care more consistent with their preferences than patients without ADs.[45] At the same time, discovering what makes some discussion and planning activities better than others remains open for continued study.

The POLST (physician orders for life-sustaining treatment), also known as the MOLST (medical orders for life-sustaining treatment) in New York, is a new advance care planning document designed for individuals with terminal illness or actively progressive chronic disease (for example, congestive heart failure, chronic obstructive pulmonary disease, chronic renal disease, cirrhosis, Alzheimer's disease).[46] Taking the idea of disease-specific planning one step further, the POLST is essentially an intensity of care document that enables an individual to choose: in Section A, CPR (cardiopulmonary resuscitation) or no CPR; in Section B, comfort measures only, limited additional interventions (for example, intravenous fluids, antibiotics), or full treatment; and in Section C, no artificial nutrition (that is, tube feeding), a trial of artificial nutrition, or long-term artificial nutrition.

Once signed by a patient—or surrogate—and by the patient's physician, the POLST is a legal physician order that travels with the patient from clinical site to clinical site (that is, from home to hospital to skilled nursing facility and back, et cetera). In this way, the POLST is the ultimate end-of-life advance directive. Patients and physicians are advised not to sign the document, however, unless the patient's clinical situation and prognosis are clear and they have had an opportunity to discuss the stability of the patient's choices, the likelihood of anticipated scenarios, and the role of surrogate judgment and shared decision making. The patient (or the surrogate) and the physician should make a commitment to review the POLST at least once a year, and they should also review it every time the primary site of clinical care changes.

INTEGRATION AND THE NEW PROCEDURAL STANDARD OF SURROGATE EMPOWERMENT

Reconciling what is known about surrogate decision making and advance care planning and integrating this information into a holistic, practical approach that honors our pluralistic society is not straightforward. Several authors have attempted to do this from a variety of perspectives.

Sabatino takes a distinctly legal approach to the process, beginning with a discussion of the legal history of proxy decision making, in general, and the legal history of medical surrogacy, in particular.[47] He then reviews the current status of diverse state laws on the topic, emphasizing the tension between what he terms the "legal transactional approach" of tools and forms and the "communications approach" of discussion and conversation. Finally, he makes five recommendations that he believes will improve physician-surrogate relationships:

1. Allow the appointment of immediately effective proxies, who would serve as official patient advocates or advisors for patients still having capacity and who would become legal surrogate decision makers when patients lose capacity.
2. Require medical providers to identify proxies as early as possible for patients "suffering from chronic or acute illness or condition that could lead to death."
3. Require medical providers to provide writ-

ten information and counseling to surrogates.
4. Define a method of informed consent that emphasizes the physician-surrogate discussion process.
5. Recognize the authority of proxies over written living will directives.

Pope also presents a legal review of medical surrogacy, starting by identifying five distinct types of surrogates:
1. Surrogates designated by patients via ADs,
2. Surrogates designated by patients via oral directives to their physicians,
3. Court-designated surrogates such as guardians and conservators,
4. Default surrogates such as family members who are identified by physicians and/or who follow hierarchical guidelines according to state law,
5. Special surrogates such as temporary guardians, hospital ethics committees, regional surrogate committees, et cetera, for patients who do not have family or friends able to serve as surrogates.[48]

He then outlines problems with surrogate decision making and suggests several general solutions to these problems, including a recommendation for surrogate education—although he does not clearly define what this education should comprise in practice.

Torke and colleagues, in contrast, take a very different approach to integration, describing a conceptual model of surrogate decision making founded upon "information processing" and "relationship building" between surrogates and clinicians that leads to "high quality medical decisions."[49] While the authors describe the theoretical steps to their communication-based approach, they do not provide a detailed description of how to apply these steps in practice.

Vig and colleagues describe five "actual processes of surrogate decision making" based on conversations with individuals who previously served as surrogates.[50] These surrogates based their decisions on the following primary factors:
1. Past conversations with patients (66 percent),
2. The surrogates' own beliefs, values, and preferences (28 percent),
3. Consensus-building discussions with patients' other family members and friends, clergy, and clinicians (18 percent),
4. Past life experiences shared with patients (16 percent), and
5. Patients' written documents (10 percent).

Vig and colleagues do not conclusively describe *why* surrogates chose the primary basis they did for their decision-making process.

Braun and McCullough outline a very detailed set of algorithms summarizing what they see as the current, common "best interests" practice of providing life-sustaining treatment by default.[51] They write that a combination of three factors leads to continuing life-sustaining treatment:
1. The presumption of preserving life when a patient's preferences are unknown or when the prognosis is not absolutely certain,
2. Surrogates' requests to "do everything" out of fear, guilt, and so on,
3. The path of least resistance, in which clinicians do not really engage surrogates to think through what "doing everything" means.

Their suggestion for how to address these complex scenarios is actually fairly simple: clinicians must actively encourage patients and surrogates to discuss and communicate preferences and decisions early and often, both orally and in writing. They do not describe in detail, however, *how* to make this happen.

In a manner fairly similar to the argument made at the beginning of this article, Berger, DeRenzo, and Schwartz note that the bioethical hierarchy of the three traditional standards of surrogate decision making—advance directives, substituted judgment, and best interests—are often inadequate in practice.[52] In response they propose a multidimensional approach that honors our society's complex and pluralistic patient population and reconciles ethical theory with clinical practice. In preparation for the future, they encourage physicians to assist their

patients in completing ADs by discussing prognosis, broad goals of care, and the role of their directive either "as binding, as weighty but not binding, or as merely informative." Clinicians should also assist patients in identifying their best proxy and best decision-making process. Once a patient with an AD becomes incapacitated, Berger and colleagues believe that clinicians should:

1. Review the patient's previously written specific directives in light of a current assessment of benefits and burdens,
2. Assess who the patient's best surrogate might be, and
3. Review with that surrogate how to implement the patient's advance directive, including whether it should be followed strictly or whether there is reason to diverge from it.

When caring for a patient without an AD, clinicians should assist the surrogate in constructing a narrative for that patient that includes the patient's preferences and values.

Sudore and Fried emphasize preparation for "in-the-moment decision-making" by patients and surrogates rather than the completion of advance directive documents.[53] They write that the first part of this preparation is to assess a patient's readiness to engage in advance planning and then, when the patient is ready, to help him/her execute three steps:

1. Choose an appropriate surrogate decision maker,
2. Clarify and articulate personal values, and
3. Establish leeway in surrogate decision making.

They conclude their article with brief sample language for clinicians wishing to engage in this process.

In a systematic review of empiric studies on the effects of surrogate decision making, Wendler and Rid assert that at least one-third of surrogates in the studies experience emotional stress and burden due to a variety of factors, including uncertainty regarding patients' preferences, uncertainty regarding prognosis, and poor clinician communication.[54] Noting that preparation and prior discussion decrease surrogates' stress, the authors propose three general behaviors to promote the surrogate process:

1. Identify treatment consistent with patients' preferences,
2. Respect patients' preferences regarding how decisions should be made, and
3. Protect family and loved ones.

In a separate systematic review of studies evaluating individual patient goals for surrogate decision making, Kelly, Rid, and Wendler[55] note that most patients want three things:

1. The involvement of their family members,
2. To be treated in accord with their stated preferences (although the authors acknowledge that patients vary greatly with regards to how much leeway they wish their surrogates to have), and
3. To minimize the burden of their situation on their families.

In a policy paper on how to improve the surrogate process, Rid and Wendler advocate shared decision making between surrogates and clinicians, and they encourage identifying and incorporating patients' preferences in as detailed and specific a manner as possible.[56] They strongly promote future research on how to integrate patients' treatment preferences into shared surrogate-clinician decision making, as well as research on the development of an instrument to survey these preferences.

Meanwhile, although several general advance care planning resources are available,[57] there remains a need to develop practical clinical tools to assist patients in planning for the future and to assist surrogates—indeed to empower them—to handle their role when called upon. What we know is this:

- Documenting specific advance directives is good, but many patients change their minds over time.
- Clear decisions not to want certain types of treatment are more stable than other decisions.
- Patient-surrogate agreement on specific treatment decisions, in the best situations, occurs only about two-thirds of the time.

- Patient-surrogate discussions of values and scenarios do not necessarily improve agreement. Discussion does appear to decrease surrogates' stress. Disease-specific scenario discussions may improve agreement more than generic discussions do.
- Some patients want their directives followed strictly. Many patients want their directives to inform their surrogates' decisions, but they prefer that their surrogates use judgment in decision making.
- Narratives, interest-based conversations, and covenantal relationships might help some patients and surrogates prepare for and fulfill their respective roles and duties.
- Shared decision making is central to all approaches.

A new clinical standard of surrogate empowerment is therefore proposed to reconcile and integrate these observations. Surrogates must be empowered—by preparation as well as by explicit endorsement by patients and clinicians—to fulfill their role thoughtfully, responsibly, and with the respect and support of patients' other family members, friends, and the healthcare team. This clinical standard acknowledges the stress of the surrogates' role, the strengths and limitations of current standards, the need to incorporate patients' preferences for treatment and decision-making style, and the need for a process that has practical clinical utility. It both honors societal diversity and the pluralism of patients, and it addresses real-life clinical situations. Finally, it is open to be the focus of empiric research and future refinement.

The procedure for this clinical standard is outlined here.

PROCEDURE FOR HEALTHCARE PROFESSIONAL WITH THE PATIENT

The healthcare professional can use this "script" in discussions with patients on planning.

1. I think that all patients [or all patients in certain categories: terminal illness, advanced chronic disease, any chronic disease, patients who are older than 65 . . .] should think about advance care planning. How should medical decisions be made for you, if you were not able to make them for yourself because of illness or because of the effects of medication or other treatments?

2. Who could or should make decisions for you? Can you identify one or two best substitute or "stand-in" decision makers? Doctors usually use the word "surrogate" or "proxy" for this person. If several possible surrogates come to mind—for example if you have several children or several siblings—would you like help in identifying which one or two would be the best surrogate(s) for you? Would you like help in talking to your family about who your surrogate(s) should be?

3. Or is your family one in which everybody makes important life decisions together? If so, can you identify one or two family members who might be best able to pull your family together and be the best spokesperson(s) for you? Please remember that surrogate decision making is often very stressful for family and friends. The more you are able to plan ahead, the better you will be able to take care of them and keep your family and friends from feeling guilty and stressed when the time comes for them to make decisions for you.

4. Are there specific treatments or interventions that you are *completely certain* you want to have done, if medically indicated, or that you are *completely certain* you would never want done, even if they might be options for care? For example, undergoing cardiopulmonary resuscitation (CPR), being intubated and put on a breathing machine, having a feeding tube placed, [et cetera].

5. Are you comfortable discussing specific medical scenarios with your surrogate or family and talking about what you might want or not want done under particular circumstances? What if you developed Alzheimer's and had no memory and couldn't recognize people? Or what if you developed terminal cancer and had a prognosis of only six to 12 months? Or what if you had a severe stroke and couldn't talk or eat? Or what if you developed severe lung disease and needed long-term ventilator treatment? What might you want or not want in those situ-

ations? Talking about these situations is very difficult, but it will help your surrogate to make decisions, as much as possible, in the same way that you would make them for yourself if you could.

Would you like help on how to have these kinds of conversations?

5.A. [For patients who have a specific terminal illness or a very serious/advanced chronic illness.] Given your current medical situation, there are a couple of disease-specific scenarios that are very possible. Would you be comfortable discussing those scenarios and the kinds of decisions that will likely need to be made should they occur?

6. Are you comfortable discussing your medical and personal values with your surrogate and family? Some people, for example, really want to avoid pain—even if that means that they might die sooner or be "drugged up" a lot of the time because of pain medication. Others, often for religious reasons, want to live as long as possible regardless of how or where they live (for example, on a breathing machine in the hospital). Some people want to live only if they can be awake, talking, and thinking clearly. Still others want treatments only if those treatments will help them get out of the hospital and back home. Some people want to be certain that they do not become a burden to their family.

What kinds of things are important to you?

Would you like help on how to have these kinds of conversations?

7. Many patients prefer not to be too specific in stating prior wishes, however, because: (A) They are too uncomfortable—or simply too uncertain about medical care in general—to discuss their medical and personal values. (B) They know their medical situation might change and they just can't predict the choices they might have to make. Or (C) like lots of patients, they know they might change their minds as their situation develops over time. Many of these patients would like their surrogates simply to follow community standards about medical decision making—that is, what most people want in these situations. Would you like us to discuss with your surrogate what most people in your situation usually want done?

8. Other patients prefer that their surrogate [or their family, if the patient has expressed interest in a family-consensus style of decision making] simply use his or her judgment in making decisions. Does this sound like what you would like?

9. If you would like your surrogate to use his or her judgment in making decisions for you, would you be comfortable telling him/her that? That is, would you be comfortable telling your surrogate to do his/her best with whatever happens? In a sense, you are empowering your surrogate to write a part of your story, because you trust them to do so.

10. Another way to prepare your surrogate to make decisions for you is to empower him/her to make decisions the same way he/she would for him/herself in the same medical situation. Does it sound like something you would be comfortable telling your surrogate to do?

11. If you are able to be specific about these areas, you should document your wishes in an advance care directive document:

A. Name your surrogate(s).

B. List specific treatments about which you are completely certain you would accept or decline in particular situations.

C. List the medical and personal values that are most important to you.

D. Give direction to your surrogates about whether you want them to follow your directives strictly or whether they should use their judgment, including the judgment to make decisions for you the same way they would make decisions for themselves.

E. Write down any other guidance for your surrogates.

12. [If the patient has a terminal illness or a serious, advanced chronic illness, and if the POLST is available in your state, provide the patient a copy and review it with him/her.]

PROCEDURE FOR HEALTHCARE PROFESSIONAL WITH THE SURROGATE

The healthcare professional can use this script in discussions with surrogates.

1. Thank you for helping us make medical decisions for your friend or loved one because

of your special role/relationship in his/her life. [If the surrogate is a "default" decision maker, mention his or her relationship to the patient. If the surrogate was appointed, mention the fact that the patient must trust him/her a great deal in order for the patient to have appointed him/her to perform this special, difficult duty.] We know that this can be difficult and stressful, and we know that you will do your best. We would like to help you make the best decisions you can by asking some questions that usually help people who serve this role for their friends and loved ones.

2. Did you know that you would be making these kinds of decisions for your friend or loved one? Have you discussed advance care planning together at all?

3. Many surrogates want to share decision making with the doctors and staff caring for the patient. Would you like to make decisions independently? Or would you prefer to talk about how we can work together to make decisions?

4. Has your friend or loved one given you specific directions or expressed specific wishes about what he/she would want done in this situation? Does he/she have an advance directive, and, if so, have you discussed it? Do you have a copy? Have you discussed the kinds of medical scenarios or situations that might arise for him/her? Have you discussed the kinds of things that might be important to him/her—special values or interests—that might help you make decisions?

5. If your friend or loved one has not expressed clear wishes about what he/she would want done, and if you have not discussed specific scenarios or specific medical values, do you feel like you know him/her well enough, overall, to make decisions in a way that simply "fits with" what you do know about him/her? Do you think you can tell the story of what should happen now?

6. If you do not have a clear idea about exactly what your friend or loved one would want done in this situation, and if even the idea of "telling his/her story" seems awkward or too hard, or just not right, would you be comfortable making decisions for him/her the same way you would make them for yourself in this situation? After all, you are the person he/she asked to make decisions for him/her [or: After all you are the person with the closest relationship to him/her], so he/she must trust you a great deal.

7. Is there anything that I or anyone else on the healthcare team can do to assist you serve as the surrogate for your friend/loved one? We are here to share information with you and to share in the decision-making process as much as you need us. Is there specific information that you think would be helpful? Would you like to speak to a social worker or a chaplain or a member of the hospital's palliative care team or ethics committee to help you understand what is going on and to help you make decisions?

8. [If the POLST is available in your state, provide the surrogate a copy and review it with him/her.]

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Michelle Daniel, "Bedside Resource Stewardship in Disasters: A Provider's Dilemma Practicing in an Ethical Gap," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 331-5.

Disaster Response

Bedside Resource Stewardship in Disasters: A Provider's Dilemma Practicing in an Ethical Gap

Michelle Daniel

ABSTRACT

During disasters, clinicians may be forced to play dual roles, as both a provider and an allocator of scarce resources. At present, a clear framework to govern resource stewardship at the bedside is lacking. Clinicians who find themselves practicing in this ethical gap between clinical and public health ethics can experience significant moral distress. One provider describes her experience allocating an oxygen tank in the intensive care unit at a hospital in Port-au-Prince, Haiti, immediately following the 2010 earthquake. Using a clinical vignette and reflective narrative she attempts to identify the factors that influenced her allocation decision, opening up the factors for commentary and debate by an ethicist. A better paradigm for the ethical care of patients during disasters is needed to better guide provider choices in the future.

I arrived in Haiti 10 days after the 12 January 2010 earthquake. I am an emergency physician with prior experience working in developing countries, including 15 months in Haiti, but I had never before deployed in a major disaster. I was assigned by Partners in Health to work the night shifts at the badly damaged University Hospital in downtown Port-au-Prince. The physical and psychological environments were unlike anything I had ever experienced. I routinely worked 14 to 16 hours at a stretch. Finding sleep was a challenge. My tent was a pressure cooker in the noonday sun, and the roosters and incoming cargo planes created a cacophony that even utter exhaustion couldn't overcome. I was lucky if I slept three hours a day.

At the hospital each night, I was faced with an overwhelming number of patients in need of care. In my sleep-deprived state, I found myself making critical clinical and ethical decisions almost reflexively. I triaged, I rationed, and I allocated scarce resources at the bedside. I made decisions and I moved on. I did not stop to reflect on my choices. Had I done so, I might have become incapacitated by the moral weight of those choices. It was only later, in my quiet moments alone, that I began to contemplate what I had done. I wondered if I had made the "right" decisions.

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One of the scenarios that haunts me involved multiple patients in the intensive care unit. I arrived one evening to find four individuals in respiratory distress. They were all exhibiting significant air hunger, were tachypneic, and had oxygen saturations in the low 80s. Intubation was not a viable option. There were no ventilators. In fact, I had only one functional oxygen tank—the others were effectively useless, as they had no regulators.

I had to choose which patient to give the oxygen to, knowing the others would suffer and even die as a consequence of my decision. The patients were:

1. A 15-year-old girl with a past medical history significant for meningoencephalitis. She was neurologically devastated at baseline and completely dependent on others for her care. She had a treatable pneumonia. Antibiotics and intravenous fluids were available.
2. A 40-year-old woman with HIV. Her chest x-ray showed cavitary lesions highly suspicious for tuberculosis (TB). She had three children at her bedside (ages five to 15.) They kept imploring me to help their mother. The medications needed to treat her TB and HIV were not yet available, and I did not know when they would be.
3. A 25-year-old previously healthy male nurse, three days post-op from major bowel surgery for perforated typhoid enteritis. He had not been receiving heparin prophylaxis and likely had a pulmonary embolism (PE.) Limited supplies of heparin and warfarin for treatment were available.
4. A heart-breakingly beautiful 18-year-old girl with acute decompensated heart failure. She had marked cardiomegally and a loud washing machine murmur on exam. Her acute heart failure was easily correctable, but the underlying condition (probably a congenital heart defect or a valve disorder) was not correctable in Haiti.

Which of these four patients should have been given the oxygen? Why? If another oxygen source became available, who should have been treated next? Why? How do providers make these choices? How should providers make these choices?

Before being confronted with these patients, I thought I knew how to prioritize patients to receive care. In my daily practice in the United States, patients with the greatest need are treated first, with little regard for the resources they consume. Faced with multiple patients, each with an equal need for a limited resource, I found myself trying to determine in whom the resource could be used most effectively. When it became apparent that need and medical effectiveness alone were not sufficient to assign priority to these four patients, I considered other factors to help me determine for whom the resource use seemed the most appropriate.

In retrospect, one of the reasons these cases gave me such angst is that it quickly became clear that the most medically salvageable patient in the short term, the 15-year-old neurologically devastated child with a treatable pneumonia, was not the patient I prioritized to receive the oxygen. Indeed, she was the last person I would have given the oxygen to. Did I make a medical judgment based on a co-morbidity or a value judgment based on my own latent biases? I am honestly not sure. Let me try to make explicit in words what was implicit in my decision making, so that it can spur discussion and debate.

To help me determine in whom the resource would be most medically effective, I first considered short-term salvageability. Many scoring systems exist (SOFA, APACHE, MODS, and modified versions of each) to help predict short-term survival. They all have their limitations, and many of the data points needed to calculate such scores were largely unavailable in Haiti. My best estimation was that Patient #1 had the greatest likelihood of short-term survival, followed by Patient #4, Patient #3, and Patient #2. Should short-term survivability alone define effective medical care or should a more long-range view be used?

I next considered long-term survivability. A resource might be defined as "wasted" if used on a patient that lived for a week, but succumbed to her or his illness the next week (or month, or year.) Given the size and scope of the

disaster in Haiti, and the fractured healthcare system in that country at baseline, long-term patient survival and the potential for continued use of healthcare resources seemed to warrant consideration. I tried to make some reasoned predictions for long-term survivability and resource consumption based on the patient's current, pre-existing, and co-morbid conditions. I recognize that there are significant problems with making such predictions, but I still considered it an important part of the equation.

