The Journal of Clinical Ethics

VOLUME 24, NUMBER 2 SUMMER 2013

The Journal of Clinical Ethics

2 Public Square, Suite 207, Hagerstown, Maryland 21740 USA

240-420-8850 • fax: 240-718-7100 jce@clinicalethics.com www.clinicalethics.com

The Journal of Clinical Ethics, ISSN 1046-7890, print and electronic versions.

The Journal of Clinical Ethics is a peer-reviewed, refereed journal, indexed in PubMed, Research Alert, and Cumulative Index to Nursing & Allied Health Literature.

Please contact Mary Gesford at 240-420-8850 or jce@clinicalethics.com for assistance with subscriptions.

At the Bedside

Why Careproviders May Conclude that Treating a Patient Is Futile

Edmund G. Howe

ABSTRACT

I shall examine one way that careproviders may come to judgments of "futility" in cases that are less than clear-cut, in the hope that, if such judgment is unwarranted, it may be avoided.

In this issue of *The Journal of Clinical Ethics*, in "Repetitive Foreign Body Ingestion: Ethical Considerations," Sarah Lytle, Susan J. Stagno, and Barb Daly describe a 19-year-old patient who is as badly off as a patient can be. She has swallowed a knife blade—*again.* Careproviders balk when asked to remove it. One reason is that they see removing it *again* as futile—or at least too futile to warrant "the costs."

This view may not be uncommon. One researcher, for example, says that medical students and "physicians in training" are taught this kind of response in a "hidden curricula."[1] They are taught, he says, that some patients are "more deserving than others," and this translates to the provision of compromised care to the "less deserving."[2] Eventually, he says, physicians recognize the "ultimate authority" of using moral judgments to determine how they should discriminate among patients:[3] patients must comply with the values of the hospital to be fully "worthy of care," and that this worthiness should determine "which patients to see, for how long, which tests to order, and which treatments to offer. . . ."[4]

How careproviders responded in this case may be an example of this. If there is "hidden" teaching as the researcher claims, this is frightening; especially so, because the patients that careproviders would judge as "less deserving" may be among those worst-off. Therefore, this essay will examine one way careproviders may come to judgments of "futility" in cases that are less than clear-cut, in the hope that, if such judgment is unwarranted, it may be avoided.

In the case above, the patient has symptoms characteristic a diagnosis of a borderline personality disorder (BPD).[5] In a nutshell, patients with a BPD tend to be "stably unstable." For example, this patient swallowed knife blades repeatedly and now threatens her careprovider. But it is possible for these patients to do well, and this judgment of futility is simply wrong.

Why might such a chain of events occur?[6] The answer is important to *all* careproviders, psychiatric and nonpsychiatric, who may find themselves considering whether a patient's treatment is futile, or too futile to warrant "the costs." How careproviders might come to a

Edmund G. Howe, MD, JD, is Professor of Psychiatry and Director of Programs in Medical Ethics at the Uniformed Services University of the Health Sciences in Bethesda, Maryland; and Editor in Chief of *The Journal of Clinical Ethics.*

judgement of futility, erroneously, without even imagining that they are doing so, may be instructive to all careproviders.

I will consider patients with a diagnosis of a BPD as "paradigmatic patients," to show how patients with such symptoms may evoke fear and anger in careproviders. Such feelings may prompt careproviders to distance themselves from these patients—even only internally—and to judge treating them as futile. To rationalize this judgement, careproviders may then deny the validity of any additional data that might refute what they are thinking and doing.

I will describe what a patient with a diagnosis of BPD needs, ideally, and give three specific examples of questions for careproviders to consider when they treat these patients, who may, especially early on, feel suicidal.

Finally, I will report on new research findings and consider their practical implications for careproviders who may be in a position to make decisions regarding futility.

HOW PATIENTS WITH A BPD MAY EVOKE FEAR AND ANGER

Sometimes it seems as though it is a small percentage of patients who need the most help. Patients with a BPD, like the patient who swallowed a knife blade, are surely among these.

Patients with a BPD

The patient who swallowed a knife blade had done so before, and threatened a careprovider after the careprovider suggested that surgically removing the knife blade, again, might constitute futile treatment, given the costs of the surgery and the likelihood the patient would swallow the blade again.[7] Baum-Baicker and Sisti report the case of a patient who called her psychiatrist one night to say she was standing in a bathtub full of water and was about to drop her running hair drier into it.[8] My colleagues relate the case of a patient who was discharged from a psychiatric ward, picked up the medicines prescribed to her, ate them all, called the ward, told the staff what she had done, and refused to say where she was. Fortunately, she was found and survived. These examples illustrate why careproviders may respond to patients with a BPD with fear and anger. This is particularly so, because, as Lytle, Stagno, and Daly note, the patients' risk of attempting and succeeding in committing suicide is much increased.

If, due to fear or anger, careproviders distance themselves, this is the opposite of what the patients most need. Distancing makes the patients worse and can trigger their feeling acutely suicidal, because it may leave them feeling abandoned.[9] I shall now describe this in somewhat more detail.

How Careproviders May Respond

Careproviders who see a patient like the one who swallowed the knife blade may have strong feelings of fear and anger, which may reduce their capacity to care for patients. Later in this essay I will outline new research findings that suggest that careproviders may have greater capacity to control, and even to eliminate, such fear, at least over the longer run, than previously known.[10] This capacity may extend to fear in the short term, and to anger, as well.

The research suggests that people may actually be able to erase fearful memories, rather than being able to just suppress them. This is critically important, because if fearful memories remain with us, as they were thought to do before this research was reported, they may harm patients in two ways: first, they may reemerge and cause distancing later, or they may "fester" and cause distancing "all of the time."