Patient #3 was otherwise healthy, and if he could get over the current insult of a PE and major abdominal surgery, he would likely return to his pre-morbid level of good health. He had the best chance of long-term survival, and would presumably not be a continued drain on resources. Patient #1 was neurologically impaired at baseline. She could not communicate verbally and required help with feeding, toileting, and other activities of daily living. She was potentially susceptible to sacral decubital ulcers, aspiration events, and other illnesses due to her chronic invalid state. Prior to the earthquake, she was cared for at home by her family, but their resources for her continued care in the wake of the earthquake were uncertain. Patient #2 had HIV, TB, and possibly AIDS. The patient would require administration of directly observed therapy for TB for one year to avoid the emergence of a multi-drug resistant infection. She would also need antiretroviral treatment. If she did have AIDS, she would be susceptible to opportunistic infections until her immune system could be reconstituted. I may have been more optimistic for this patient's long-term survival if I had known when and where HIV and TB medications would be available. Patient #4 had a congestive heart failure (CHF) exacerbation and an ill-defined underlying condition. She might return to her premorbid functioning with just mild limitations in her activity level, or she may have continued, frequent exacerbations until she ultimately succumbed to her disease. Cardiac ultrasound would have been helpful to further define her anatomy and better predict her likelihood of long-term survival. In summary, Patient #1, Patient #2, and Patient #4 all had significant co-morbid illnesses likely to affect their long-term prognosis. The nuances of each of their diseases made accurate forecasting difficult, and I had trouble ranking these patients. What was clear, however, was that Patient #3, who had no co-morbidities, was the individual to whom giving the oxygen to would seem most medically effective in the long term.

At this point, my dilemma intensified. I could not determine who should receive the resource based on need—they all had equal need. I could not determine to whom I should give the resource based on medical effectiveness, as it depended on how I defined "medically effective." Is medical effectiveness a short- or a long-term phenomena? How good are our predictions of each? If I chose the short-range view, I should give the resource to the neurologically devastated child, Patient #1. If I chose the long-range view, I should give the resource to the nurse with the PE, Patient #3. If my predictions were accurate (and this is a BIG "if"), the nurse had a slightly higher probability of dying in the short-term, but a better chance of surviving long-term. If assigning priority based on medical effectiveness was not adequate, what other factors could I reasonably use to help make a decision?

One factor I considered was the patients' role or function in society. Patient #3 was a nurse. The nursing school on the hospital grounds had collapsed in the earthquake, killing 140 nursing students, effectively wiping out the next generation of Haiti's healthcare providers. The recovery of the nation's fragile health system would depend on people with the skill set this patient had acquired. If a main goal of disaster response is to get society back up and functioning as quickly as possible, arguably it may be appropriate to consider a patients' instrumental value in disaster recovery. I also gave weight to the possibility that the nurse may have contracted his typhoid enteritis in the line of duty. If healthcare providers put themselves at increased risk of exposure to illness after disasters, we may have an additional moral obligation to care for them when they fall ill.

Another factor that influenced my decision was the idea of saving or sacrificing one life to help save the lives of others. Saving the life of the nurse would potentially save the lives of future patients. Saving the life of the mother would help save the lives of her three dependents. Her kids were desperately tugging on my shirt sleeves and imploring me to help. I was not immune to their pleas. They had already lost their father in the earthquake, could I allow them to lose their mother too? Unfortunately, that same mother was refusing to wear a mask and was actively and violently coughing. She had the potential to spread TB to her children and the patients around her. Should she be allowed to die in an attempt to stop the spread of contagion? Were there other goods I needed to consider beyond the individual patients' survival?

An additional influence on my patient prioritization was that of a certain kinship and empathy bred from shared experiences. I am a healthcare provider who is on the front lines, exposing myself to harm to treat patients during disasters. Did this lead me to prioritize the nurse? I am also a mother with two dependent children. Did this make me more sympathetic to the plight of the mother? Is this a personal bias or a societal one? If I were the mother of a disabled child, would I have been more inclined to use the oxygen on Patient #1? The girl with CHF was stunningly beautiful. Was I influenced by her appearance to choose her over the less attractive child? Not consciously, but it is these very hidden biases in our nature that can lead even the best-intentioned individuals astray. If asked, I would say that personal feelings should not influence decisions about resource stewardship, but I am human. I cannot honestly say that these factors held no sway in my decision.

Finally, I questioned whether judgments regarding quality of life played any role in my decision. As I looked at the neurologically impaired child, I am sure I assumed her quality of life was poor. This potential influence on my decision troubles me the most. After all, who am I to judge? Given the setting and time constraints, I had no opportunity to try to assess quality from the patient's and her family's perspectives. I understand that my own interpretation of quality of life is limited by my own good health. Quality of life considerations should not have played a role here, because the necessary information wasn't available. Still, I cannot help but think that my interpretation of the more rational criteria was affected by my underlying beliefs about a life worth living.

In the end, I cannot offer a mathematical equation to explain how I made my final allocation decision. First and foremost, I considered short- and long-term survivability in determining medical effectiveness, recognizing the inherent inaccuracies of such predictions. I then considered the patients' roles in society and disaster recovery, their dependents, and their potential for saving or harming others. I likely also considered our shared life experiences, the empathy a given patient evoked, and their perceived quality of life.

I ultimately prioritized the patients as follows:

1. Patient #3 (the nurse with the PE),
2. Patient #2 (the mother with HIV/TB),
3. Patient #4 (the young woman with CHF),
4. Patient #1 (the neurologically devastated child with pneumonia).

My decision was made in less than five minutes. I applied the oxygen to the nurse. I treated the other patients as best I could with the resources at hand. Midway through the night, one of the soldiers stationed at the hospital devised a way to split the oxygen tubing between two patients. His ingenuity allowed me to give oxygen to the mother as well. The disabled child progressively deteriorated and died the next night on my watch. The beautiful girl with heart failure responded transiently to lasix and nitroglycerin, but she ultimately succumbed as well. The mother never did get the drugs needed to treat her TB and HIV. She was ultimately deprioritized from the oxygen when another, more salvageable, patient came along. The nurse with the blood clot was slowly improving a week later when I boarded the plane home. Did I make the "right" decisions? I still don't know.

Interestingly, I have now presented these cases to more than 100 physicians, students,

and laypeople, and an overwhelming majority chose the patient I chose—Patient #3 (the male nurse.) Patient #2 (the mother of three children) is usually chosen next, followed by Patient #4. Patient #1, the disabled child, is almost always last. By no means were the votes unanimous, but there seems to be at least a consensus. The reasons people cited for their choices have been as varied as mine.

My approach to the problem of resource allocation in Haiti was largely based on my very basic medical school training in ethics, some experience with ethics committee work, and several years as a practicing emergency physician. These experiences formed the foundation for what Jeffrey Berger would term my "moral intuition."[1] My residual anxiety over these cases led me to conclude that my current training wasn't adequate to make such complex decisions. My moral intuition is strong, but perhaps my latent and unfair biases are stronger. A clear framework for decision making in disasters would be invaluable to providers who find themselves having to make these difficult choices at the bedside.

MASKING OF THE CASES

Some details regarding the patients discussed in this article have been changed to protect their privacy.

NOTES

1. J.T. Berger, "Imagining the Unthinkable, Illuminating the Present," *The Journal of Clinical Ethics* 22, no. 1 (Spring 2011): 17-9.

Jeffrey T. Berger, "Resource Stewardship in Disasters: Alone at the Bedside," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 336-7.

Resource Stewardship in Disasters: Alone at the Bedside

Jeffrey T. Berger

ABSTRACT

Discussions about resource allocation commonly invoke concerns of unfair and variable decisions when physicians ration at the bedside. This concern is no less germane in disaster medicine, in which physicians make triage and allocation decisions under duress, and patients and their families may be challenged to self-advocate. Unfortunately, a real-time mechanism to support a process for ethical decision making may not be available to medical relief workers. Yet, resources for ethics decision support can be important for the moral well-being of the clinician, the ethical integrity of the relief effort, and to bolster the trust and confidence of the population receiving medical services. The need for clinical ethical support should be anticipated in disaster preparedness planning.

The dilemma so poignantly described by Michelle Daniel, MD, would trigger moral paralysis in many physicians.[1] To her credit, Daniel made reasoned and defensible decisions under duress and in a highly compressed time frame. Unfortunately, for Daniel and many other disaster relief medical workers, clinical ethical support is not a common feature of disaster medicine, whether that is an ethical briefing of triage scenarios likely to be encountered, or real time peer support for actual clinical dilemmas. One might argue that the unpredictability of the earthquake in Haiti and the enormity of the crisis allowed no time to attend to the ethics of disaster relief. Yet Daniel had "prior experience working in developing countries, including 15 months in Haiti," and was "assigned" by a well-established relief organization to her station in Port-au-Prince. The World Medical Association implies that ethical rules should be ". . . defined and taught beforehand."[2] The question was not *if* ethics support would be needed within the scope of disaster medicine, but rather *when* would it be needed.

For physicians at the bedside during disasters, triage is expectedly unavoidable. The Agency for Health Care Research and Quality (AHCRQ), in its report, *Altered Standards of Care in Mass Casualty Events,* recognizes that allocation decisions should follow a process that is "fair, open, transparent, accountable, and well understood by both professionals and the public. . . ."[3] Yet Daniel found herself without a

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real-time mechanism to support a process for decision making. This left her process of decision making closed, without external references for fairness, and accountable only to her personal sense of morality. It was a process not well understood by the public generally, or by her four patients who were assumedly disempowered by illness, illiteracy, and a culturally based deference to authority. This process of decision making was not well understood even by Daniel, whose grappling with the issues was contemporaneous to the crisis. Even though Daniel was mindful of the various competing objectives, interests, and biases that came to bear on her decisions, it is not fair to her, to other physicians similarly situated, or to the patients who bear the consequences of these decisions, to have individual physicians making allocation decisions without support. I suspect that Daniel would have had far less moral distress, anxiety, and concerns of *post-hoc* peer criticisms if her decisions were made with any sort of peer support or external referencing, particularly because her patients and their family members were not positioned to evaluate her actions.

Ultimately, Daniel's choice was most influenced by concerns of utility which, in times of *extremis,* often emerges over other relevant considerations as the least morally intolerable imperative for decision making. This application of utilitarianism, Kipnis submits, can be supported by two considerations: social contract and stewardship of resources.[4]

The social contract justification suggests that rational and reasonable members of a community would agree to some system of triage and allocation and would accept its consequences. Hence, healthcare workers would be ethically empowered to make decisions with reference to the triage priorities of a community, as long as these priorities are not unfair. It would require that triage and rationing be informed by domestic norms of culture, religion, and morality. For example, would the facts that, in Haitian culture, children are considered a gift, yet disease is considered a curse or punishment, influence the care of Daniel's 15-year-old girl patient?[5]

If such local input was never considered prior to a catastrophe, it is not likely to be integrated during a catastrophe. Therefore, physicians like Daniel may have little more than personal integrity with which to buffer utilitarian imperatives.

An additional buffer would have been for her to turn to her community of medical colleagues, whose professional values may provide an ethical framing for her dilemmatic decisions. This peer support can be critical in a physician's management of ethically dilemmatic cases and for managing one's moral distress. Peer support recognizes physicians as a community that is defined not only by expertise, but by experiences and respective moral weight attached to their role.

Reliance on peers alone can also be problematic, however, because the legitimacy, quality, and value of its product depend, in part, on the composition of the peer group and its processes for deliberation. The more insular a group is in composition, the greater the risk for groupthink and other decision-making biases. Moreover, if the group is wholly composed of internationally deployed emergency medical workers, its imported Western biomedical ethics may not resonate closely with some local norms.

Certainly, in times of crisis, the pull of utility can make attention to ethical congruence and fidelity seem irrelevant. However, to the extent that the need for ethical support can be anticipated, the disaster itself is no excuse for lack of preparation.

NOTES

1. M. Daniel, "Bedside Resource Stewardship in Disasters: A Provider's Dilemma Practicing in an Ethical Gap," in this issue of *JCE.*

2. *http://www.wma.net/en/30publications/10policies/d7/,* accessed 23 November 2012.

3. *http://archive.ahrq.gov/research/altstand,* accessed 10 November 2012.

4. K. Kipnis, "Overwhelming Casualties: Medical Ethics in a Time of Terror," *Accountability in Research* 10 (2003): 57-68.

5. *http://www.state.in.us/isdh/files/Haiti_Cultural_and_Clinical_Care_Presentation_Read-Only.pdf,* accessed 23 November 2012.

Matthew R. Hunt, Christina Sinding, and Lisa Schwartz, "Tragic Choices in Humanitarian Health Work," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 333-44.

Tragic Choices in Humanitarian Health Work

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ABSTRACT

Humanitarian healthcare work presents a range of ethical challenges for expatriate healthcare professionals, including tragic choices requiring the selection of a least-worst option. In this paper we examine a particular set of tragic choices related to the prioritization of care and allocation of scarce resources between individuals in situations of widespread and urgent health needs. Drawing on qualitative interviews with clinicians, we examine the nature of these choices. We offer recommendations to clinical teams and aid organizations for preparing and supporting frontline clinicians in their efforts to determine the least-worst option, and in their responsibility for making such choices.

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Many health professionals travel to other countries to participate in humanitarian aid work in contexts of armed conflict or extreme poverty, or in the aftermath of disaster. The provision of care, as well as many other facets of living and working in low resource and sometimes insecure settings, is associated with a range of logistical, clinical, and personal challenges. Clinicians are also confronted by ethical questions and dilemmas, and their training and experience in "ordinary" practice contexts may provide limited reference points for assessing and resolving them—particularly if their home countries are resource-rich and relatively stable politically. A clinician from Canada characterized the settings where international humanitarian aid is delivered, and the scope of available resources to meet local needs, as situations in which "People need a lake and you

are offering a glass of water"[1]: a profoundly "second-best world"[2] where local and international actors seek to address priority concerns but where the collective response is frequently insufficient to meet many pressing and competing needs.

A prominent set of ethical issues that arises in such circumstances, and that must be responded to by clinicians, encompasses decisions to prioritize care and allocate resources between individuals.[3] In this article we draw on qualitative interviews conducted with clinicians who have participated in humanitarian aid projects to illuminate the nature of these decisions and how they are frequently experienced by clinicians as inescapable tragic choices.[4] Such decisions represent an important source of ethical uncertainty in humanitarian work for which clinicians often feel ill prepared. We offer recommendations for how clinical teams and aid organizations can help prepare and support those responsible for making such choices.

INESCAPABLE TRAGIC CHOICES

Alex de Waal has described the humanitarian's tragedy as the reality that well-intentioned efforts to provide assistance to communities in need are associated with escapable and inescapable cruelties.[5] He sees the "escapable" as the negative consequences that arise from technical failings and miscalculations of humanitarian actors. Such lapses and their impacts can and should be reduced by improving operational planning and implementation, and enlarging the evidence base of humanitarian aid. De Waal describes another set of situations as "inescapable cruelties," when assistance must be prioritized between individuals who all have significant and pressing needs. He pictures surgical triage as the most representative case, where patients are sorted by a prioritization scheme and surgical interventions are allocated in consequence. Such allocation choices are not limited to surgery. Humanitarian healthcare practice involves decisions on allocating medications, blood, and other finite resources, as well as staffing and beds. Some patients who, in other settings—including the home countries many of the expatriate workers come from—would in due course receive a particular resource,[6] would not have access to it due to the scarcity of resources in humanitarian settings and the elevated health needs of the population. Decisions to allocate limited resources between individuals may thus be unavoidable for local teams. Micro-level allocation choices are, however, unfamiliar to many clinicians who are new to humanitarian health work, nor are all such situations resolved more easily with experience.

In considering the nature of decisions to allocate limited resources in humanitarian healthcare, it is important to underline that the need to make such decisions is related to how the world is organized—the (un)availability of resources is shaped by a range of external features and decisions. So while teams struggle with limited resources and make seemingly inescapable choices, at a broad level situations of scarcity are not "natural."[7] For example, if the international community has been slow to respond to the signs of a developing famine, the opportunity to address the crisis early on will be missed, leaving aid teams that respond at the height of the famine with inescapable choices of whom to prioritize. It is in such contexts that de Waal describes how "the impulse to ameliorate suffering leads humanitarian workers and institutions into the unwelcome situation of acting cruelly," resulting in dissonance between their goals and effects.[8]

Clinicians who are involved in humanitarian work strive to provide assistance and alleviate suffering. They do not wish to be associated with cruelties. Those who are not selected or prioritized in a local project might well experience the prioritization schemes, narrow project mandates, or cutoff points established by humanitarian practitioners, including clinicians, as callous. Some expatriate clinicians who are expected to make these judgments also describe feeling that some of the decisions that they must make are indeed cruelties.[9]

De Waal identifies these clinical and operational choices as tragic, as well as inescapable.[10] Such decisions are tragic in the ancient Greek

sense that acknowledges that aspects of human suffering and catastrophe may be insoluble.[11] In such settings, the ideals held by humanitarians and health professionals collide with the harsh reality of crisis or catastrophe. Often clinical practice in such settings does not permit the simple resolution of ethical issues through application of idealized moral principles and values because the contexts themselves are inherently unjust.[12] Technical expertise and the material and human resources of humanitarians are often dwarfed by the scale and magnitude of a major disaster or protracted civil conflict. Contextual demands such as security needs, cultural differences, historical antecedents, and political instability may be additional sources of challenge. Healthcare needs also intersect with other needs of the population. This reality is highlighted in an interview with one of the Canadian physicians providing care in a post-conflict setting. She asserted that access to medications was not the only relevant concern, saying that patients need "access to clean drinking water to wash down [their] antiretrovirals."[13] Providing quality care to all in need is obstructed in such contexts.

Tragic choices are ones in which all options are morally problematic in some way and that, whatever choice is enacted, something of moral significance will have been lost.[14] There are multiple ways in which tragic choices are manifest in humanitarian healthcare practice, such as situations when providing needed care to a patient exposes others to security risks. A prominent set of tragic choices includes situations when clinicians must decide who amongst their patients will receive priority assistance when all need urgent help, or more poignantly still, to select some to receive a particular treatment or resource that is in short supply while others who also are in need will not receive it at all. For their part, clinicians may be seriously distressed by having to make these choices, when their professional ideal of providing quality care for all patients conflicts with making best use of a shallow pool of resources—and when "best use" is by no means clearly defined. They may experience regret or angst. Others burn out or do not continue with humanitarian work. Obviously, the consequences are much graver for those who cannot access the help or care they need. The heaviest costs associated with allocation decisions are borne by those who are not prioritized for, or do not receive any, assistance.

NARRATIVES OF ALLOCATING RESOURCES, PATIENT SELECTION, AND TRAGIC CHOICES

We have conducted three qualitative studies with Canadian health professionals with experience in international aid work, including the provision of care in settings of acute disaster or armed conflict and post-disaster or post-conflict reconstruction.[15] In total, we interviewed 45 doctors, nurses, and allied health professionals. Across the narratives of these clinicians there were many stories of tragic choices involving micro-level resource allocation and dilemmas of "patient selection."[16] Dilemmas of patient selection include situations when clinicians consider not providing care to a patient or group of patients because of the scarcity of resources, as well as scenarios in which organizational policies, public health rationales, or project mandates direct that clinicians not treat some individuals who are ill or injured.[17] For example, some participants were involved in programs that focused on a single disease, and in which treatment was reserved for those individuals whose diagnosis matched the externally defined priorities of the project. Some of these clinicians struggled with implementing these policies or considered providing care to patients whose conditions fell outside the clinical focus of the project.

In other settings, only individuals whose injuries were the direct result of a disaster were eligible for treatment, and clinicians sometimes sought to provide care to individuals with health needs not related to the disaster event. A range of situations also arose when clinicians needed to select which patients would receive particular forms of assistance and to allocate resources between patients, also sometimes weighing the needs of current patients against future patients. In the latter type of cases, clini-

cians typically reflected like so: If we use this resource now it won't be available for a patient who arrives one hour from now, and who may need it more or have a better chance of survival if the assistance is given. Should we preserve the resource?

Clinicians related these stories as ethical challenges—and in describing their choices, they explicitly or implicitly invoked a range of factors, including likelihood to survive, maximization of benefits across communities, degree of need or vulnerability, personal relationship with the patient or family, their own identity and commitment as a health professional, their acceptance (or not) of agency mandates to deny or limit treatment in certain circumstances, or prioritization based on patients' age, as rationales for their decisions. This list demonstrates the diversity of features included in decisions that are related to access to resources. Widely accepted distributive criteria including clinical considerations such as likelihood to survive, as well as population health considerations such as optimizing benefits across a community, were prominent. Other features were also raised in discussions around resource allocation, including prioritization of children over adults. In some instances, clinicians also acknowledged that a feeling of compassion for a patient or family influenced a decision to provide a resource outside of agency policy or standard procedures. In other cases, social considerations influenced decision making. For example, a nurse reported arguing with her colleagues that they should provide care to a child because the child was the last survivor amongst her siblings.

Overall, two broad sets of representations were offered around decisions to provide treatment—or not—to a particular patient.[18] On the one hand, those telling the story emphasized medication, beds, equipment, even staff, as limited resources to be stewarded for the good of the many—a justification for why not treating was right. On the other hand, patient care interventions were represented as something owed by health professionals to people who are ill or suffering—an explanation for why not treating a patient was wrong.

In the interviews with health professionals, what is striking are the stories in which both types of representations were presented as pulling in opposite directions, never fully resolved. A narrative might be offered in which resources are withheld from one patient so as to be provided to others, and that this decision was both right and wrong. A nurse described struggling with the consequences of deciding whether to transfer a child who had a severe neurological injury to the regional hospital or to send the child home without treatment, thus preserving her limited budget to be able to care for other patients: "There are a lot of kids with pneumonia that need resources and if you give them the resources they will get better. So I decided not to transfer the kid and he went home. I will always remember that kid. I think I made a right decision. I let him down. I may not have let these other kids down in the sense that those resources were available for others, but I let him down."[19]

In this quotation we hear the nurse saying both that she did wrong (by letting this particular child down, by not transferring him to where he could receive needed treatment) and she did right (by acting so as to ensure that many more children would receive treatment). In contrast, other stories were narrated where resources were provided, even though the participant felt that withholding the resource would have been more ethically defensible: "Even though the ethical choice may have been not to take her and keep the space for somebody else I still feel it was the right thing to do [to admit the patient]."[20] In this particular narrative, the rationale offered for the rightness of the decision to admit the patient was not one of efficient use of resources, but of the importance of offering some form of tangible assistance, even if it was likely to be ineffective, to a family who had suffered greatly.[21] Even in those cases when one option seems clearly preferable, a clinician may still experience distress or regret "over the frustration of other significant concerns."[22] To put it another way, even when a decision may have appeared justified, it did not always feel just.

With more details about individual cases, one might form an opinion about the decision

that was made and the judgments behind it; one could agree or disagree with the evaluation that the clinicians offer about the wrongness or rightness of an action. For the purpose of this article, what we wish to emphasize is that, in evaluating some allocation decisions, clinicians report value conflicts that cannot be tidily resolved and are sources of moral uncertainty. The presence of such tensions underscores the tragic nature of the situation in which the decision is made, indeed the tragic nature of the limited options available. During the interviews, some clinicians related such decisions as impacting on their identity as health professionals when their ideals and core professional and moral commitments were challenged by the choices they faced.

PREPARING AND SUPPORTING HEALTH PROFESSIONALS FOR TRAGIC CHOICES IN HUMANITARIAN WORK

Clinicians engaged in humanitarian work and facing dilemmas of patient selection or needing to prioritize limited resources between individuals will struggle, almost inevitably, and this struggle is exacerbated when there is a lack of guidance or support. De Waal notes that this topic is not "one that humanitarian workers are trained to anticipate and cope with."[23] In practice, teams are faced with and make such decisions about how resources will be allocated. For example, participants in our studies related stories about project teams who developed their own processes for making allocation decisions, including a team who established criteria for allocating their dwindling supply of transfusable blood, and another team who faced recurrent choices of which patients would receive oxygen from their only oxygen machine, which was run by a single generator that could not function continuously. Decisions of this type were often grim, and sometimes the source of conflict within a team.

There is an emerging literature related to ethical issues in humanitarian work and disaster response, including discussions of resource allocation and supports for humanitarian workers.[24] We wish to conclude by drawing links between the reflections offered so far and approaches to address tragic choices in health-related humanitarian work. Some scenarios of resource allocation and prioritization are amenable to organizational policies, and clear guidance may diminish the weight of particular choices. For example, an organization might develop a guideline for how limited blood supplies will be allocated. Triage protocols adapted for disaster and mass casualty events could also provide guidance, such as the framework proposed by McCullough, which considers emergency situations when resource shortages preclude treatment for all who are injured.[25] However, it is also clear that standards and policies can't be generated for all scenarios, and that more general guidance will be difficult to apply in many particular settings. Inevitably, there is much that cannot be captured by formal guidelines due to the diversity of circumstances and important uncertainties involved in humanitarian work. Not only can policies not capture all eventualities; some moral problems may be better addressed by creating opportunities to support the ethical judgment of those involved rather than creating additional policies. Even the best allocation policy cannot expunge all feelings of uncertainty or angst, and so preparing and supporting clinicians for tragic choices is crucial.

Providing tools that will assist clinicians to reason well, and to develop ethically defensible responses in very difficult circumstances, will be a valuable support. Other supports are also necessary. Strong team relationships are important sources of practical and psychological support.[26] One strategy to support clinicians faced with tragic choices and unfamiliar allocation decisions is to create opportunities to share the weight of triage and micro-level allocation decisions, particularly in acute crisis situations. Under this approach, challenging allocation choices would be made by several team members working in partnership, rather than by individuals in isolation.[27] Teams can also establish opportunities and mechanisms for deliberating over challenging cases, such as at regular team meetings, and for debriefing difficult and recurrent issues. It is also important that clini-

cians and teams who are responsible for implementing policies and guidelines have opportunities to convey to policy makers how the policies are working, what impact they are having, and what may need to be changed—bridging the gap between headquarters and field operations (that some clinicians experience as problematically wide) and contributing to refining policy.

Pre-departure training is an important venue in which ethical dimensions of humanitarian work can be addressed. Such training presents an important opportunity to discuss the moral implications of situations of great need, where some who are needy will not receive care, communicating the types of ethical challenges and seemingly inescapable and tragic choices involved. To promote engagement with these topics, the reality of resource allocation and the nature of tragic choices should be explored, guidelines and tools presented, and discussion promoted.

One method that we have employed for creating opportunities for reflection and discussion of ethical challenges in humanitarian work is reading longer excerpts from our research transcripts—narratives selected for the way that they bring to the fore the complexity of ethical issues in humanitarian work—followed by a facilitated discussion.[28] This approach allows for a different type of discussion than a traditional case study—focusing attention not only on problem-solving, but also on the experience of struggle: struggle with the situation, with figuring out what to do, and with the tragic choices. Such an approach can help, but only partly so, to address a key limitation of ethics preparation activities: the gulf between one's ability to imagine the implications of making a tragic choice in the controlled environment of a pre-departure training activity, where case studies may be assessed in a relatively dispassionate manner, and the reality of such choices in practice.

Tragic choices are often inescapable for clinicians who take part in humanitarian work. The need to allocate limited resources between individuals who all have elevated health needs is a prominent form of such choices, and frequently a source of moral uncertainty for those responsible for making them. Providing preparation, clear guidelines and policies, mechanisms for mutual support during field projects, and debriefing opportunities will help support clinicians for these realities and assist them to make well considered and ethically defensible decisions.

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NOTES

1. M. R. Hunt, "Ethics beyond borders: How health professionals experience ethics in humanitarian assistance and development work," *Developing World Bioethics* 8, no. 2 (2008): 59-69, 64.

2. F. Terry, *Condemned to repeat? The paradox of humanitarian action* (Ithaca, N.Y.: Cornell University Press, 2002), 216.

3. L. Schwartz et al., "Ethics in humanitarian aid work: learning from the narratives of humanitarian health workers," *American Journal of Bioethics—Primary Research* 1, no. 3 (2010): 45-54.

4. We focus here on the micro-level of resource allocation decisions made within local teams. For discussion of resource allocation at the organizational level, see S.A. Hurst, N. Mezger, and A. Mauron, "Allocating Resources in Humanitarian Medicine," *Public Health Ethics* 2, no. 1 (March 2009): 89-99; J. Rubenstein, "Humanitarian NGOs' Duties of Justice," *Journal of Social Philosophy* 40, no. 4 (Winter 2009): 524-41; T. Pogge, "Moral Priorities for International Human Rights NGOs," in *Eth-*

ics in Action: the ethical challenges of international human rights nongovernmental organizations, ed. D. Bell and J.-M. Coicaud (Cambridge, U.K.: Cambridge University Press, 2007), 218.

5. A. de Waal, "The humanitarians' tragedy: Escapable and inescapable cruelties," *Disasters* 34, Supp. 2 (April 2010): S130-37.

6. Such as blood transfusion, the administration of oxygen, or admission to a hospital.

7. See T. Schrecker, "Denaturalizing scarcity: A strategy of enquiry for public-health ethics," *Bulletin of the Wo*rld Health Organization 86, no. 8 (August 2008): 600-5.

8. de Waal, "The humanitarian's tragedy," see note 5 above, p. S130.

9. Schwartz et al, "Ethics in humanitarian aid work," see note 3 above.

10. de Waal, "The humanitarian's tragedy," see note 5 above.

11. M.C. Nussbaum, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (New York, N.Y.: Cambridge University Press, 2001).

12. L. Tessman, "Idealizing Morality," *Hypatia* 25, no. 4 (2010): 797-824.

13. M.R. Hunt, "Moral experience of Canadian health care professionals in humanitarian work," *Prehospital and Disaster Medicine* 24, no. 6 (2009): 518-24, 521.

14. R. Hursthouse, *On Virtue Ethics* (New York, N.Y.: Oxford University Press, 1999).

15. Hunt, "Ethics beyond borders," see note 1 above; Schwartz et al, "Ethics in humanitarian aid work," see note 3 above; Hunt, "Moral experience of Canadian health care professionals in humanitarian work," see note 13 above.

These studies were based on semi-structured, in-depth interviews with Canadian health professionals who had worked with international non-governmental organizations in a range of low-resource settings in the global south in situations of disaster, armed conflict, or extreme poverty.

16. The term "patient selection" is drawn from R.C. Fox and E. Goemaere, "They call it 'patient selection' in Khayelitsha: The experience of Medecins Sans Frontieres-South Africa in enrolling patients to receive antiretroviral treatment for HIV/AIDS," *Cambridge Quarterly of Healthcare Ethics* 15, no. 3 (2006): 302-12.

17. Hunt, "Ethics beyond borders," see note 1 above; C. Sinding et al., " 'Playing God because you have to': Canadian health professionals' experiences of rationing care in humanitarian and development work," *Public Health Ethics* 3, no. 2 (2010): 147-56.

18. Ibid.

19. Hunt, "Ethics beyond borders," see note 1 above, p. 64.

20. Ibid.

21. The ethical evaluation of providing treatment, knowing that it will be ineffective, but with the goal of providing some measure of comfort to a suffering family, would need to be conducted in relation to what might be lost by this strategy, such as lack of resources to treat other individuals who stood a better chance to benefit. However, the assessment of such situations will also differ from other rationales to provide ineffective care such as doing so for more instrumental goals including political objectives.

22. Nussbaum, *The Fragility of Goodness*, see note 11 above, p. 27.

23. de Waal, "The humanitarian's tragedy," see note 5 above, p. S132.

24. See for example, J. Sheather and T. Shah, "Ethical dilemmas in medical humanitarian practice: cases for reflection from Médecins Sans Frontières," *Journal of Medical Ethics* 37 (2011): 162-5; N. Ford, R. Zachariah, E. Mills, and R. Upshur, "Defining the limits of humanitarian action: Where, and how, to draw the line?" *Public Health Ethics 3,* no. 1 (2010): 68-71; O. Merin et al., "The Israeli Field Hospital in Haiti—Ethical Dilemmas in Early Disaster Response," *New England Journal of Medicine* 362 (March 2010): e38.

25. L.B. McCullough, "Taking seriously the "What then?" question: An ethical framework for the responsible management of medical disasters," *The Journal of Clinical Ethics* 21, no. 4 (Winter 2010): 321-7.

26. D. Hilhorst and N. Schmiemann, "Humanitarian principles and organisational culture: Everyday practice in Médecins Sans Frontières Holland," *Development in Practice* 12, no. 3-4 (2002): 490-500.

27. O. Merin et al., "The Israeli Field Hospital in Haiti, see note 24 above, p. e38. However, such an approach may be more time consuming and could lead to delays in the provision of care if decisions are contentious.

28. C. Sinding, L. Schwartz, and M. Hunt, "Staging ethics: The possibilities and perils of research-based performance," *Canadian Theatre Review* 146 (2011): 32-37.

Stephen Malnick, Orit Faraj, and Alan Jotkowitz, "Endoscopy During a Missile Attack: A Military Dilemma for Physicians," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 345-7.

Perspectives

Endoscopy During a Missile Attack: A Military Dilemma for Civilians

Stephen Malnick, Orit Faraj, and Alan Jotkowitz

ABSTRACT

In modern warfare, civilian populations may find themselves under immediate personal danger with very little warning. While there are ways to minimize this danger, there is a paucity of literature discussing this modern dilemma, and it is therefore important to try to address these situations in advance both logistically and ethically. Discussion of this case includes several relevant ethical principles.

INTRODUCTION

Medical staff obviously has a responsibility and an obligation to the best interests of their patient. There are also situations when there may be conflicts of loyalty that can impact medical care. One problematic area is the dual loyalty of military physicians under duress. In modern warfare, the battlefield is often civilian urban centers. Citizens of Israel can find themselves in acute war situations within seconds, in which issues of personal safety arise. While performing a routine screening colonoscopy recently, we were suddenly thrust into an acute ethical dilemma.

CASE REPORT

A 54-year-old man was due to have a screening colonoscopy on Monday, 12 March 2012, in the late afternoon in the city of Ashdod in southern Israel. The procedure was to be performed in the Assouta Medical Center. Three days previously, hostilities had erupted between Israel and the Palestinian Authority in Gaza. This involved several hundred missiles being fired at civilian centers in southern Israel. There were several cases of the rockets penetrating the Iron Dome anti-missile system and landing in civilian areas, with both damage to property and injury of civilians. The Iron Dome system identifies a rocket launch from Gaza, calculates the trajectory, sounds an alarm in the targeted areas (approximately two minutes) and, if the rocket is projected to land in a populated area, it will launch a missile to destroy the rocket. It seems to be more than 80 percent effective.

While the first author was parking at the hospital site, there was an alarm followed by a successful shooting down of a missile. About an hour earlier, a similar rocket had landed in a shopping center not far away, causing damage to several shops in the area.

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The screening colonoscopy was performed by standard techniques and the patient received sedation with 5 milligrams of midazolam and 50 micrograms of fentanyl. The patient was monitored with pulse oximetry. As the colonoscopy was inserted to the mid-transverse colon, another alarm was sounded. The hospital had a protected area with concrete reinforcement, but at a distance from the endoscopy suite.

Both the physician and the nurse made an immediate decision to continue with the procedure and not leave a sedated patient with no medical supervision and approximately 60 centimeters of an endoscope inserted via the rectum. We thought that an unobserved period of several minutes would pose a danger to the patient. It may not have been possible to stop the procedure and transfer the patient to a safe area within the 90-second warning period provided by the alarm.

DISCUSSION

We report this episode since it presents an acute modern ethical dilemma. There is no doubt that a direct hit on the hospital is a potentially life-threatening episode to people who are not in a protected area. Several years ago a Grad missile severely injured a gynecologist in an ambulatory clinic in the nearby city of Ashkelon. A number of ethical principles are relevant to this case.

1. The Principle of Non-Abandonment

There is a well-established tradition of not deserting a wounded combatant in the midst of battle. We would argue that a similar obligation applies to a civilian physician treating a patient. The doctor-patient relationship also mandates that a physician not abandon his or her patient similar to the obligation not to flee in the midst of an infectious disease outbreak. The medical staff has an obvious responsibility to the best interest and physical safety of the patient they are treating, and non-abandonment is a cardinal tenant of medical professionalism.

2. Organizations Should Ensure Maximal Protection

If it is rightfully expected by society that healthcare workers will put themselves at risk to care for their patients, then healthcare organizations have to ensure that maximum protection, in terms of protective gear and reinforced environments, is given to staff and patients. For example, in the care of patients with highly communicable diseases, physicians are typically provided with high-tech masks and outerwear. In the current situation, efforts should be made to provide for the patient and staff, by providing care in as safe an environment as possible.

3. Effect of Stress on Performance

Stress or tiredness can affect the performance of medical procedures. There is evidence suggesting that the performance of colonoscopy is worse in the afternoon than in the morning, possibly due to fatigue on the part of the colonoscopist.[1] It is possible that the stress of a potentially life-threatening event, together with the unknown situation of friends and loved ones who live or work in an adjacent area, may negatively impact the performance of the colonoscopy. The physician with consultation must then decide if it is reasonable to cancel elective procedures, notwithstanding the difficulties this may cause.

A complicating issue in this case is the rapidity with which such situations arise—literally within the space of a few minutes. Colonoscopy requires preparation at least one day in advance and thus is difficult to reschedule.

4. Dual Loyalty

Physicians in the military may have a dual loyalty to the patient and to a third party, such as a military commander. In civilian situations, there may also be a dual loyalty to a medical insurance provider, which may impact the decision to perform a procedure. There is also an issue of personal safety and obligation to family, friends, and colleagues. There is a paucity of discussion of this issue in the literature.[2]

As this case demonstrates in modern warfare, civilian populations may find themselves under immediate personal danger with very little warning. There are ways to minimize this danger. Sometimes decisions need to be made unexpectedly and in a timely fashion. There is

a paucity of literature discussing this modern dilemma, and it is therefore important to try to address these situations in advance both logistically and ethically.

MASKING OF THE CASE

Some details in this case were changed to protect the identity of the patient.

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Daniel R. George, "Making "Social" Safer: Are Facebook and Other Online Networks Becoming Less Hazardous for Health Professionals?" *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 348-52.

Making "Social" Safer: Are Facebook and Other Online Networks Becoming Less Hazardous for Health Professionals?

Daniel R. George

ABSTRACT

Major concerns about privacy have limited health professionals' usage of popular social networking sites such as Facebook. However, the landscape of social media is changing in favor of more sophisticated privacy controls that enable users to more carefully manage public and private information. This evolution in technology makes it potentially less hazardous for health professionals to consider accepting colleagues and patients into their online networks, and invites medicine to think constructively about how social media may add value to contemporary healthcare.

After watching a young child in the perinatal intensive care unit (PICU) take her final breath, the 29-year-old resident exited the room where she privately grieved before pulling out her smart phone. Opening her Facebook app as the tears flowed, she typed a short, cathartic status update that was instantly published to her network of hundreds of friends: "An angel has a new pair of wings."

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During the next 24 hours, more than 40 responses were posted beneath the resident's original thread, with friends and family from around the world comforting her for having witnessed the child's death. Eventually, the child's parents—from whom the resident had previously accepted a Facebook friend request—each commented, thanking the doctor for her compassion and posting funeral information for their child. Realizing that the innocent status update had become a vessel for identifiable patient information, the resident promptly deleted the post.

This story sets off a fusillade of ethical questions: Did the resident violate confidentiality, even though this was not her intent? What would her liability have been if other families with children in the PICU had seen the post and surmised that it was about their child? Is it appropriate or practical for medical professionals to invite patients and their family members into one's Facebook friend network in the first place? Do online friendships contribute to, or only endanger, healing relationships? And indeed, if we consult the academic literature, we will find it replete with admonishments of how social media can endanger health profession-

als;[1] enabling all manner of distasteful content to be publicly posted by medical students, residents, and other healthcare providers;[2] violating the sanctity of the patient-physician relationship by facilitating online "friendships;"[3] and generally reducing privacy.[4]

However, the resident's story does not merely indicate a lapse in her judgment or reinforce the need for stricter social media guidelines for health professionals. It also profoundly implicates the privacy control problems that have dogged social networking sites such as Facebook and proven especially hazardous to users from the health professions. Specifically, Facebook—which has now enlisted more than one billion users worldwide—has clumsily organized each person's network by grouping disparate members of one's social circle (family, friends, colleagues, high school classmates, fringe acquaintances, et cetera) into a common pool of "friends." Whereas we would never simultaneously occupy a single room with all of these people, Facebook has simulated this surreal encounter by mashing everyone together into one online space. Thus, whenever a user has published a status update—such as the rueful sentence posted by the resident—this content has been potentially viewable to every member of the user's friend network unless the user has meticulously blocked certain content from specific friends. For this reason, health professionals—whose use of social networks generally mirrors that of the general population—have largely opted to establish separate personal and professional Facebook accounts, if not abstaining from online social networking altogether.[5]

CHANGING TIMES

However, the landscape of social media is changing in favor of greater privacy controls, and, perhaps ironically, it has much to do with the emergence of Google's fading social network, Google+. Launched in summer 2011, the stated mission of Google+ is to make sharing on the web more like sharing in real life. Unlike the indiscriminate mash-up of friends on Facebook, Google+ allows users to segment their network into "circles" (that is, "family," "friends," "work colleagues," et cetera) and share particular information with the relevant subgroup of one's network. For example, a post about a political subject could be shared with "family" and "friends" circles, but rendered invisible to a circle of "work colleagues." Google+ also enables users to customize their profile information for different circles. For instance, one's personal contact details, present location, and relationship information can be rendered visible only to one's "friends" circle, while employment history and education can be visible only to one's "professional colleagues." This empowers the user to control their private and public information in ways that have not hitherto been possible (or comprehensible to the average user) on Facebook.

Although more than 400 million users had registered with Google+ as of fall 2012, less than 100 million are active on a monthly basis, and it is questionable whether the network will survive, much less pose a viable challenge to Facebook. Nevertheless, even if Google+ fails, it has already succeeded in engendering improved privacy controls on Facebook, which quickly responded with an initiative called "friend lists" that mimics the functionality of Google+. Now, Facebook allows users to easily and intuitively group existing friends into smaller, segmented "lists" akin to Google+ circles; when adding new friends, users are automatically prompted to sort the person into a particular list.

Facebook has also created an "audience selector" within all profiles that enables users to manage the privacy of status updates, photos, and information, using lists. Users who post status updates—such as the one composed by the grieving PICU resident—can simply use the selector dropdown menu beneath their update box to choose whether posts go "public" (to anyone on the internet), to "friends" (to anyone in one's network), to "friends except acquaintances" (to only those in one's network identified as "close friends"), or to other "customized" lists of specific friends one can tag in the post. Users may also select the persons they want to hide particular posts from, eliminating

confusion about which friends can see content. Thus, for the PICU resident, the new privacy settings of both Google+ and Facebook would have allowed her to share the post only with "close friends," "family," or "work colleagues" lists, while blocking it from a "patient families" list.

IS "SOCIAL" SAFER?

These shifts in favor of improved social media privacy controls invite the question of whether Facebook and Google+ might soon enable health professionals to feel greater comfort accepting colleagues and patients into their networks—a subject that has been mostly taboo in modern healthcare. After all, if one can safely curate the data that one's online friends have access to, it perhaps reduces (if not totally eliminates) some of the privacy concerns that have been so stifling for the medical professions, despite signs that these technologies can be used to enhance self-directed lifelong learning, professional networking, and communication with patients, and can play a role in improving the efficiency and effectiveness of health systems.[6] These systemic changes may also make it more feasible for medical professionals to enlist patients in their network in ways that can add to the art of medicine and enhance the provision of healthcare. For instance, one can imagine a social-media-savvy family doctor creating a Facebook list specifically for "patients" and using it to disseminate general information such as guidance on keeping blood pressure low, reminders on how to prepare for doctor's visits, postings about the availability of seasonal vaccines, or even links to salient medical research, archives of healthy recipes, or podcasts about innovative exercise programs. Additionally, doctors could even post short mobile phone videos reaffirming the values they bring to their work, showing a more human side of the clinic and its workers, or encouraging patients who are trying to lose weight. Because social networks are built for efficiency and have norms of pithy communication, doctors could post such content daily, weekly, or monthly in relatively little time, thereby reinforcing clinical directives with dozens—if not hundreds—of patients and family members who would be blinded to their doctor's online musings with friends and family. Healing relationships that start in the clinic could continue growing in online spaces in a format that is admittedly less personal than an office visit, more personal than an email, and certainly better than nothing.

Quite understandably, the expected response of most healthcare professionals who practice in the long shadow cast by patient protection laws such as the Health Insurance Portability and Accountability Act (HIPAA) would be that the social media environment is still too high risk. As one of my medical students wrote me (ironically, in response to a post about privacy control settings sent to my "Students" circle on Google+): "It still seems somewhat risky . . . the punishment for the misuse of social media is so severe for medical professionals that the risks outweigh the benefits. We have much to lose and little to gain by connecting our personal and professional lives." And indeed, the dangers posed by social media are myriad: the technology can blur professional boundaries; serve as a conduit for the display of unprofessional behavior; contribute to building an irreversible online image; open the door for fines, litigation, and imprisonment; and serve as a massive time drain.[7]

However, in an era in which authoritarian regimes have fallen thanks in part to social media, and when more than a billion people (the majority of whom are presumably someone's patient) are on Facebook, it can be fairly asked whether these powerful tools of our time can help society's healers build deeper and more enduring connections with their patients and make greater progress on important public health goals such as lowering chronic and infectious disease burden, improving patient outcomes, avoiding emergency room visits, and reducing overall healthcare costs. The changes set in motion by Google+ and accelerated by Facebook may be a harbinger of a social media landscape in which healthcare professionals can more discerningly protect their private content while building more effective healing relationships with modern patients, a growing ma-

jority of whom are using social networks and other online sources to seek health information.[8]

THE SOCIAL MEDIA LEARNING CURVE

Continuing education researchers, practitioners, and policy makers have much to contribute to applying and evaluating the impact of social network-based information exchange on the art and science of medicine. Researchers can publish detailed qualitative accounts of successful social networking strategies by health professionals, delineating the strengths and limitations of existing approaches, and critically exploring the evolving nature of online relationships. So too can strategies be evaluated on the basis of whether they improve the provision of healthcare in both the short- and long-term. For instance, can connectivity through social media assist health professionals in building greater rapport with patients before they enter the exam room as well as in between visits? Can these ongoing online relationships guide patients to more scientifically valid sources of online health information and support networks? Can they potentiate measurable benefits, as evidenced by fewer hospital visits, improvements on vital signs, or increased patient-satisfaction scores? Further, can social media better connect colleagues via online networks and thus increase the transfer of ideas, practices, and career strategies? Those who successfully implement social media in their professional lives can help colleagues replicate best practices, and provide content suggestions, guidance on safety protocols, as well as interpretation of changes in privacy settings and evolutions in technology, all of which will continue to be moving targets.

Those formally involved in faculty and professional development may find specific value in developing institutional strategies to utilize social media in educating health professionals and adding value to career development. For instance, academic medical centers might find it useful to develop training workshops for successful social media strategies in healthcare as an indispensable component of new employee orientation. Moreover, as we have demonstrated at the Penn State Milton S. Hershey Medical Center,[9] those involved in junior faculty development programs might find it advantageous to reach out to nonmedical disciplines (communications, marketing, information technology, humanities, and so on) to provide useful social media knowledge, skills, resources, strategies, and ethical and professional guidance that can be valuable not just to younger health professionals but also to established practitioners. To incentivize such inter-professional (and perhaps even intergenerational) learning, continuing medical education credits can be used to encourage participation. Given the amount of time that young professionals like the PICU resident spend on Facebook each day, program directors might also set up "faculty and professional development" closed groups on Facebook as a complementary platform for disseminating information to junior faculty about setting career goals, promotion and tenure, characteristics of excellent professionals, conflict resolution, grant and manuscript writing, and so on. Further, as has been identified as a growing trend in academic medicine,[10] social media could be encouraged as a means of strengthening mentor-mentee relationships—particularly for mentors who are savvy with social media and might connect with younger professionals more effectively on this platform than email.

Policy-wise, those who develop professional and institutional guidelines should take care to conceptualize rules, not merely with expectations of misuse, but with openness to the changing nature of information exchange between patients and professionals, and awareness of the emerging culture of social learning and exchange in medicine. Administrators might even entertain the notion of how to compensate social networking professionals for their time, or factor in such efforts to the promotion and tenure process—particularly for those who amass large networks of patient (and colleague) followers. Preaching abstinence from all social media is simply no longer an option, and it risks contributing to a generation of doctors further disconnected from patients and colleagues who are increasingly migrating to social media platforms.

The next decade will invariably give rise to greater "social" advancements in medicine, and this will be exciting—if occasionally consternating—to witness. In the short-term, the trend towards improving social networking privacy controls can be reassuring to health professionals such as the PICU resident, who regard tools like Facebook not as an absolute danger, but as an indispensable asset in their personal and professional lives.

MASKING OF THE CASE

Some details of the case presented at the beginning of this article were changed to protect the identities of the persons involved.

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Law

Legal Briefing: POLST: Physician Orders for Life-Sustaining Treatment

Thaddeus Mason Pope and Melinda Hexum

ABSTRACT

This issue's "Legal Briefing" column covers recent legal developments involving POLST (physician orders for life-sustaining treatment.)[1] POLST has been the subject of recent articles in *JCE*.[2] It has been the subject of major policy reports[3] and a recent *New York Times* editorial.[4] And POLST has been the subject of significant legislative, regulatory, and policy attention over the past several months. These developments and a survey of the current landscape are usefully grouped into the following 14 categories:

1. Terminology
2. Purpose, function, and success
3. Status in the states
4. Four legal routes of implementation
5. Which professionals can authorize POLST?
6. Is the patient's signature required?
7. Can surrogates consent to for incapacitated patients?
8. If a POLST conflicts with an advance directive, which prevails?
9. Is offering POLST mandatory?
10. What are the duties of healthcare providers?
11. What is the role of electronic registries?
12. What is the role of the federal government?
13. International adoption
14. Court cases

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1. TERMINOLOGY

While the POLST paradigm is established or developing in almost every U.S. state, it goes by at least 14 different names.[5] For the sake of clarity, this article will use the acronym POLST, as it is the acronym used by most states. Even among these states, POLST stands for three different terms. In most of the states, POLST stands for physician orders for life-sustaining treatment.[6] In Minnesota and Montana, it stands for provider orders for life-sustaining treatment.[7] In Pennsylvania, POLST stands for Pennsylvania orders for life-sustaining treatment.[8]

The remaining states use 11 additional acronyms. Two are similar to POLST. Vermont uses COLST (clinical orders for life-sustaining treatment);[9] Delaware, Maryland, Massachusetts, New York, Ohio, and Rhode Island use MOLST (medical orders for life-sustaining treatment).[10]

Four other acronyms focus on scope of treatment rather than on life-sustaining treatment. Idaho, Indiana, South Carolina, Tennessee, Vir-

ginia, and West Virginia use POST (physician orders for scope of treatment).[11] Louisiana uses LaPOST (Louisiana physician order for scope of treatment).[12] Alaska, Colorado, Kentucky, New Mexico, and North Carolina use MOST (medical orders for scope of treatment).[13] Iowa uses IPOST (Iowa physician orders for scope of treatment).[14] Nevada uses SMOST (summary of physician orders for scope of treatment).[15]

Four final acronyms are far more different.[16] Kansas and Missouri use TPOPP (transportable physician order for patient preference).[17] Utah calls its POLST a death with dignity order.[18] Illinois legislated that POLST "may be referred to" as the department of public health uniform DNR advance directive.[19] The Veterans Health Administration refers to POLST as SAPO (state authorized portable orders).[20]

2. PURPOSE, FUNCTION, AND SUCCESS

Both law and practice support a presumption that each patient will receive aggressive interventions to prolong her/his life as long as possible. Patients can rebut this presumption and decline treatment, even if that choice hastens their death. But many patients lack the capacity to make healthcare decisions at the end of life. For decades, many medical and legal experts have looked to the advance directive as a central mechanism to assure that patients are treated in accordance with their preferences.

Unfortunately, the advance directive has had very limited success.[21] There are several reasons. First, many patients have not completed one. And most of the advance directives that have been completed are unavailable when needed. Moreover, even if available, advance directives must be reduced to medical orders. But advance directives are often vague, leaving providers uncertain as to how the instructions apply to a patient's current clinical circumstances. For example, take the phrase, "if I am close to death": does that mean within weeks, or within hours? Furthermore, even once orders are written, they do not travel outside an institution.

POLST helps address these problems.[22] Meant to supplement, not replace, traditional advance directives for patients expected to die within the next year, POLST has several advantages. First, it is signed by the healthcare provider. There is no need for interpretation and translation, because POLST is an immediately actionable medical order. Second, since POLST is on a single-page, standardized form, it is easy to follow. Third, unlike DNR (do-not-resuscitate) orders, POLST addresses not just CPR (cardiopulmonary resuscitation), but an entire range of life-sustaining interventions, such as IV (intravenous) fluids, antibiotics, a feeding tube, and artificial breathing. Fourth, POLST is transportable. It is a brightly colored, clearly identifiable form that remains in the patient's chart and travels with the patient from hospital, to nursing home, to ambulance, to the patient's home. POLST is recognized and honored across all these different treatment settings.[23]

POLST protects and promotes patient autonomy better than advance directives in at least four ways. First, POLST is usually created with a healthcare provider at or near the time when an acute or serious chronic condition develops. It addresses the patient's current situation, not a possible future scenario. Consequently, it has a greater chance of being more informed and more relevant to the specific medical situation at hand. Second, since the POLST form is highly visible, portable, and travels with the patient's medical records, it is more likely available when a decision must be made. Third, since it is written in precise medical language on a standardized form, it is better understood. Fourth, since POLST is signed by a provider, it has a greater chance of compliance by other providers.

While documentation is the centerpiece, POLST is more than a form, it is a tool providing a framework for end-of-life care conversations between patients, families, and healthcare providers. Providers are encouraged to discuss specific scenarios and treatment options. Patients and families have the chance to ask questions and make their wishes known.[24] In short, it gives patients more control of end-of-life care. A universal medical order honored across care facilities, POLST changes how end-of-life treatment is provided. Healthcare providers know immediately what patients do and do not want,

and they can provide treatment and care consistent with those preferences.[25]

3. STATUS IN THE STATES

Since its inception, POLST has become a national phenomenon. As of September 2012, at least 46 U.S. states or communities had a POLST program of some form.[26] A program can roughly be classified as either "endorsed" or "developing," based on the degree to which it has implemented the core elements of POLST and established itself within the state or community. Because there is considerable variation within these classifications, healthcare and other professionals involved in end-of-life decision making must pay careful attention to the progress and status of the POLST program in their own state and community.

Origin of POLST

In the early 1990s, the Center for Ethics in Health Care at Oregon Health & Science University (OHSU) brought together representatives from stakeholder healthcare organizations to develop a portable form that translated patients' preferences regarding life-sustaining treatment into medical orders. This form was ultimately named POLST.[27] POLST was first released for use in Oregon in 1996. The evidence base that Oregon established regarding the efficacy of POLST facilitated its refinement and clinical acceptance within Oregon and encouraged its spread across the U.S.[28] The POLST form and procedures from Oregon's efforts provided a paradigm for other states.

A handful of other states were quick to adopt Oregon's POLST model. As early as 1997, leaders of local health systems in western Wisconsin adopted POLST as an alternative to the state's statutorily established DNR program.[29] By the early 2000s, support emerged for POLST and POLST pilot programs in New York,[30] Pennsylvania,[31] Washington,[32] and West Virginia.[33]

In 2004, POLST leaders within these five states, as well as Oregon, became the original members of the National POLST Paradigm Initiative Task Force (NPPTF).[34] NPPTF was formed to facilitate the development of POLST programs in other states and to further policy development and research related to POLST.

Endorsed POLST Programs

For the sake of gaining a big-picture understanding of the status of POLST programs across the country, it is helpful to break them down by their relative maturity. In this respect, the classification of programs as "endorsed" or "developing" is a good starting point. For a state or community program to be given "endorsed" status by NPPTF, the program must meet a set of specific requirements.[35] Some of the criteria relate to the core elements of POLST. Most visibly, NPPTF requires a standardized form that allows a patient to request or limit treatment in four categories covered by the form: (1) CPR, (2) intensity and location of other life-sustaining treatment, (3) antibiotics, and (4) artificially administered nutrition. The standardized form must transfer across healthcare settings and it must constitute medical orders.

The "endorsed" program criteria also relate to whether a form is implemented in a manner consistent with the aims of the POLST paradigm (for example, requiring safeguards to ensure that POLSTs are based on patient preferences). To earn "endorsed" status, a program must be sustainable; for example, there must be an entity willing and able to accept leadership of the program. And there must be a plan for ongoing evaluation. As of September 2012, 15 states had programs classified as "endorsed." These include Oregon and the early adopters, New York, Pennsylvania, Washington, West Virginia, and Wisconsin, as well as California, Colorado, Hawaii, Idaho, Louisiana, Montana, North Carolina, Tennessee, and Washington.[36]

A few states, including Oregon, West Virginia, New York, and California stand out as relatively more established. These four states have already achieved broad clinical acceptance of POLST and have ensured its continued expansion and evolution. Use of POLST is particularly well documented in Oregon and West Virginia, whose POLST programs have been the subject of published research reporting that the vast majority of nursing facilities or hospices in the states use POLST.[37] Although California's

POLST program is relatively young, its efforts have achieved broad dissemination of POLST in a short period, despite the challenges posed by the geographic size of the state and the heterogeneity of the state's population.[38]

These four states have also made significant efforts to ensure the continued expansion and refinement of their POLST programs. They provide regular, ongoing training of physicians, and have made available extensive educational resources, including training curricula, instructional guides, and video tutorials.[39] This promotes further penetration of POLST into clinical practice and encourages its use consistent with the goal of honoring patient preferences. Moreover, these four states have ensured the sustainability and refinement of their programs both through the maintenance of effective statewide and local coalitions and through significant financial support.[40]

In contrast, other endorsed programs have not reached the same level of establishment. For example, Tennessee's Board for Licensing Health Facilities adopted rules for POST and a POST form in 2005, but, as of 2010, Tennessee POST still lacked a "true home or program" and was largely unfunded. This poses significant challenges to widespread implementation.[41] Similarly, Hawaii's POLST program was legislatively recognized in 2009, but its adoption by healthcare facilities and professionals has been slow, despite the education efforts of a strong, statewide end-of-life coalition.[42]

Developing POLST Programs

Reflecting the relative newness of POLST, the majority of states[43] or communities[44] (29 altogether) have POLST programs that are classified as "developing." This classification is applied to programs that are not so established as to meet the criteria for "endorsed" programs, but have started to lay the necessary groundwork for implementation of POLST. These criteria include: (1) leadership by an effective local or statewide coalition, (2) involvement of key stakeholders, and (3) development of a standardized form that will comply with the form requirements for an endorsed program.[45]

The POLST programs classified as "developing" represent a spectrum of stages of development. Some have already laid the groundwork for effective implementation of POLST. They have created a standard form, secured the approval of key stakeholders, and addressed legal or practical barriers to implementation.

Massachusetts is a good example of a program that has already addressed most of these elements. It developed a standard form with the input of stakeholders and experts,[46] and it conducted a legislatively authorized demonstration program in Worcester.[47] Then, Massachusetts authorized EMTs (emergency medical technicians) to honor MOLST forms,[48] and initiated a statewide MOLST expansion plan.[49] As of April 2012, Massachusetts MOLST expanded statewide. Healthcare institutions and professionals were on notice they should: (1) honor MOLST forms, (2) implement MOLST policy, and (3) use the training and supplemental materials provided on the Massachusetts MOLST website.[50]

Iowa is another example of a relatively advanced developing program. Iowa first conducted legislatively authorized pilot programs. It followed the pilots, in 2012, with legislative establishment of POLST on a permanent, statewide basis.[51] The Iowa Department of Public Health published a statewide (IPOST) form.[52]

In contrast to Massachusetts and Iowa, other states have programs that are just starting to get off the ground.[53] For example, in 2011, a New Mexico task force developed a POLST form for regional pilot programs, scheduled to start in 2012, but the form is not yet officially recognized by the New Mexico Department of Health or EMS [emergency medical services] Bureau.[54] In Ohio, POLST advocates are in the process of trying to change complicated state DNR laws, which present a legal barrier to implementation of POLST outside healthcare facilities.[55]

4. FOUR LEGAL ROUTES OF IMPLEMENTATION

The most effective strategy for development of a POLST program depends on each state's unique circumstances, including: (1) existing laws relating to end-of-life healthcare decision making, (2) political climate, and (3) attitudes toward POLST within the medical and broader

community. Accordingly, different states and regions have taken four different legal approaches to implementation. First, many states have authorized POLST by statute. Second, other states have authorized POLST by administrative regulations. Third, some states rely on only informal guidelines and clinical consensus. Fourth, POLST advocates have frequently taken an incremental approach.

Statutory Recognition of POLST

Using either statutes or regulations to establish POLST helps ensure the form and program will be uniform throughout a state. Moreover, statutory recognition of POLST has three additional advantages. First, legislation can amend existing state laws that conflict with or limit the utility of POLST. Legal barriers include: (1) detailed out-of-hospital DNR form requirements, (2) medical preconditions for out-of-hospital DNRs, and (3) lack of default surrogates.[56]

Second, legislation is the most authoritative way to immunize healthcare providers from criminal prosecution, civil liability, or disciplinary sanctions for their actions complying with POLST.[57] This can be helpful to achieve the support of, and participation by, healthcare professionals.[58] The experiences of advocates indicates it is "important to health care professionals that POLST statutes assure them that they will be immune from liability for acting in good faith based on the orders contained within a POLST form."[59]

Third, authorizing POLST by statute better clarifies its legal status.[60] While a state's existing healthcare decision laws might be interpreted as broad enough to permit use of POLST, its explicit recognition by the legislature makes it clear that POLST is consistent with state law. This encourages risk-averse healthcare providers to adopt POLST, and such legal clarity can make it more likely that POLST will withstand legal challenges in the courts.[61] Also, a statute permits Veterans Health Administration (VHA) facilities in a state to use POLST, since they can do so only if "authorized by state law."[62]

States with POLST statutes. There are 18 states with statutes authorizing POLST: California, Colorado, Georgia, Hawaii, Idaho, Illinois, Iowa, Louisiana, Maryland, New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, Tennessee, Utah, Vermont, and West Virginia.[63] These POLST statutes vary in the level and type of detail provided. At one end of the spectrum are states like Louisiana whose statutes specify much of the actual text to be used in a POLST form.[64] At the other end of the spectrum are states like Georgia, Illinois, New York, Pennsylvania, and Tennessee, whose statutes are chiefly concerned with authorizing a state health department or other regulatory body to establish a POLST form and procedures.[65] In Pennsylvania, for example, the 2006 statute simply authorizes the establishment of an "advisory commission" to determine the advisability of a "standardized form containing orders . . . that detail . . . life-sustaining wishes." The department of health formed a Patient Life-Sustaining Wishes Committee that developed a form approved by the department in October 2010. Similarly, New Jersey delegated the development of a form to a federally designated patient safety organization.[66]

Many states, however, use legislation to establish some minimum requirements for a POLST form and procedures, leaving room for flexible implementation and evolution of a POLST program.[67] For example, California's statute recognizes POLST as a valid medical order but it does not specify the POLST form. Instead, it requires in general terms that the form provide standardized directions to healthcare providers regarding resuscitative and other life-sustaining measures.[68] California's statute focuses on other key issues like: (1) distinguishing POLST from advance directives,[69] (2) ensuring patient protections,[70] (3) clarifying the role of a legally recognized decision maker,[71] (4) establishing provider immunity,[72] and (5) mandating the applicability of POLST across all healthcare settings.[73]

Other states statutorily provide more detail regarding the POLST form, but with enough generality to allow the form to evolve without amending state law. For example, West Virginia's POST statute requires the state form provide: (1) a physician's orders relating to CPR, level of medical intervention, antibiotics, and hydration and nutrition; (2) a physician's signature; (3) a place to indicate whether a patient

has an advance directive or appointed decision maker; (4) the signature of the patient or patient's representative; and (5) documentation of any review of the form's orders.[74]

Recent POLST legislation. Seven of the 18 states with POLST statutes enacted them within the past two years: Georgia, Iowa, Illinois, Maryland, New Jersey, Rhode Island, and Vermont.[75] Georgia simply added immunity for acting in good faith in accordance with a POLST.[76] Illinois's statute is very brief, directing the Illinois Department of Health to develop a standard form that meets the "minimum requirements to nationally be considered a POLST."[77] Maryland, Iowa, New Jersey, and Rhode Island provide more detailed requirements.[78] While Vermont's 2005 Advance Directive Statute created a DNR/COLST form, use of this form was only recommended. In 2011, to ensure better uniform implementation of POLST, Vermont enacted the Hospice and Palliative Care Act, which requires that healthcare providers use the standard form issued by the Vermont Department of Health.[79]

Recent efforts to pass POLST legislation. The pool of states with POLST legislation will likely continue to grow in the next few years, given the number of states with developing POLST programs and ongoing and increasingly well-organized efforts of POLST advocates. In addition to the six states that enacted POLST legislation in the past two years, several states introduced and considered POLST bills.

In early 2012, POLST legislation was introduced in Indiana, Kentucky, and Wyoming, but none of the three bills made it out of committee.[80] The bills would have authorized the development of a standard POLST form and provided basic guidelines for its use and content. Washington introduced legislation that, if enacted, would have provided immunity for action "in accordance with the directions contained in a [POLST] form."[81] Ohio has repeatedly failed to pass legislation that would replace the state's DNR forms with POLST.[82] Even though POLST advocates have not introduced legislation in Ohio since the 2009-2010 session, the Midwest Care Alliance is reportedly still working to get a POLST bill re-introduced and adopted by the Ohio legislature.[83]

Administrative Regulation of POLST

While statutory establishment of POLST provides clear benefits, the statutory route is not always feasible or necessary. Where POLST would be consistent with existing state law, regulations can, like statutes, assure uniformity of POLST forms or procedures across the state. At the same time, a regulatory approach allows POLST advocates to avoid the lengthy and uncertain legislative process.[84] Regulations are generally easier to enact and change than statutes. Regulations provide greater flexibility and are less likely to attract a heated political debate.[85] States use regulations in two ways. Some states use them instead of statutes. Other states use them to supplement POLST-specific statutes.

Regulations in states without POLST statutes. Regulations have been used to promote POLST in states without explicit statutory recognition. Regulations in these states are promulgated pursuant to general statutes that broadly recognize a health agency's authority to oversee healthcare facilities, emergency medical services, and/or DNR forms. For example, Tennessee has a statute authorizing the Tennessee Board for Licensing Health Facilities to develop "universal do-not-resuscitate orders." A UDNR is defined as "a written order that applies regardless of the treatment setting and that is signed by the patient's physician that states that in the event the patient suffers cardiac or respiratory arrest, cardiopulmonary resuscitation should not be attempted."[86] Interpreting this statute to permit development of a form that addresses life-sustaining treatments other than resuscitation, the Tennessee Board for Licensing issued formal regulations in 2005, establishing a statewide POLST form and procedures for its use in licensed healthcare facilities.[87]

More recently, Delaware issued regulations to replace its pre-hospital advance care directive form with MOLST. The Delaware EMS agency developed a MOLST form and protocol. It provided detailed rules to guide its implementation, including: (1) methods to identify a patient with a MOLST, (2) procedures for revoking a MOLST, and (3) requirements for periodic review of the form.[88] But due to concern over whether the regulations were consistent

with the governing statutes, in November 2012, the Delaware Department of Health and Social Services instructed all healthcare providers to "refrain from further use" of MOLST.[89]

Like Delaware, Oregon also has no statute explicitly addressing POLST. And like Delaware and Tennessee, Oregon used a regulatory agency to promote POLST. While Delaware used its EMS agency, Oregon used its board of medical examiners.[90] Specifically, Oregon BME used its authority to oversee the scope of practice of EMTs to amend the agency's rules, allowing first responders to follow the orders on a POLST.[91]

Regulations in states with POLST statutes. While states like Tennessee, Delaware, and Oregon use regulations in the absence of a POLST statute, other states use regulations to supplement an existing statute. In these states, agency regulations play a critical role in fleshing out the details of a POLST form and program.[92] In many states, including California, Illinois, Iowa, Maryland New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, Utah, and Vermont, the POLST form must be approved by a health department or other regulatory body.[93] POLST forms are currently awaiting development or final approval by health departments or related entities in states that recently adopted POLST legislation, including Illinois, Maryland, and New Jersey.[94] In contrast, Iowa, which enacted POLST legislation in 2012, has already published its IPOST form.[95]

POLST Programs Developed Primarily Through Clinical Consensus

While most POLST programs are defined by statutes and/or regulations, nongovernmental organizations (NGOs) play a major role in implementation.[96] In most states, guidelines and supplemental educational materials have been developed and made available by health professional organizations or end-of-life coalitions. Particularly notable are West Virginia's Center for End-of-Life Care, New York's Community-Wide End-of-Life/Palliative Care Initiative, California's Coalition for Compassionate Care, Hawaii's Kokua Mau coalition, and the Washington State Medical Association.[97]

In some states, NGOs have sought to implement POLST primarily or solely through reliance on clinical consensus. Advocates in these states aim to establish POLST as the standard of care.[98] While developing a POLST program with the support of neither legislation nor regulation can result in inconsistency, it provides flexibility for a program to adapt to clinical needs without constraint by regulatory or legislative processes.[99]

This approach was effective in Oregon and is being used in Kentucky, Michigan, Nebraska, and Nevada.[100] Perhaps the most notable use of the clinical consensus approach is in Kansas, Maine, Minnesota, Missouri, and North Dakota.[101] While Oregon did selectively seek changes in regulations to allow POLST to be effective (for example, to permit EMTs to honor POLST orders), the Oregon Health & Science University Center for Ethics largely relied on a "grassroots approach" to integrate POLST into the standard of medical care. This entailed: (1) using a train-the-trainer model to initially educate health professionals about use of the form, (2) facilitating research to demonstrate the efficacy of POLST, and (3) providing for ongoing POLST education and program refinement.[102] POLST is now the standard of medical care in Oregon, and is used by nearly all the state's hospice and nursing facilities.

Minnesota and Maine have also met with a degree of success implementing POLST solely through clinical consensus. Minnesota's standardized POLST form, developed by an interdisciplinary task force endorsed by the state's EMS regulatory board, has already been adopted by key health systems in the Twin Cities area and greater Minnesota.[103] Maine has also been successful, achieving geographically widespread, although sporadic, use of POLST by way of outreach and education, as well as the involvement of healthcare systems.[104]

Incremental Approach to Implement POLST

A number of states found it necessary or useful to take an incremental approach to implementing POLST.[105] California, Iowa, Massachusetts, New York, North Carolina, and West Virginia are notable examples of states that used such an approach successfully. Such strategies frequently begin with pilot programs. They then use the evidence base from such programs to

take POLST statewide, through legislation, regulation, or expanded clinical acceptance.[106]

For example, use of POLST in New York outside healthcare facilities ultimately required legislation because of conflicts with state DNR laws.[107] New York passed legislation in 2008, permitting use of MOLST in all settings on a permanent, statewide basis. Such legislation was facilitated by earlier step-wise progression: (1) voluntary use by hospital and nursing facilities in the Rochester region in 2003, (2) state department of health approval for use of MOLST within healthcare facilities in 2005, (3) legislatively established pilot programs to test nonhospital use of the form.[108]

Similarly, Iowa enacted legislation in 2012, authorizing use of the Iowa POST form throughout the state.[109] This was facilitated by earlier legislatively authorized pilot programs in Cedar Rapids and Jones County.[110] These local projects reported to an advisory council that made recommendations to the state legislature.

5. WHICH PROFESSIONALS CAN AUTHORIZE POLST?

Legal concerns surrounding POLST do not end once a POLST program is established. It takes years for a POLST program to become fully implemented.[111] Even established POLST programs continually evolve and can raise issues concerning how POLST fits within a state's existing framework of healthcare laws. This and the following sections (5 to 12) highlight the eight most troublesome legal questions raised by POLST.[112]

As a form containing medical orders, POLST universally requires a healthcare professional's signature to be valid.[113] The question remains, however, whether to expand the authority to sign a POLST form beyond physicians. POLST programs have taken two different approaches. At least nine states have limited authority to physicians: California, Georgia, Hawaii, Illinois, Kansas, Missouri, Nevada, New York, Tennessee, and West Virginia,[114] but the larger trend is to extend authority to other health professionals. At least 14 states extend authority to sign a POLST to nurse practitioners (NPs), advanced practice nurses, and physician assistants (PAs): Colorado, Iowa, Idaho, Maryland, Massachusetts, Minnesota, Montana, New Jersey, North Carolina, Oregon, Rhode Island, Utah, Vermont, and Washington.[115]

There are three main rationales for the trend toward expansion of signing authority. First, in rural, geographically isolated areas, physicians can be a rarity, making the question of which healthcare professionals can authorize a POLST an issue of accessibility. This issue was a significant concern in Alaska, where many rural and village communities have no physicians available.[116] Utah's original POLST statute authorized only physicians. But amendments in 2007 and 2008 expanded authorized signers to include NPs and PAs. Rural access likely motivated 2012 amendments to Idaho's POST law to permit NPs and PAs to sign.[117]

Second, just as physicians are often unavailable in rural areas, they are often a rarity in long-term care facilities.[118] A recent survey reports, "more than one third of [more than 16,000 U.S.] nursing homes reported difficulty in obtaining physician participation in POLST completion and having physicians sign the POLST."[119]

Third, extension of authority to sign acknowledges the reality that nonphysicians (nurses, social workers, advanced care planning facilitators) are more likely than physicians to actually engage patients in a discussion about end-of-life care.[120] This issue is recognized not only by expanded signing authority in many states, but also by the presence of an additional box on several state POLST forms to identify the professional who helped prepare the form. POLST forms in California, Hawaii, Iowa, Minnesota, North Carolina, and Utah have a place to indicate the identity of the preparer, while still requiring the signature of an authorized healthcare professional to be valid.[121]

6. IS THE PATIENT'S SIGNATURE REQUIRED?

The core objective of POLST is to ensure that a patient's preferences for end-of-life care are respected. To that end, many of NPPTF criteria for an "endorsed" POLST program relate to patient protections. Notable among these is the documentation of the patient's consent by

signature.[122] Similarly, some Roman Catholic bishops and theologians are concerned that the lack of a patient's signature raises grave concerns as to whether a POLST accurately reflects and protects the patient's wishes.[123]

In fact, the majority of states require the signature of the patient or, if the patient lacks capacity, the patient's legal representative. Montana, for example, provides that "a form lacking the patient or legal decision maker signature . . . is invalid,"[124] but this is not universal. At least four states, Minnesota, New York, Oregon, and Wisconsin, strongly recommend that a POLST be signed by the patient, but fall short of requiring it.[125] New York permits verbal consent with two witnesses. Vermont requires a patient signature except when CPR would be "futile."[126]

Most state POLST programs lack a related safeguard often required of advance directives. In California, for example, advance directives completed by long-term care residents are not effective "unless a patient advocate or ombudsman . . . signs the advance directive as a witness."[127] California and other states require an extra signature "to recognize that some patients in skilled nursing facilities are insulated from a voluntary decision making role, by virtue of the custodial nature of their care, so as to require special assurance that they are capable of willfully and voluntarily executing an advance directive." No such safeguard is required for POLST. On the other hand, increasing safeguards entails costs and can increase the risk of error. For example, lack of qualified witnesses could mean that far fewer POLSTs are completed.

7. CAN SURROGATES CONSENT FOR INCAPACITATED PATIENTS?

Closely connected to the requirement of a patient's signature is the question of whether a surrogate can consent to a POLST for a patient who lacks decision-making capacity. Surrogates complete about 30 to 40 percent of POLSTs.[128] Recognizing the importance of this issue, NPPTF recommends that POLST programs permit surrogates to complete POLSTs for incapacitated patients. But NPPTF acknowledges this is complicated by state laws governing surrogates and healthcare decision making.[129]

A number of states impose certain limitations on the scope of surrogate authority.[130] For example, some states require the satisfaction of certain medical preconditions like the diagnosis of a "terminal condition."[131] Others, like California and Minnesota, authorize a "legally recognized healthcare decision maker" to consent to a POLST on behalf of a patient who lacks capacity, but fail to fully define who qualifies as a legally recognized decision maker[132] or to specify who can serve as a surrogate if the patient has not appointed one ahead of time.[133]

States vary in the limits that they place on the authority of a surrogate regarding POLST.[134] The language of many POLST statutes or regulations in many states would automatically permit a surrogate to revoke or modify a patient-created POLST. There is substantial logic to this approach. POLSTs are supposed to be reviewed periodically and updated: (1) if there is a substantial change in a patient's health status, (2) if a patient's treatment preferences change, or (3) if a patient is transferred from one treatment setting or care level to another. Indeed, 24 percent of POLSTs are rewritten to reflect a patient's changed circumstances, primarily for more comfort-focused care.[135] Often, a POLST must be updated after a patient loses capacity.

But some states, like New Jersey and Tennessee, prohibit a surrogate from altering or revoking a patient-created POLST form unless expressly authorized to do so by the patient.[136] The New Jersey MOLST form provides a place for a patient to indicate this authorization.[137] Other states impose far narrower limitations. Rhode Island requires that a "recognized health care decision maker" of a patient who lacks capacity consult with the "MOLST qualified health care provider" prior to requesting modification of the patient's MOLST.[138] Other states, like Delaware, have limited the authority of surrogates to revoke a POLST in emergency situations, recognizing the difficulty involved in identifying authorized decision makers under such circumstances.[139] Still other states, like Utah and New York, impose special process re-

quirements for legal surrogates to consent to POLST forms on behalf of the mentally ill, the developmentally disabled, or minors.[140]

Thus, while POLST programs almost universally permit legal surrogates to complete, modify, or revoke a POLST on behalf of a patient lacking decision-making capacity,[141] states face different challenges regarding the question of surrogate authority and handle it in different ways. This makes it important for healthcare professionals to be aware of the specific laws or rules in their state.

8. IF A POLST CONFLICTS WITH AN ADVANCE DIRECTIVE, WHICH PREVAILS?

Another important question is, which form prevails, should the orders in a POLST conflict with a patient's advance directive? States that addressed this issue in POLST statutes, regulations, or guidelines have generally taken one of three approaches, directing: (1) a POLST form prevails over an advance directive;[142] (2) an advance directive prevails over POLST;[143] or (3) the most recently completed document prevails.[144] Other states have not explicitly addressed the question of what happens when a POLST and an advance directive conflict.[145]

Failure to address the issue of conflicting forms creates uncertainty for healthcare professionals and patients. Efforts to address the problem of conflicting forms have created additional concerns. One concern raised by California's POLST law is that the "latest in time" rule to resolve a conflict between a POLST and a previously created healthcare instruction, in combination with the ability of a legally authorized representative to complete a POLST on behalf of an incapacitated patient, creates a situation in which a third party can override a patient's previously expressed treatment preferences.[146]

States with more recently adopted POLST statutes, including Colorado[147] and New Jersey,[148] seem to have avoided this problem by specifically stating that the most recent *patient*-completed document will control in the event of a conflict. So a surrogate-completed POLST could not contradict a patient's advance directive.[149] Unfortunately, this seems overbroad in that it would also preclude a surrogate-completed POLST from contradicting not only the patient's advance directive, but also an earlier patient-completed POLST. The VHA is more flexible: the most recent document controls "unless there is sufficient reason to conclude that the more recent information does not actually reflect the patient's current preferences."[150]

9. IS OFFERING POLST MANDATORY?

A number of states require hospitals or long-term care facilities to offer POLST to certain groups of patients. This requirement parallels the duty under the Patient Self-Determination Act (PSDA) to "provide written information . . . concerning . . . right to formulate advance directives."[151] For example, Maryland requires that completion of its MOLST form be offered to patients in assisted living and nursing facilities, hospices, home health agencies, and dialysis centers, as well as to hospital inpatients being transferred to long-term care.[152] Utah requires a similar range of facilities to determine, on admission, whether each individual has a POLST. These facilities must determine which individuals without a POLST should be offered the opportunity to complete one.[153]

Such requirements encourage widespread clinical implementation of POLST, but surveys of states and facilities implementing POLST raise concerns that healthcare facilities, especially nursing homes, misinterpret "mandatory offer" to mean all residents must have a POLST form.[154] To be sure, completion of POLST is not the same as dictating a particular treatment plan. POLST accommodates varying treatment preferences. Even if completion were required, patients and residents could complete POLST any way that they wanted. Nearly one-quarter of patients completing POLSTs chose "full treatment." Many choosing DNAR (do not attempt resuscitation) on their POLST want other kinds of treatment like hospitalization, antibiotics, and artificial nutrition and hydration.[155]

Still, requiring completion arguably undermines the premise that a POLST is based on the voluntary, informed consent of a patient.[156] Accordingly, no state requires that a patient complete a POLST form.[157] Nevertheless, these concerns about confusing "offer" and "com-

plete" have led multiple states, particularly those like Iowa and Colorado that have recently adopted POLST legislation,[158] to mandate that completion of a POLST cannot be a condition of receiving healthcare services or insurance.[159] North Carolina requires that its official MOST form contain, in bold, directly over the signature line, the statement, "You are not required to sign this form to receive treatment."[160] Rhode Island provides, "The MOLST is a voluntary option for qualified patients. No patient is required to elect a MOLST."[161] These clarifications are similar to those regarding advance directives in the federal PSDA[162] and in the healthcare decisions acts (HCDAs) of many states.[163] Indeed, PSDA and HCDA prohibitions are directly applicable in states where POLST qualifies as an advanced directive.

10. WHAT ARE THE DUTIES OF HEALTHCARE PROVIDERS?

While it is not mandatory for a patient to complete a POLST, many states have imposed duties on healthcare providers with regard to POLST. First, as noted above, some states have mandated that certain healthcare facilities offer POLST to patients. Second, many, if not most, states have explicitly imposed a duty on healthcare providers to comply with orders communicated by a POLST.[164]

This duty to comply raises questions regarding: (1) the obligations of a healthcare professional who objects to the withholding of life-sustaining treatment on policy, moral, or religious grounds; (2) the obligations of healthcare providers to respect POLSTs signed by physicians without admitting privileges to a particular facility; and (3) the obligations of providers to respect POLSTs created in other states.

States have addressed the first by requiring that healthcare professionals who are unwilling to comply with a POLST take all reasonable steps to transfer a patient to another physician or facility.[165] States have addressed the second issue by making it clear that a POLST must be honored, regardless of the admitting privileges of the signing physician.[166] Facilities worried about compliance with Joint Commission medical staff standards can review the POLST and write new orders on admission.[167] States have addressed the third issue with reciprocity provisions, expressly recognizing that there is a duty to comply with POLSTs completed in other states, provided that the forms comply with the laws of the treating state.[168]

It should be noted that even in the absence of a statute or regulations explicitly imposing a duty on healthcare providers to comply with a POLST, they may still have such a legal duty if the POLST paradigm has become the standard of medical care in that state or community. Notably, North Carolina does not expressly state that a healthcare provider has a duty to comply with POLST, but its immunity statutes will not apply to healthcare professionals who refuse to comply with POLST, despite knowing of the form's existence.[169]

11. WHAT IS THE ROLE OF ELECTRONIC REGISTRIES?

While the development and use of electronic POLST registries is primarily a question of organization and funding, rather than a legal question, the movement toward registries is a growing trend that merits attention. Because paper POLST forms can be difficult to locate in emergency situations, around 25 percent of POLST forms are not immediately available.[170] Electronic repositories of POLST forms have the potential to increase the efficacy of POLST by facilitating the communication of POLST orders across healthcare settings. Registries can be particularly useful in allowing first responders to quickly determine a patient's treatment preferences during medical emergencies, situations in which time is critical. Quick access to a POLST can make a difference in whether a patient's preferences are respected. In one study, POLST orders changed the treatment plan for 45 percent of patients.[171]

For example, Oregon developed a statewide electronic registry that operates in conjunction with the state's 24-hour trauma communication center, allowing EMTs and emergency departments to, with a phone call, determine whether a patient has a POLST and what orders are contained within the form.[172] Oregon's registry is large and well established. Since its creation in

2009,[173] the registry has received 135,000 POLST forms and the call center has received nearly 2,000 POLST-related emergency calls.[174]

At least five other states, including Idaho, Montana, New York, Utah, and West Virginia, have electronic POLST registries in varying stages of development.[175] While these registries share the same goal of increasing the accessibility of POLST forms, they differ in a number of respects. First, only some have been implemented statewide (Oregon, Idaho, West Virginia). Second, only a few permit electronic completion of POLST forms (New York, Utah). Third, only some state registries also contain non-POLST advanced directives and other healthcare documents (Idaho, West Virginia).[176]

Oregon is the only state that mandates the submission of completed POLST forms to the registry, unless the patient opts out.[177] This mandate not only permits Oregon's registry to comply with HIPAA (Health Insurance Portability and Accountability Act) guidelines, but also ensures that enough POLSTs are submitted for the registry to be useful, both in terms of emergency accessibility and in terms of data for POLST research and quality assurance.[178]

The trend toward registries is likely to continue to expand. As of September 2012, California was in plans to develop and test a POLST registry.[179] Other states, such as Montana and Vermont, do not specifically have a POLST registry, but already have an advanced directive or DNR registry that could potentially be extended to POLST.[180] And more registries are coming online. Michigan, for example, authorized a "peace of mind registry" in 2012.[181]

12. WHAT IS THE ROLE OF THE FEDERAL GOVERNMENT?

As the previous discussion has illustrated, POLST is largely a matter of state law and policy. However, the federal government also has a role to play in POLST. Three examples illustrate the potential for the federal government to encourage POLST implementation: (1) HITECH (Health Information Technology for Economic and Clinical Health Act) and electronic health records, (2) Medicare and voluntary advance care planning, and (3) VHA policy.

HITECH and Electronic Health Records

The HITECH Act of 2009 seeks to facilitate more widespread adoption of electronic health records (EHR),[182] a tool that has the potential to make POLST more effective. Under HITECH, hospitals and physicians can qualify for Medicare and Medicaid incentive payments when they adopt certified EHR technology and utilize that technology to achieve "meaningful" healthcare objectives.[183] While HITECH and its regulations do not explicitly refer to POLST, they incentivize greater use and development of technology that can help address the patient care goals of POLST, increasing its accessibility and facilitating monitoring and evaluation of the POLST process.[184]

Medicare and Voluntary Advance Care Planning

Early forms of the bill that would become the Affordable Care Act contained a provision that would have reimbursed physicians under Medicare for periodically consulting with patients about advance care planning and discussing POLST, where available and applicable.[185] But political backlash (involving talk of "death panels") ultimately forced the removal of this provision.[186]

Still, the March 2010 enacted version of the ACA did authorize "annual wellness visits" under Medicare.[187] So, through regulations, the U.S. Department of Health and Human Services authorized Medicare coverage of POLST conversations as an element of this "annual wellness visit."[188] But this also proved controversial.[189] So the regulation was rescinded just six weeks later.[190] More recently, U.S. Representative Earl Blumenauer (D-Oregon), the proponent of the (ultimately eliminated) POLST language in the original ACA, introduced new legislation, the Personalize Your Care Act of 2011.[191] This bill would provide Medicare and Medicaid coverage for POLST conversations and grants to develop POLST programs.

Veterans Health Administration

While the VHA has its own advance directive, VHA facilities must honor advance directives and POLSTs that are valid under state law.[192] When presented with a SAPO (state-au-

thorized portable order), VA clinicians have two basic obligations. First, they must act in accordance, write corresponding orders, and scan the SAPO into the electronic health record. Second, they must encourage and educate the veteran regarding completion of a SAPO on discharge.[193]

13. INTERNATIONAL ADOPTION

While primarily a U.S. program, POLST has been spreading to other countries. For example, NPPTF and Respecting Choices have been consulting with policy makers in Brazil and Singapore.[194] POLST has been implemented somewhat in Germany.[195] And POLST has been particularly popular in Canada and Australia.

Canada

A 2008 Health Canada report notes that "some Canadian jurisdictions are exploring or using the POLST model."[196] Indeed, POLST is being used by Canadian healthcare systems in at least four of its 10 provinces. For example, Fraser Health in British Columbia is using a MOST.[197] Hamilton Health Services in Ontario is using POST.[198] Alberta Health Services is using a "goals of care designation order."[199] And, in March 2012, the Regina Qu'Appelle Health Region in Saskatchewan implemented MVLST ("my voice for life sustaining treatment").[200]

Australia

While developed independently from NPPTF, the Australian state of Queensland has implemented a program quite similar to POLST. The acute resuscitation plan (ARP), a pink form of medical orders, was piloted in 2009, and was rolled out across the state in 2010.[201] But while consent should be obtained, there is no patient signature requirement, and the ARP instructions expressly recognize a process by which patient choices can differ from those in the ARP. While allied health professionals can be involved with completing an ARP form, it must be signed by the "most senior medical officer available."

14. COURT CASES

While POLST is relatively new to most U.S. jurisdictions, there has already been some litigation and regulatory enforcement. There have been four types of cases. First, families have sought damages for healthcare providers' failure to comply with a POLST. Second, families have sought judicial permission to override a POLST. Third, there have been several cases involving forged POLSTs. Fourth, there have been cases involving uninformed POLSTs.

Failure to honor POLST

Most POLST statutes require healthcare providers to honor POLST, unless they have a good faith belief that the POLST is invalid. In late 2011, Compassion & Choices filed the first lawsuit seeking to enforce this legal duty, *DeArmond v. Permanente Medical Group*.[202] In this case, a young woman named Emily DeArmond had been ill her entire life due to brain cancer. In August 2010, her mother completed a POLST for her, ordering "do not intubate." In November 2010, Miss DeArmond was found in bed, unresponsive, by her mother. An ambulance transported Miss DeArmond to Kaiser Medical Center, where an emergency room physician intubated her despite the known POLST.

The DeArmond family filed a lawsuit for damages in the Superior Court of Orange County, California. The complaint alleges causes of action for: (1) neglect of a dependent adult, (2) intentional infliction of emotional distress, (3) negligent infliction of emotional distress, (4) deceptive and unfair trade practices, (5) violation of the Health Care Decisions Act, and (6) violation of the California Consumer Legal Remedies Act. In May 2012, the court granted Kaiser's petition to compel arbitration of the dispute. While the DeArmond family may still prevail on the merits, it will be without the publicity or transparency that normally attends litigation.

Excuse from POLST Compliance

In *Zornow,* a New York court excused compliance with a patient's MOLST.[203] Joan M. Zornow, 93, had advanced Alzheimer's and was living in a nursing home. Her daughter, Carole Zornow, applied to be appointed her guardian. Carole Zornow and her siblings disagreed about their mother's wishes and a previously enacted MOLST. Relying heavily on Joan Zornow's Roman Catholic faith, the court found clear and

convincing evidence that she would have wanted most life-sustaining interventions. Consequently, in a poorly reasoned and widely criticized opinion, the court revoked all of the orders in her MOLST, except the DNAR order. The court ruled that no "blanket directives" should be used for Mrs. Zornow, because it could never be confidently determined that any treatment decision therein would be consistent with Roman Catholic moral theology.

Forged POLST

In the past two years, there have been several high-profile cases involving forged advance directives. In 2011, a Minnesota court found that Lana Barnes had criminally altered the advance directive of her husband, Albert Barnes.[204] She had been demanding treatment that healthcare providers at numerous facilities had determined was inappropriate and non-beneficial. In fact, Mr. Barnes had specifically rejected such treatment in his 1993 advance directive. But his wife had cut, pasted, and recopied the document to omit those instructions. Moreover, Mr. Barnes's entire 1993 advance directive had been revoked by a 1994 advance directive in which he appointed his son, instead of his wife, as his healthcare agent.

While Lana Barnes altered an advance directive to indicate a patient's preference to continue treatment, Susan Elizabeth Van Note altered an advance directive to indicate a patient's preference to stop treatment. In September 2012, a Kansas City grand jury indictment was unsealed, alleging that Van Note, a Kansas estate planning attorney, forged her father's name to an advance directive. In 2010, William Van Note was shot and stabbed in his home. Ms Van Note soon showed up at the hospital with an advance directive stating that her father did not want prolonged treatment to keep him alive. Accordingly, doctors and nurses stopped their lifesaving efforts, and the patient died. Ms Van Note is alleged to have committed the shooting and stabbing.

More recently, several cases have involved allegations of a forged POLST. *Krela v. Kryla* is eerily similar to the Van Note case. A son alleges that his stepmother poisoned his father and that she forged a POLST to facilitate this plan.[205] The case is still in the preliminary motions phase. In *Scottrade v. Davenport,* the former girlfriend of the decedent disputed an online brokerage's distribution plan.[206] She claimed that the other beneficiaries murdered the decedent and forged a POLST to facilitate this plan and the destruction of evidence. But the court found these claims to be frivolous. Finally, in *Costello v. University of Washington Medical Center,* the plaintiff claimed that the patient's POLST had been "fraudulently presented."[207] That case was dismissed because it was filed after the statute of limitations.

Uninformed POLST

While POLST has proven a tremendous tool for protecting and promoting patient autonomy, there remains significant concern with potential abuse. Patient advocates are concerned that POLST may be implemented in a coercive and manipulative manner, such that the resulting POLST does not reflect the patient's preferences and values. Indeed, there is some evidence to ground such concerns. In 2010, the California Department of Public Health sanctioned Cresthaven Nursing Home in Santa Cruz regarding its use of POLST. Based on interviews, observation, and clinical record review, the CDHP found the facility in violation. It had failed to ensure that the attending physician obtained residents' informed consent prior to completing POLSTs.[208]

CONCLUSION

POLST helps patients. It documents a patient's wishes for life-sustaining treatment in the form of a medical order. It streamlines the transfer of patient records between facilities. It clarifies treatment intentions and minimizes confusion about patient preferences. It assists physicians, nurses, emergency personnel, and healthcare facilities in promoting patient autonomy. It optimizes comfort care of patients.

Because the POLST paradigm is well organized and well publicized, it is driving other related reforms. Most notable is greater attention to advance care planning. Not only are more POLSTs being completed, but more advance directives and advance care planning discus-

sions are being completed. Furthermore, at a legal level, POLST has prompted re-examination of long-latent gaps in healthcare decisions laws, such as the lack of default surrogate rules. When physicians, lawyers, and others get together to discuss POLST, these related concerns receive attention and salience.

NOTES

1. This article focuses on legal issues intrinsic to POLST. Other commentators have already examined extrinsic legal obstacles to adopting POLST. S.E. Hickman, C.P. Sabatino, A.H. Moss, J.W. Nester, "The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation," *Journal of Law, Medicine, and Ethics* 36, no. 1 (2008): 119-40. Nor does this article discuss related issues pertaining to advance directives, surrogate decision making, or out-of-hospital DNAR orders.

2. R. Miller, "Physician Orders to Supplement Advance Directives: Rescuing Patient Autonomy," *The Journal of Clinical Ethics* 20, no. 3 (Fall 2009): 212-9; T. Pope, "Legal Briefing: Advance Care Planning," *The Journal of Clinical Ethics* 20, no. 4 (Winter 2009): 289-96.

3. C.P. Sabatino, *Improving Advanced Illness Care: The Evolution of State POLST Programs* (Washington, D.C.: AARP, 2011).

4. "Care at the End of Life," editorial, *New York Times,* 25 November 2012, at SR10.

5. POLST goes by even more names other countries. See section 13 above.

6. Alabama, California, Florida, Georgia, Hawaii, Illinois, Indiana, Maine, Michigan, Nebraska, New Hampshire, New Jersey, North Dakota, Oklahoma, Oregon, South Dakota, Texas, Washington, Wisconsin, and Wyoming.

7. Minnesota Medical Association, "POLST Communications," *http://www.mnmed.org/Key Issues/POLSTCommunications/tabid/3291/Default.aspx,* accessed 10 December 2012; Montana Board of Medical Examiners, "POLST," *http://bsd.dli.mt.gov/license/bsd_boards/med_board/polst.asp,* accessed 10 December 2012.

8. Aging Institute of UPMC Senior Services, "Professionals in Aging: Pennsylvania Orders for Life-Sustaining Treatment (POLST)," *http://www.aging.pitt.edu/professionals/resources-polst.htm,* accessed 10 December 2012.

9. 18 Vt. Stat. Ann. § 9708.

10. "Program Description for: Connecticut," *http://www.ohsu.edu/polst/programs/connecticut.htm,* accessed 10 December 2012; 16 Del. Admin. Code 4304-1.0-14.0; Md. Code. Ann., Health-Gen. § 5-608.1; 2008 Mass. Acts, ch. 305, sec. 43; N.Y. Department of Health, Bureau of Emergency Medical Services, "Policy Statement 11-02 (1 March 2011); "Program Description for: Ohio," *http://www.ohsu.edu/polst/programs/documents/OHProgramDescription.pdf* (27 October 2008); R.I. Code § 23-4.11-2(10).

11. Idaho Code § 39-4512A; Ind. H.B. 1114 (2012); M.A. O'Rourke et al., "Physician Order for Scope of Treatment (POST) in South Carolina (SC)," *Journal of Clinical Oncology* 30 (2012): Suppl. 34, abstract 21; Tenn. Comp. R. and Regs. 1200-08-01-.13; "Program Description for: Virginia," *http://www.ohsu.edu/polst/programs/documents/developing stateform—Virginia—5-29-12.pdf,* accessed 10 December 2012; W. Va. Code § 16-30-25.

12. La. Rev. Stat. Ann. § 40:1299.64.2(5).

13. "Program Description for: Alaska," *http://www.ohsu.edu/polst/programs/documents/AKProgramDescription.pdf* (5 December 2008); Colo. Rev. Stat. Ann. § 15-18.7-104; Ky. S.B. 217, 2012 Leg., Reg. Sess. (2012); Program Description for: New Mexico," *http://www.ohsu.edu/polst/programs/documents/NMdevelopingstateform.pdf* (23 January 2012); N.C. Gen. Stat. Ann. § 90-21.17.

14. Iowa Code § 144D.1-.4.

15. Nevada Center for Ethics and Health Policy, "An Introduction to the Nevada SMOST," *http://www.unr.edu/ncehp/spost_summary.html,* accessed 10 December 2012.

16. Still other similar acronyms have some currency. K.B. Newport et al., "The 'PSOST': Providers' Signout for Scope of Treatment," *Journal of Palliative Medicine* 13, no. 9 (2010): 1055-8. But PSOST has a narrower mission than POLST. It is an internal tool for smooth transitions on nights and weekends.

17. "Transportable Physician Orders for Patient Preferences (TPOPP)," *http://www.practicalbioethics.org/initiatives/transportable-physician-orders.html,* accessed 10 December 2012.

18. Utah Bureau of Emergency Medical Services, "Life with Dignity/POLST/DNR," *http://www.health.utah.gov/ems/polst,* accessed 10 December 2012.

19. 20 Ill. Comp. Stat. § 2310-600(b-5).

20. Department of Veterans Affairs, Veterans Health Administration, *VHA Handbook,* § 1004.04 (25 October 2012).

21. C.P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," *Milbank Quarterly* 88, no. 2 (2010): 211-39; L.S. Castillo et al., "Lost in Translation: The Unintended Consequences of

Advance Directives Law on Clinical Care," *Annals of Internal Medicine* 154, no. 2 (2011): 121-8; K.E. Sonderling, "POLST: A Cure for the Common Advance Directive—It's Just What the Doctor Ordered," *Nova Law Review* 33, no. 2 (2009): 451-80; M.B. Kapp, "The Nursing Home as Part of the POLST Paradigm," *Hamline Law Review* 36, no. 2 (2013); H.S. Perkins, "Controlling Death: The False Promise of Advance Directives," *Annals of Internal Medicine* 147, no. 1 (2007): 51-7; A. Fagerlin and C.E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report* 34, no. 2 (2004): 30-42.

22. P.A. Bomba, M. Kemp, and J.S. Black, "POLST: An Improvement over Traditional Advance Directives," *Cleveland Clinic Journal of Medicine* 79, no. 7 (2012): 457-464; C. Spillers and B. Lamb, "Is the POLST Model Desirable for Florida?" *Florida Public Health Review* 8 (2011): 80-90.

23. For detailed explanations of POLST (customized for clinician, lawyer, and patient audiences in multiple languages), see the extensive training resources on the California, New York, Oregon, and West Virginia program websites. Coalition for Compassionate Care of California, "POLST—Physician Orders for Life-Sustaining Treatment: For Health Care Providers," *http://www.capolst.org/?for=providers,* accessed 10 December 2012; Compassion and Support at the End of Life, "Medical Orders for Life-Sustaining Treatment—Professionals," *http://www.compassionandsupport.org/index.php/for_professionals/molst_training_center,* accessed 10 December 2012; Center for Health Care Ethics, Oregon Health and Science University, "Oregon POLST Information for Health Care Professionals, POLST," *http://www.ohsu.edu/polst/programs/OregonHealthCareProfessionals.htm,* accessed 10 December 2012; West Virginia Center for End-of-Life Care, "Information about Completing Effective Advance Directives and POST Forms," *http://www.wvendoflife.org/POST,* accessed 10 December 2012.

24. P.A. Bomba, "Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning Including MOLST," *Widener Law Review* 17, no. 2 (2011): 475-500.

25. B.J. Hammes et al., "The POLST Program: A Retrospective Review of the Demographics of Use and Outcomes in One Community Where Advance Directives Are Prevalent," *Journal of Palliative Medicine* 15, no. 1 (2012): 77-85; S.E. Hickman et al., "The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment Form," *Journal of the American Geriatrics Society* 59, no. 11 (2011): 2091-9; S.E. Hickman et al., "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," *Journal of the American Geriatrics Society* 58, no. 7 (2010): 1241-8; S.E. Hickman et al., "Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting," *Journal of Palliative Medicine* 12, no. 2 (2009): 133-41; M.A. Lee et al., "Physician Orders for Life-Sustaining Treatment (POLST): Outcomes in a PACE Program," *Journal of the American Geriatrics Society* 48, no. 10 (2000): 1219-25; S.W. Tolle, V.P. Tilden, C.A. Nelson and P.M. Dunn, "A Prospective Study of the Efficacy of the Physician Order Form for Life-Sustaining Treatment," *Journal of the American Geriatrics Society* 46, no. 9 (1998): 1097-102.

26. See Center for Ethics in Health Care, Oregon Health and Science University, "POLST State Programs," *http://www.ohsu.edu/polst/programs/state+programs.htm* (September 2012). Maryland also has a legislatively established MOLST program that is not registered with the National POLST Paradigm program. Md. Code. Ann., Health-Gen. § 5-608.1 (*West* 2012); "Maryland MOLST," *http://marylandmolst.org/,* accessed 10 December 2012. Four other states (Alabama, Arkansas, Oklahoma, and South Dakota) also have no POLST program affiliated with NPPTF. But, like Maryland, some of these states have been developing a POLST program.

27. Center for Ethics in Health Care, Oregon Health and Science University, "History of the POLST Paradigm Initiative," *http://www.ohsu.edu/polst/developing/history.htm,* accessed 10 December 2012.

28. See Sabatino, note 3 above, p. 15.

29. "Program Description for: Wisconsin," *http://www.ohsu.edu/polst/programs/documents/WIProgramDescription.pdf* (28 July 2005).

30. "Program Description for: New York," *http://www.ohsu.edu/polst/programs/documents/NYProgramDescription082908FINAL.pdf* (29 Aug. 2008).

31. "Program Description for: Pennsylvania," *http://www.ohsu.edu/polst/programs/documents/ProgramDescriptionPA_END.pdf* (1 November 2010).

32. See Sabatino, note 3 above, pp. 45-6.

33. Ibid., 49.

34. See note 27 above.

35. Center for Health Care Ethics, "Program Requirements," *http://www.ohsu.edu/polst/developing/core-requirements.htm* (26 April 2012).

36. See note 27 above.

37. S.E. Hickman et al., "Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting," *Journal of Palliative Medicine* 12, no. 2 (2009): 133-41, 135,

reporting that 100 percent of hospices in Oregon and 85 percent of hospices in West Virginia used POLST. The vast majority of these hospices (92 percent in Orgeon and 73 percent in West Virginia) had POLST forms for more than half of their patients.

38. N.S. Wenger et al., "Implementation of Physician Orders for Life Sustaining Treatment in Nursing Homes in California: Evaluation of a Novel Statewide Dissemination Mechanism," *Journal of General Internal Medicine* (10 August 2012); DOI: 10.1007/s11606-012-2178-2. Only 18 months after POLST was introduced in the state, 81 percent of responding nursing homes had completed a POLST with a resident and that 54 percent of nursing home residents had a completed POLST; 69 percent of responding nursing homes also reported receiving a patient with a completed POLST from another care venue, suggesting that use of POLST in California is spreading across healthcare settings.

39. See Sabatino, note 3 above, p. 41; see note 23 above.

40. See Sabatino, note 3 above, p. 36; D.M. Zive and T.A. Schmidt, *Pathways to POLST Registry Development: Lessons Learned* (2012) (describing the efforts of California, New York, Oregon, and West Virginia to develop and fund electronic POLST registries in effort to reduce barriers to use of POLST in emergency situations and generate data for research and monitor/evaluation).

41. See Sabatino, note 3 above, pp. 47-8; "Program Description for: Tennessee," *http://www.ohsu.edu/polst/programs/documents/TNProgramDescription.pdf* (6 February 2009).

42. See Sabatino, note 3 above, p. 45; "Program Description for: Hawaii," *http://www.ohsu.edu/polst/programs/documents/HIProgramDescription.pdf* (26 October 2009).

43. Alaska, Arizona, Connecticut, Delaware, Florida, Illinois, Iowa, Indiana, Maine, Massachusetts, Michigan, Nebraska, New Hampshire, New Jersey, New Mexico, Ohio, South Carolina, Texas, and Vermont.

44. Kansas, Minnesota, Missouri, Nevada, North Dakota, and Wyoming.

45. "Program Requirements," *http://www.ohsu.edu/polst/developing/core-requirements.htm,* accessed 10 December 2012.

46. "Program Description for: Massachusetts," *http://www.ohsu.edu/polst/programs/documents/MAProgramDescription.pdf* (10 May 2010).

47. 2008 Mass. Acts, ch. 305, sec. 43 (directing the establishment of a POLST pilot program, which would facilitate recommendations for establishment of a statewide MOLST program). The Massachusetts MOLST website also provides links to the reports and recommendations based on the demonstration program experience. "About MOLST in Massachusetts," *http://www.molst-ma.org/about,* accessed 10 December 2012.

48. Massachusetts Dept. of Publ. Health, Office of Emergency Medical Services, "Emergency Medical Services Pre-Hospital Treatment Protocol," *http://www.mass.gov/eohhs/provider/guidelines-resources/clinical-treatment/public-health-oems-treatment-protocols.html* (10th ed., 1 March 2012).

49. Massachusetts Dept. of Publ. Health, "Circular Letter DHCQ 12-3-560," *http://www.molst-ma.org/sites/molst-ma.org/files/DHCQ_560.pdf* (20 March 2012).

50. "MOLST Expansion Throughout Massachusetts Has Begun," *http://www.molst-ma.org/healthcare-professionals,* accessed 10 December 2012.

51. Iowa H.F. 2165, codified as Iowa Code § 144D.1-.4 (West, 2012).

52. Iowa Dept. of Publ. Health, "Iowa Physician Orders for Scope of Treatment Form," *https://idph.state.ia.us/IPOST/Form.aspx* (25 June 2012). The IPOST website also provides a links to guidelines for completion and use of IPOST. *https://idph.state.ia.us/IPOST/Form.aspx,* accessed 10 December 2012.

53. A number of states have fledgling POLST programs that still have to address legal barriers to POLST implementation. See, e.g., Program Descriptions for South Carolina, Florida, Kansas, Missouri, and North Dakota.

54. "Program Description for: New Mexico," *http://www.ohsu.edu/polst/programs/documents/NMdevelopingstateform.pdf* (23 January 2012).

55. "Program Description for: Ohio," *http://www.ohsu.edu/polst/programs/documents/OHProgramDescription.pdf* (27 October 2008); D. Cluxton and M. Sweterlisch, "Getting Acquainted with MOLST," (22 February 2011), *http://206.21.86.11/SiteObjects/B6766D956ACCFA782F13938BE01AD760/MOLSTHandouts.pdf,* accessed 10 December 2012. POLST advocate, the Midwest Care Alliance, "continues to work on draft legislation to replace DNR law in Ohio with Medical Orders for Life Sustaining Treatment (MOLST). We are working with the many stakeholders involved to reach consensus on legislative language before the bill can be introduced. To that end, a stakeholder meeting has been scheduled for September 25, 2012." Midwest Care Alliance, "Pulse," *http://www.ohpco.org/aws/MCA/pt/sd/news_article/62980/_PARENT/layout_details/false* (4 September 2012). Bills introduced in earlier sessions had been defeated. Ohio H.B. 601 (2008); Ohio H.B. 241 (2009).

56. See Hickman et al., note 1 above, pp. 121-2

(noting that existing state laws can impose a number of barriers to implementation of POLST, including limits on the authority of surrogate decision makers, lack of default surrogate laws, medical preconditions or witnessing requirements for withholding of life-sustaining treatment, and detailed out-of-hospital DNR laws). While most of these barriers, particularly medical preconditions or lack of default surrogate provisions, are not an absolute bar, they can limit the utility of POLST or make implementation of POLST more difficult.

57. Ga. H.B. 247 (2011), enacted as 2012 Ga. Act 580, codified at Ga. Code Ann. § 29-4-18(k)(3).

58. See Hickman et al., note 1 above, p. 124 (stating that the primary advantage of ensuring that there is a statutory basis for POLST is that healthcare professionals will be "immune from prosecution, disciplinary action, and civil action for their conduct in compliance with the statute.").

59. K.L. Cerminara and S.M. Bogin, "A Paper about a Piece of Paper: Regulatory Action as the Most Effective Way to Promote Use of Physician Orders for Life-Sustaining Treatment," *Journal of Legal Medicine* 29, no. 4 (2008): 479-503, 500.

60. La. Atty. Gen. Op. 08-0289 (26 November 2007). Notably, due to concern over whether new MOLST regulations were consistent with governing EMS statutes, the Department of Health and Social Services instructed all healthcare providers to "refrain from further use" of MOLST. Letter from K.T. Rattay, Director, Division of Public Health, Delaware Department of Health and Social Services (14 November 2012), *http://www.medsocdel.org/Portals/1/In%20the%20News/MOLST%20Form%20Letter%20111412.pdf,* accessed 10 December 2012.

61. See Cerminara and Bogin, note 59 above, pp. 500-1 (noting both that courts respect statutes in a way they do not respect administrative regulations, due to the fact that administrative agencies derive their power from the legislature, and that statutory establishment should ensure that POLST complies with applicable state law, limiting "potential misunderstandings and ambiguities").

62. *VHA Handbook* 1004.04 §§ 3(f) and 7(a).

63. Cal. Prob. Code §§ 4780-86 (West 2012) (adopted 2009); Colo. Rev. Stat. Ann. § 15-18.7 (West 2012) (adopted 2010); Ga. Code Ann. § 29-4-18(k)(3) (West 2012) (adopted 2012); Haw. Rev. Stat. §§ 327K-1 to K-4 (West 2012) (adopted 2009); Idaho Code Ann. §§ 39-4512 to -4514 (West 2012) (adopted 2006); 20 Ill. Comp. Stat. Ann. § 2310/2310-600(b-5) (West 2012) (adopted 2011); Iowa Code Ann. § 144D.1-.4 (West 2012) (adopted 2012); La. Rev. Stat. Ann. § 1299.64.1-.6 (2012) (adopted 2010); Md. Code Ann., Health-Gen. § 5-608.1 (West 2012) (adopted 2011); N.C. Gen. Stat. Ann. § 90-21.17 (West 2012) (adopted 2007); N.J. Stat. Ann. § 26:2H-130 to -140 (West 2012) (adopted 2011); N.Y. Pub. Health Law § 2994-dd(6) (McKinney 2012) (adopted 2010, although 2008 legislation permitted statewide use of MOLST across healthcare settings); 20 Pa. Cons. Stat. Ann. § 5488 (adopted 2006); R.I. Gen. Laws Ann. § 23-4.11-3.1 (West 2012) (adopted 2012); Tenn. Code Ann. § 68-11-224 (West 2012) (adopted 2004; creates a "universal DNR" law that does not explicitly authorize POLST, but permits regulations that do); Utah Code Ann. § 75-2a-106 (West 2012) (adopted 2008); Vt. Stat. Ann. tit. 18, §§ 9701, 9707, 9709 (West 2012) (adopted 2005, amended 2011); W. Va. Code § 16-30-25 (West 2012) (adopted 2002).

64. See La. Rev. Stat. Ann. § 40:1299.64.2(8).

65. Ga. Code Ann. § 29-4-18(l); 20 Ill. Comp. Stat. Ann. § 2310/2310-600(b-5); N.Y. Pub. Health Law § 2994-dd(6); 20 Pa. Cons. Stat. Ann. § 5488; Tenn. Code Ann. § 68-11-224; Sabatino, note 3 above, p. 10.

66. N.J. S.2197, enacted as 2011 Pub. Laws Ch. 145, codified as N.J. Stat. Ann. § 26:2H-130 to -140. A Wyoming bill similarly would have delegated the details. Wyo. H.B. 75 (2012).

67. "Simplicity and economy of language are also highly recommended to retain sufficient clinical flexibility to make continuing improvements to the program." Center for Ethics in Health Care, Oregon Health and Science University, "Considering Legislation: When Selected Regulation Change is Not Enough," *http://www.ohsu.edu/polst/resources/legalissues.htm,* accessed 10 December 2012.

68. Cal. Prob. Code § 4780(a)(2)(B)(3).

69. Cal. Prob. Code § 4780(c) (directing that "the health care provider, during the process of completing the Physician Orders for Life-Sustaining Treatment form, should inform the patient about the difference between an advance health care directive and the Physician Orders for Life-Sustaining Treatment form").

70. See, e.g., Cal. Prob. Code § 4780(c) (requiring that the form be completed based on patient preferences and signed both by the physician and the patient or the patient's legally-recognized decision-maker); Cal. Prob. Code § 4783(a) (requiring the following language be included on the form: "by signing this form, the legally recognized health care decision maker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form").

71. See, e.g., Cal. Prob. Code § 4780(b) (authorizing a legally recognized healthcare decision maker to execute a POLST on behalf of a patient if the pa-

tient lacks capacity or has authorized the decision maker to do so on his/her behalf); Cal. Prob. Code § 4781.2 (requiring a legally recognized health care decision maker to consult with the patient's physician before attempting to modify the patient's POLST).

72. Cal. Prob. Code § 4782.

73. Cal. Prob. Code § 4785.

74. W. Va. Code § 16-30-25(b)(1)-(5).

75. Ga. H.B. 247 (2011), enacted as 2012 Ga. Act 580, codified at Ga. Code Ann. § 29-4-18(k)(3); Ill. H.3134 (2011), codified at 20 Ill. Comp. Stat. Ann. § 2310/2310-600(b-5); Iowa H.F. 2165 (2012), codified at Iowa Code Ann. § 144D.1-.4; Md. H.B. 82, enacted as Md. 2011 Acts Ch. 434, codified at Md. Code Ann., Health-Gen. § 5-608.1; N.J. S.2197, enacted as 2011 Pub. Laws Ch. 145, codified at N.J. Stat. Ann. § 26:2H-130 to -140; R.I. H.B. 7735 and S.B. 2361 (2012), enacted as Pub. Laws 187 and 199, codified at R.I. Gen. Laws Ann. § 23-4.11-3.1; Vt. H. 201, enacted as 2012 Acts 60, codified at 18 Vt. Stat. Ann. § 9708.

76. In 2010, Georgia had enacted a statute instructing the "Department of Public Health [to] develop and make available a Physician Order for Life-sustaining Treatment, a specific form voluntarily executed by a patient and his or her authorized representative and a physician which provides directions regarding end of life care." 2010 Ga. Laws, Act 616, codified at Ga. Code Ann. § 29-4-18(l).

77. 20 Ill. Comp. Stat. Ann. § 2310/2310-600(b-5) (West 2012). The Illinois Department of Health is expected to approve a proposed form in early 2013.

78. Iowa Code Ann. § 144D.1-.4; Md. Code Ann., Health-Gen. § 5-608.1; N.J. Stat. Ann. § 26:2H-130 to -140; R.I. Gen. Laws Ann. § 23-4.11-3.1.

79. Vt. Stat. Ann, tit. 18, § 9708(b). Vermont healthcare facilities and residential care facilities "may document DNR/COLST orders in the patient's medical record in a facility-specific manner when the patient is in their care," but are required to use the Department of Health-issued form for patients who are not admitted to healthcare/residential care facilities or who are transferred from such facilities. Vt. Stat. Ann. tit. 18, § 9708(c).

80. Ind. H.B. 1114 (2012); Ky. S.B. 217, 2012 Leg., Reg. Sess. (2012); Wyo H.B. 75, 61st Leg., Budget Sess. (2012).

81. Wash. H.B. 2462 (2012).

82. Ohio H.B. 241, 128th Gen. Assembly (2009); Ohio H.B. 601, 127th Gen. Assembly (2008).

83. Midwest Care Alliance, "Networks and Task Forces," *http://www.ohpco.org/aws/MCA/pt/sp/networks,* accessed 10 December 2012; Midwest Care Alliance, see note 55 above.

84. See Cerminara and Bogin, note 59 above, pp. 496-97.

85. See Cerminara and Bogin, note 59 above, pp. 497-8 (noting that issuance of regulations requires some public disclosure through notice and opportunities for comment, but also recognizing that administrative actions attract less public attention, permitting POLST advocates to avoid heated political battles).

86. Tennessee authorizes the development and use of "universal do-not-resuscitate orders," which the statute defines as "a written order that applies regardless of the treatment setting and that is signed by the patient's physician that states that in the event the patient suffers cardiac or respiratory arrest, cardiopulmonary resuscitation should not be attempted." Tenn. Code Ann. § 68-11-224(e)(6). An opinion of the attorney general interpreted this statute to permit the Board for Licensing Health Facilities to promulgate a POST form, which addresses life-sustaining treatments that go beyond CPR. See Sabatino, note 3 above, pp. 47-8 (citing Atty. Gen. Op. No. 05-093, 13 June 2005).

87. Tenn. Comp. R. and Regs. 1200-08-01-.13 & -.15; 1200-08-06-.13 & -.15; 1200-08-10-.13 & -.15 (2012).

88. 16 Del. Admin. Code 4304-1.0 – 14.0 (2012) (adopted 2012).

89. Letter from K.T. Rattay, Director, Division of Public Health, Delaware Department of Health and Social Services (14 November 2012), *http://www.medsocdel.org/Portals/1/In%20the%20News/MOLST%20Form%20Letter%20111412.pdf,* accessed 10 December 2012.

90. See Cerminara and Bogin, note 59, above, p. 493.

91. Ore. Admin. R. § 847-035-0030(6) (2012).

92. See Sabatino, note 3 above, p. 10.

93. See note 63 above, for California, Iowa, Illinois, Maryland, New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, Utah, and Vermont's POLST statutes authorizing regulatory bodies to develop and/or approve POLST forms or procedures.

94. Chicago End-of-Life Care Coalition, "IDPH Uniform DNR Advance Directive and the Evolution of POLST lllinois," *http://www.cecc.info/resource-links/physicians-order-for-life-sustaining-treatment-polst,* accessed 10 December 2012; New Jersey Hospital Association, "DHSS Selects NJHA to Lead New Jersey's POLST Initiative," *http://www.njha.com/html/DailyMessage.aspx?id=13733,* accessed 10 December 2012; "10.01.21 Medical Orders for Life-Sustaining Treatment (MOLST) Form—Procedures and Requirements," Maryland Register 39, no 16 (10 Aug.

2012); Maryland MOLST, *http://marylandmolst.org/pages/molst_form.htm,* accessed 10 December 2012.

95. Iowa Dept. of Pub. Health, "IPOST Form and Guidance," *http://www.idph.state.ia.us/IDPHChannelsService/file.ashx?file=1EC05976-26E1-4950-B60B-02CABD2A4A66* (25 June 2012); *http://www.idph.state.ia.us/IDPHChannelsService/file.ashx?file=4162F2B4-7E54-4717-B5EA-F3F60A72C6DF,* accessed 10 December 2012.

96. See Sabatino, note 3 above, p. 10.

97. These websites contain guidelines and supplemental materials to facilitate POLST implementation: *http://www.wvendoflife.org/POLST,* accessed 10 December 2012; *http://www.compassionandsupport.org/index.php/for_patients_families/molst,* accessed 10 December 2012; *http://www.capolst.org/,* accessed 10 December 2012; *http://www.wsma.org/POLST,* accessed 10 December 2012; *http://kokuamau.org/polst,* accessed 10 December 2012.

98. POLST is well-established in Lacrosse, Wisconsin, but not in the rest of the state. Unfortunately, the Wisconsin Medical Society decided not to include POLST in a statewide program to encourage advance care planning. In light of opposition from Roman Catholic bishops in the state, the Medical Society determined that POLST is too much of a "lightning rod." A. Johnson, "End-of-Life Medical Care Initiative Prompts Worries about Abuse," *Milwaukee Sentinel-Journal* (17 October 2012).

99. See Hickman, note 1 above (acknowledging that most day-to-day activity of health care providers does not have explicit statutory protection).

100. Hospice of the Bluegrass, "Kentuckians Deserve the MOST," *http://www.hospicebg.org/most.html,* accessed 10 December 2012; J. Ard,"Rule Making or Legislation: Test Cases from Health Care," *State Bar of Michigan Administrative Law Journal* 35 (2009): 2-7; J. Wilson, "End-of-Life Wishes," *Columbus Telegram,* 25 March 2005; Nevada Center for Ethics and Health Policy, "An Introduction to the Nevada SMOST," *http://www.unr.edu/ncehp/spost_summary.html,* accessed 10 December 2012.

101. See Cerminara and Bogin, note 59 above, p. 488; Center for Practical Bioethics, "Transportable Physician Orders for Patient Preferences (TPOPP)," *http://www.practicalbioethics.org/initiatives/transportable-physician-orders.html,* accessed 10 December 2012; "Program Description for: Minnesota," *http://www.ohsu.edu/polst/programs/documents/MNProgramDescription.pdf* (11 March 2010); "Program Description for: Maine," *http://www.ohsu.edu/polst/programs/documents/MaineDevelopingProgramDescription_INFO-1docmmc2011.pdf* (7 July 2011); Maine Hospice Council, *http://mainehospicecouncil.org/polst/,* accessed 10 December 2012; "Program Description for: North Dakota," *http://www.ohsu.edu/polst/programs/documents/NDProgramDescription.pdf* (30 December 2008).

102. Center for Health Care Ethics, Oregon Health and Science University, "History of the POLST Paradigm Initiative," *http://www.ohsu.edu/polst/developing/history.htm,* accessed 10 December 2012.

103. Minnesota Medical Association, "POLST Communications" *http://www.mnmed.org/KeyIssues/POLSTCommunications/tabid/3291/Default.aspx,* accessed 10 December 2012; L. Vawter and E. Ratner, "The Need for POLST: Minnesota's Initiative," Minnesota Medicine 93, no. 1 (2010): 42-46, *http://www.minnesotamedicine.com/CurrentIssue/ClinicalRatnerJan2010/tabid/3294/Default.aspx.*

104. "Program Description for: Maine," *http://www.ohsu.edu/polst/programs/documents/MaineDevelopingProgramDescription_INFO-1docmmc2011.pdf* (7 July 2011).

105. The AARP report, which surveyed 12 states with POLST programs, found that the use of a "deliberately incremental strategy" was one of the three most frequently identified variables that facilitated successful implementation of POLST. See Sabatino, note 3 above, p. 13.

106. See Sabatino, note 3 above, pp. 13, 44-50. For example, the California POLST was developed and piloted in 2007-2008. It was authorized in 2008 and went in effect in 2009. Cal. A.B. 3000 (2008), enacted as Chapter 266, codified as Cal. Prob. Code § 4780. Illinois enacted a POLST statute in 2011. Ill. H.B. 3134, enacted as Ill. Pub. Acts 97-0382, codified at 20 Ill. Comp. Stat. § 2310-600(b-5). In late 2012, a task force submitted a draft form to the Illinois Department of Public Health. Once the form is approved, POLST will be piloted in two or three communities before a statewide rollout. See Chicago End-of-Life Coalition, note 94 above.

107. See Sabatino, note 3 above, pp. 14, 38-31; "Program Description for: New York," *http://www.ohsu.edu/polst/programs/documents/NYProgramDescription082908FINAL.pdf* (29 Aug. 2008).

108. See Sabatino, note 3 above, pp. 45-6. P.A. Bomba and C.P. Sabatino, "POLST: An Emerging Model for End-of-Life Planning," *ElderLaw Report* 50, no. 7 (2009): 1-5; D. Meier and L. Beresford, "POLST Offers Next Stage in Honoring Patient Preferences," *Journal of Palliative Medicine* 12, no. 4 (2009): 291-295.

109. Iowa H.F. 2165, codified at Iowa Code Ann. § 144D.1-.4.

110. "IPOST: The Report of the Patient Au-

tonomy in Health Care Decisions Pilot Project," (2010), *https://idph.state.ia.us/IPOST/Resources.aspx,* accessed 10 December 2012.

111. See Sabatino, note 3 above.

112. Other legal issues about which there is more uniformity include: (1) whether copies are as valid as originals, (2) whether out-of-state POLST forms will be given reciprocity, and (3) whether providers have legal immunity for adhering to POLST orders in good faith.

113. See Center for Health Care Ethics, Oregon Health and Science University, "Program Requirements," *http://www.ohsu.edu/polst/developing/core-requirements.htm* (26 April 2012) (specifying that the treatment preferences communicated by a POLST form "require[] a medical order that needs signature by a health care professional").

114. Cal. Prob. Code § 4780(c); "Georgia POLST Form," *http://www.dph.ga.gov/POLST/,* accessed 10 December 2012; Haw. Rev. Stat. Ann. § 327K-1, K-2; Illinois Department of Public Health (IDPH), "Uniform Do-Not-Resuscitate (DNR) Advance Directive: Guidance for Health-Care Providers and Professionals," *www.idph.state.il.us/public/books/guide_hcpp.htm,* accessed 10 December 2012; "Transportable Physician Orders for Patient Preferences (TPOPP)," *http://www.practicalbioethics.org/initiatives/transportable-physician-orders.html,* accessed 10 December 2012 (Kansas and Missouri); Nevada Center for Ethics and Health Policy, "An Introduction to the Nevada SMOST," *http://www.unr.edu/ncehp/spost_summary.html,* accessed 10 December 2012; N.Y. Pub. Health Code § 2994dd; Tenn. Code Ann. § 68-11-224; Tenn. Comp. R. and Regs. 1200-08-01-.13 and -.15; 1200-08-06-.13 and -.15; 1200-08-10-.13 and -.15 (2012); W.Va. Code Ann. § 16-30-25; West Virginia Center for End-of-Life Care, "Using the POST Form: Guidance for Healthcare Professionals" (2012). Proposed legislation in Indiana would also have limited signing authority to physicians. Ind. H.B. 1114 (2012).

115. Colo. Rev. Stat. Ann. § 15-18.7-104; Idaho Code Ann. § 39-4512A(1); Iowa Code Ann. § 144D.2(c); Massachusetts Dept. of Publ. Health, "Circular Letter DHCQ 12-3-560," *http://www.molst-ma.org/sites/molst-ma.org/files/DHCQ_560.pdf* (20 March 2012); Md. Code Ann., Health-Gen. § 5-608.1; Minn. Med. Assn, "FAQ: The POLST Form," *http://www.mnmed.org/LinkClick.aspx?fileticket=FGvy4%2f9Ibco%3dandtabid=3291* (January 2010); Montana Board of Medical Examiners, "POLST," *http://bsd.dli.mt.gov/license/bsd_boards/med_board/polst.asp,* accessed 10 December 2012; N.C. Gen. Stat. Ann. § 90-21.17(c); N.J. Stat. Ann. § 26:2H-134; Ore. Admin. R. § 333-270-0030; Ore. Rev. Stat. § 127.663(6); R.I. Gen. Laws §§ 23-4.11-2(12), 23-4.11-3.1(d)(1); Utah Code Ann. § 75-2a-106(2); Vt. Stat. Ann., tit. 18 §§ 9701(5) and 9708(d); Washington State Medical Association, "POLST," *http://www.wsma.org/POLST,* accessed 10 December 2012.

116. "Program Description for: Alaska," *http://www.ohsu.edu/polst/programs/documents/AKProgramDescription.pdf,* accessed 5 December 2012.

117. See Zive and Schmidt, note 40 above, p. 18. Idaho S.B. 1294, enacted as 2012 Idaho Laws Ch. 302, codified at Idaho Code Ann. § 39-4512A(1).

118. S.C. Zweig, L.L. Popejoy, D. Parker-Oliver and S.E. Meadows, "The Physician's Role in Patients' Nursing Home Care," *Journal of the American Medical Association* 306, no. 13 (2011): 1468-1478; J.L. Meyers et al., "Physician Orders for Life-Sustaining Treatment Form: Honoring End-of-Life Directives for Nursing Home Residents," *Journal of Gerontological Nursing* 30, no. 9 (2004): 37-46.

119. See Wenger et al., note 38 above.

120. California Advocates for Nursing Home Reform, "Physician Orders for Life Sustaining Treatment: Problems and Recommendations" (2010), 3, 6.

121. Coalition for Compassionate Care of California, "California POLST Form," *http://www.capolst.org/,* accessed 10 December 2012; Kokua Mau, "Hawaii POLST Form," *http://www.kokuamau.org/professionals/polst,* accessed 10 December 2012; Iowa Dept. of Pub. Health, "IPOST Form," *http://www.idph.state.ia.us/IPOST/Form.aspx,* accessed 10 December 2012; Minn. Med. Ass'n, "FAQ: The POLST Form," *http://www.mnmed.org/LinkClick.aspx?fileticket= FGvy4%2f9Ibco%3dandtabid=3291,* accessed 10 December 2012; North Carolina Medical Society, "Using the MOST Form—Guidance for Healthcare Professionals," *http://www.ncmedsoc.org/pages/public_health_info/end_of_life.html,* accessed 10 December 2012; Utah Commission on Aging, "POLST: Utah Physician Order for Life-Sustaining Treatment: A Life With Dignity Order," *http://health.utah.gov/hflcra/forms/POLST/AdvanceDirectiveProviderGuide2011.pdf,* accessed 10 December 2012. While facilitators arguably do an even better job than physicians, their role remains controversial.

122. Center for Health Care Ethics, Oregon Health and Science University, "Program Requirements," *http://www.ohsu.edu/polst/developing/core-requirements.htm* (26 April 2012).

123. "Upholding the Dignity of Human Life: A Pastoral Statement on POLST from the Catholic Bishops of Wisconsin," (July 2012), *http://WisconsinCatholic.org,* accessed 15 December 2012; E.C.

Brugger, "A Critique of Colorado's New MOST Legislation," *Linacre Quarterly* 78, no. 2 (2011): 58-61. But other Roman Catholic thought leaders more strongly support POLST. R. Hamel, "POLST under Fire," *Healthcare Ethics USA* 20, no. 1 (2012): 30-5; G.D. Coleman and M.R. McLean, "POLST Supports Care in Context of ERDs," *Health Progress* 93, no. 6 (2012): 58-65.

124. Montana Board of Medical Examiners, "Using the Montana POLST Form: Guidance for Healthcare Professionals," *http://bsd.dli.mt.gov/license/bsd_boards/med_board/polst.asp* (30 June 2011).

125. See Sabatino, note 3 above, pp. 29, 33.

126. 18 Vt. Stat. Ann. § 9708(d)(3)(A)-(B).

127. Cal. Prob. Code § 4675.

128. B.J. Hammes et al., "The POLST Program: A Retrospective Review of the Demographics of Use and Outcomes in One Community Where Advance Directives Are Prevalent," *Journal of Palliative Medicine* 15, no. 1 (2012): 1-9.

129. See Center for Health Care Ethics, note 26 above.

130. T.M. Pope, "Legal Fundamentals of Surrogate Decision Making," *Chest* 141, no. 4 (2012): 1074-81; T.M. Pope, "Comparing the FHCDA to Surrogate Decision Making Laws in Other States," *NYSBA Health Law Journal* 16, no. 1 (2011): 107-11.

131. See Hickman, note 1 above, p. 121.

132. See California Advocates for Nursing Home Reform, note 120 above, p. 4; see Hickman, note 1 above, p. 122 (noting that 14 states, as of 2008, did not have default surrogate laws, which identify decision makers for patients who are incapacitated and have not previously authorized a legal healthcare decision maker).

133. See Sabatino, note 3 above, p. 35.

134. Vermont is seeking to resolve uncertainty by directing the Department of Health to promulgate rules on the authority of non-agent, non-guardian decision makers. Vt. H.201 (2011), enacted as 2011 Vt. Act 60, codified at Vt. Stat. Ann. § 9708.

135. S.E. Hickman et al., "The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the POLST Form," *Journal of the American Geriatrics Society* 59, no. 11 (2011): 2091-9.

136. Tennessee End-of-Life Partnership, "POLST and Surrogate Information," *http://endoflifecaretn.org/information-about-post-and-appointment-of-a-surrogate/,* accessed 10 December 2012.

137. N.J. Stat. Ann. § 26:2H-135.

138. R.I. Gen. Laws §§ 23-4.11-2(12) and 23-4.11-3.1(d)(1).

139. 16 Del. Admin. Code § 4304-7.2.

140. N.Y. Pub. Health L. § 2994-b; Utah Code Ann. § 75-2a-106(4).

141. See Sabatino, note 3 above, pp. 29, 34 (finding that all twelve states surveyed permitted surrogates to consent to POLST on behalf of a incapacitated patient).

142. See, e.g., Idaho Code Ann. § 39-4512A(2); N.C. Gen. Stat. Ann. § 90-21.17; Utah Code Ann. § 75-2a-106(7).

143. See, e.g., Iowa Code Ann. § 144D.4(1)-(3) (a POST form shall not supersede a Declaration Relating to Use of Life-Sustaining Procedures, durable power of attorney for healthcare, or an out-of-hospital DNR order); Md. Code Ann., Health-Gen.§ 5-608.1(c)(3)(ii) ("the 'Medical Orders for Life-Sustaining Treatment' form shall be consistent with [. . .] any known advance directive of the patient if the patient is incapable of making an informed decision."); W. Va. Code § 16-20-5(b).

144. See, e.g., Cal. Prob. Code § 4781.4; Colo. Rev. Stat. Ann. § 15-18.7-110; Ind. H.B. 1114 (2012); N.J. Stat. Ann. § 26:2H-135.

145. See, e.g., N.Y. Pub. Health Code § 2994-d(4)-(5) (the conflict issue is not expressly addressed, but surrogates are obligated to follow patient's known wishes, followed by patient's best interests, with additional preconditions for decision making related to end-of-life care listed in subsection 5—thus, a surrogate-completed POLST may not trump a patient-completed advance directive except under certain conditions). Minnesota, Hawaii, Oregon, Vermont have not expressly addressed the issue. See Sabatino, note 3 above, pp. 30, 35.

146. California Advocates for Nursing Home Reform, note 120 above, p. 4; Cal. Prob. Code §§ 4780(c) and 4781.4 (West 2012). The danger is substantially mitigated by two features of healthcare decisions laws. First, surrogates must make treatment decisions consistent with the patient's preferences and best interests. Second, healthcare providers face liability for complying with surrogate decisions that they know deviate from this standard. See Pope, note 130 above.

147. Colo. Rev. Stat. Ann. § 15-18.7-110 (specifying that the most recent document controls in the event of a conflict between POLST and a prior health are directive, but with the qualification that a surrogate, advanced practice nurse, or physician assistant may not revoke prior healthcare/CPR directive that was completed by the patient).

148. N.J. Stat. Ann. § 26:2H-135 (specifying that the "more recent directive from the patient" will be honored in the event of conflicting healthcare instructions).

149. Of course, foreseeing the need to update the POLST to be consistent with current health sta-

tus, the patient could, in his or her advance directive, specifically grant the surrogate permission to revoke or modify a POLST.

150. *VHA Handbook* 1004.04 § (5)(b)(2)(a).

151. 42 U.S.C. § 1395CC(f)(1); 42 C.F.R. §§ 482.13(a) and 489.102(a).

152. Md. Code Ann., Health-Gen. § 5-608.1(c)(1)(ii)(1)-(2).

153. Utah Admin. Code § 432-31-4(2)(b)-(c).

154. See Sabatino, note 3 above, p. 18; see California Advocates for Nursing Home Reform, note 120 above, p. 6 (analyzing California's POLST laws, and reporting the results of a survey of long-term care Ombudsman regarding POLST: "While the POLST form is voluntary, health care facility staff members often tell patients that their services are contingent on POLST completion. As stated before, 73% of Ombudsman reported that POLST is 'always' or 'often' presented to long-term care residents as mandatory").

155. E.K. Fromme et al., "POLST Registry Do-Not-Resuscitate Orders and Other Treatment Preferences," *Journal of the American Medical Association* 307, no. 1 (2012): 34-5; S.E. Hickman et al., "A Comparison of Methods of Communicating Treatment Preferences in Nursing Facilities: Traditional Practices versus the POLST," *Journal of the American Geriatrics Society* 58, no. 7 (2010): 1241-8; S.E. Hickman, S.W. Tolle, K. Brunnelswitch, and M.M. Carley, "Use of a POLST Program in Oregon Nursing Facilities," *Journal of the American Geriatrics Society* 52, no. 9 (2004): 1424-9.

156. See Center for Health Care Ethics, Oregon Health and Science University, "Program Requirements," *http://www.ohsu.edu/polst/developing/core-requirements.htm* (26 April 2012) (requirement number 7 for endorsed programs specifies that "Completion of the form and the decisions recorded on it should be voluntary and based on shared medical decision making").

157. See Sabatino, note 3 above, p. 18.

158. Iowa Code Ann. § 144D.4(6); Colo. Rev. Stat. Ann. § 15-18.7-108.

159. Idaho Code Ann. § 39-4514(8)(a)-(b); La. Rev. Stat. Ann. § 1299.64.1(B)(2); Ore. Rev. Stat. § 127.672; Vt. Stat. Ann. tit. 18 § 9709(e).

160. N.C. Gen. Stat. Ann. § 90-21.17(c).

161. R.I. Gen. Laws § 23-4.11-3.1(h).

162. 42 C.F.R. § 489.102(a)(3) ("Not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive.").

163. Cal. Prob. Code § 4677 ("A health care provider, health care service plan, health care institution, disability insurer, self-insured employee welfare plan, or nonprofit hospital plan or a similar insurance plan may not require or prohibit the execution or revocation of an advance health care directive as a condition for providing health care, admission to a facility, or furnishing insurance.").

164. See, e.g., Cal. Prob. Code § 4781.2; Colo. Rev. Stat. Ann. §15-18.7-104(1)(a); Haw. Rev. Stat. Ann. § 327K-2; Idaho Code Ann. §§ 39-4512B and 39-4513(5); Iowa Code Ann. § 144D.3(5) (specifies that health care providers unwilling to comply with POLST orders on policy/religious beliefs/moral convictions shall take all reasonable steps to transfer patient); Md. Code Ann., Health-Gen § 5-608.1(f); N.J. Stat. Ann. §§ 26:2H-134(a) and 139; Ore. Admin. R. 847-010-0110; R.I. Gen. Laws § 23-4.11-3.1(c)(1); W. Va. Code Ann. §§ 16-30-12, 16-30-10, 16-30C-7.165; T.M. Pope, "Legal Briefing: Conscience Clauses and Conscientious Refusal," *The Journal of Clinical Ethics* 21, no. 2 (2010): 163-80.

166. E.g., Colo. Rev. Stat. Ann. § 15-18.7-104(1)(b); Iowa Code Ann. § 144D.3(2); Md. Code Ann., Health-Gen § 5-608.1(f).

167. Joint Commission, Comprehensive Accreditation Manual for Hospitals (CAMH) §§ MS.03.01.03 (formerly MS.2.20) ("The management and coordination of each [patient]'s care, treatment, and services is the responsibility of a practitioner with appropriate privileges."), MS.05.01.03 (formerly MS.3.20).

168. E.g., Colo. Rev. Stat. Ann. § 15-18.7-104; N.J. Stat. Ann. § 26:2H-134(c).

169. N.C. Gen. Stat. § 90-21.17(d); see Sabatino, note 3 above, p. 30.

170. A 2004 Oregon study found that 25 percent of surveyed EMTs reported difficulty locating a POLST form the last time they treated a patient with a POLST. T.A. Schmidt, S.E. Hickman, S.W. Tolle, and H.S. Brooks, "The Physicians Orders for Life-Sustaining Treatment Program: Oregon Emergency Medical Technicians' Practical Experiences," *Journal of the American Geriatrics Society* 52, no. 9 (2004): 1430-4, 1432.

171. See Schmidt et al., note 170 above.

172. See Zive and Schmidt, note 40 above, p. 24.

173. Ore. Rev. Stat. Ann. § 127.663-.681.

174. See Zive and Schmidt, note 40 above, p. 26; Oregon POLST Registry, "Nov. 2012 Monthly Update," *http://public.health.oregon.gov/ProviderPartnerResources/EMSTraumaSystems/PhysicianOrdersforLifeSustainingTreatment/Pages/index.aspx,* accessed 15 December 2012.

175. Ibid., pp. 16-32.

176. Ibid., pp. 11, 17-32, 39.

177. Or. Rev. Stat. Ann. § 127.663-.681; see Zive

and Schmidt, note 40 above, p. 23.

178. See Zive and Schmidt, note 40 above, pp. 22-23, 26.

179. Ibid., p. 16.

180. Mont. Code Ann. § 50-9-501; Montana DOJ, "End of Life Registry and Advance Health Care Directives," *https://doj.mt.gov/consumer/end-of-life-registry/,* accessed 10 December 2012; Vermont Dept. of Health, "Vermont Advance Directive Registry," *http://healthvermont.gov/vadr,* accessed 10 December 2012.

181. Mich. S.B. 723 (2012), enacted as 2012 Mich. Pub. L. No. 179.

182. American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, tit. XIII (2009); DHHS, Office of the National Coordinator for Health Information Technology, "HealthIT.hhs.gov Information Related to the American Recovery and Reinvestment Act of 2009," *http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__learn_about_hitech/1233* (21 June 2012).

183. See Sabatino, note 3 above, p. 25.

184. See Sabatino, note 6 above, p. 25 (acknowledging that the utility of EHR for facilitating evaluation, monitoring, or research of the POLST process will depend on the ability to enter POLST data into an electronic form, rather than simply scanning the form into a repository).

185. H.R. 3590, § 1233, 111th Cong. (2009).

186. See Sabatino, note 21 above, pp. 211, 232.

187. Pub. L. No. 111-148, § 4103.

188. DHHS, "Medicare Program: Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2011," 75 *Fed. Reg.* 73,170 (29 November 2010).

189. R. Pear, "U.S. Alters Rule on Paying for End-of-Life Planning," *New York Times,* 4 January 2011; Letter from Rep. Fred Upton to Sec. Kathleen Sebelius (14 March 2011).

190. DHHS, "Medicare Program: Amendment to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2011," 76 *Fed. Reg.* 1366 (10 January 2011).

191. H.R. 1589, 112th Cong., 1st Sess. (2011).

192. 38 *C.F.R.* § 17.32.

193. *VHA Handbook* § 1004.04 (25 October 2012).

194. Email from Bill Pfunder to Thaddeus Pope (26 November 2012); R.K.P. Chang et al., "Sowing Seeds and Building Collaborations: Challenges Faced and Learning Points on Starting Systemic Advance Care Planning in a Hospital in Singapore," *BMJ Supportive and Palliative Tertiary Care* 2, no. 2 (2012): 201-2.

195. J. In der Schmitten et al., "A Complex Regional Intervention to Implement Advance Care Planning in One Town's Nursing Homes: Protocol of a Controlled Inter-Regional Study," *BMC Health Services Research* 11, no. 14 (2011): 1-9; C.H. Wiese et al., "[The Göttingen Palliative Emergency Card: Improvement of Emergency Medical Care for Ambulatory Palliative Care Patients: The "Yellow Card for Rescue Services]," *Deutsche Medizinische Wochenschrift* [German Medical Weekly] 133, no. 18 (2008): 972-6.

196. Health Canada, "Implementation Guide to Advance Care Planning in Canada: A Case Study of Two Health Authorities" (2008), *hc.sc.gc.ca/hcc.sss/pubs/palliat/2008_ace_guide_eesl/index_eng.php,* accessed 15 December 2012.

197. Fraser Health, "Policy: Medical Orders for Scope of Treatment (MOST) and Advance Care Planning (ACP)" (13 June 2012); email from Doris Barwich to Thaddeus Pope, 4 December 2012.

198. Email from Professor John You to Thaddeus Pope, 5 December 2012.

199. Alberta Health Services, "Advance Care Planning and Goals of Care Resources," *http//www.albertahealthservices.ca/3917.asp,* accessed 10 December 2012.

200. Regina Qu'Appelle Health Region, "About Advance Care Planning," *http://www.rqhealth.ca/programs/advanced_care_planning/index.shtml,* accessed 10 December 2012.

201. Queensland Health, "Resuscitation Planning," *http://apps.health.qld.gov.au/acp/Public_Section/Resuscitation_Planning/resuscitationPlanning3.aspx,* accessed 10 December 2012.

202. No. 30-2011-00520263-CV-PO-CJC (Orange County Sup. Ct., Cal., filed 3 November 2011).

203. No. 1017263, 2010 WL 6860446 (Monroe County, N.Y., 23 December 2010).

204. *In re Barnes,* No. 27-GC-PR-111-16 (Hennepin County Probate Ct., Minn., 4 February 2011).

205. *Krela v. Kryla,* No. 6:12-CV-01089-TC (D. Ore., filed 18 January 2012).

206. *Scottrade v. Davenport,* No. 90-CV-11-3-BLG-RFC, 2012 WL 2019679 (D. Mont., 5 June 2012).

207. *Costello v. University of Washington Medical Center,* No. 11-2-15367-3 SEA (King County Sup. Ct., Wash. 2011) (Order granting defendant's motion to dismiss), affirmed, No. 67840 (Wash. App., 24 September 2012).

208. CDPH, Licensing and Certification Division, "Statement of Deficiencies and Plan of Correction, Survey of Cresthaven Nursing Home, No. CA-070000038" (22 December 2009).