The second finding is of great importance: that feelings of fear cannot be erased when a feared outcome remains uncertain.[11] This is more likely the case for patients who are "stably unstable" or who are "chronically suicidal."[12] Fearful memories may stem from a careprovider's feelings of empathy; that is, the stronger a careprovider's fearful or angry feelings are, the more likely it is that the hurt is caused by imagining what a patient has been—and still is—going through.

Medical students and physicians in training often are told that they shouldn't take their patients' problems "home with them." But such a capacity to "compartmentalize" one's feelings may, in part, be genetically based. As a geneti-

cist once said to me, for example, "Not all people can, to the same degree, argue with their spouse over breakfast and then carry on later at work as if nothing had happened." Some careproviders are much less successful than others at not taking patients' problems home with them. If so, these may be the careproviders who are more vulnerable to feelings of fear and anger. These careproviders, who are the most empathic, may be those who most distance themselves. They may be most likely to unconsciously try to justify such distancing, to wrongly rationalize that treatment would be futile. Thus this sequence may include fear and/or anger, followed by avoidance, rationalization, and denial.

Avoidance

People typically respond to fear and anger by avoiding cues that re-elicit the painful feelings. Avoidance "rewards them" by giving them relief from their pain, by enabling them to avoid cues that would re-evoke painful feelings. As noted above, new research reports that we may be able to erase the fearful memories that feelings create. If we can recall the memories, we may be able to "update" them so that the memories are changed and rendered "safer."[13] This strips them of the capacity to continue to cause us pain—pain that can effect how we treat our patients. A capacity to erase fearful memories makes sense from the an evolutionary standpoint: to survive, our ancestors had to be able to update "old" fearful memories. For example, our ancestors might have needed to forage for food in places where they had previously experienced fear. If they couldn't update and make their memories safer, the number of places they would be able to forage would shrink and they might starve. The new research suggests that a way we may be able to overcome and erase fears is to "revisit" them in some way, and see them with a different, safer meaning. Thus, there may be a second harm if previous experience with patients evokes fear and causes us to distance ourselves from or avoid current patients: there may no new experiences allowing us to update, render safe, and erase fearful memories. We will not have the opportunity to "self-heal."

When a careprovider concludes that a patient's treatment is futile or doesn't warrant its cost, it may be the result of distancing and avoidance. And the feelings may re-emerge later or "fester."

Rationalization

We are all capable of rationalizing what we feel when we are entirely in error, without being aware that we are doing it.[14] Thus, if a careprovider avoids a patient due to fear or anger that is based on previous painful experience with a patient, the careprovider may rationalize these feelings, so that they seem justifiable. For example, a careprovider might find an explanation to justify not treating a patient, saying treatment is futile or not worth the cost.

Denial

Likewise, we may all engage in "denial" and not know it. V.S. Ramachandran states, for example, that we may engage in denial at "any given moment of our waking lives." He says that doing this lies at the heart of our human nature; we do this whether we are "temporarily ignoring bills" or "defiantly denying our death."[15] He believes that we may do this so that our brain can provide us with a "coherent perspective." He proposes that we need to be able to make up for ourselves a false yet believable "belief system" or story.[16] Such denial occurs without our knowing or willing it. A part of the brain that produces denial may have been located.[17] This "model" of denial, Ramachandran concludes, rests on the notion that we need to be able "shut off information" at times, to eliminate threats that otherwise would be too overwhelming to us.[18] Denial may be the last straw that impairs a careprovider who wants to help a patient with a BPD. The careprovider may be unable to see there is hope for the patient, and how much hope there actually is.

WHAT, IDEALLY, PATIENTS WITH A BPD NEED

When careproviders have continuing fear or anger, it may interfere with their ability to give patients the care they need to get better. Fester-

ing fear may (whether it is unconscious or not) result in careproviders' distancing themselves from patients, as noted above. What might ideal care for these patients be?

How Careproviders Might Ideally Respond at First Meeting a Patient with a BPD

Ideally, careproviders should respond in a way that communicates that they are not judging a patient with a BPD, that they are committed to doing all they can for the patient, and that there are grounds for hope. Not judging patients may be the hardest. For example, careproviders might believe that a patient is "responsible for his or her actions," and tell the patient this. Lytle, Stagno, and Daly note, for example, that they believe this when patients have dissociation that is less severe, but this may or may not be so. Patients may say that they can't predict or control what they do. I will return to the practical issue this raises when I discuss "contracting for safety," shortly.

What might be the connotation to these patients of saying this? Patients may see this, implicitly at least, as blaming them. This especially may be the case when patients feel that they lack control.[19] What might a careprovider say to a patient like the one who swallowed a knife blade on first meeting? Perhaps: "I'm so sorry you did this and that you will have to go through our removing it," and, "It may be that, later, together, we can learn better what might have moved you to do this. If we can, we may know better what you need to know so it won't happen again."[20] Perhaps, in addition, "How do you feel, right now? How bad is your pain?" And finally, "You have been through this before. Is there anything you can tell us that could make your experience better, or less worse?"

The Key Principle in Treating BPD Patients

A key principle—beyond initially being nonjudgmental, conveying commitment, and communicating hope—is starting from wherever a patient "is at," as opposed to rigidly adhering to a standard approach. This may involve going outside one's "usual" way, as opposed to insisting that a patient "comes to us." One example would be a careprovider's considering coming to a patient's home. That is, should a careprovider, with or without other members of the team, ever come to the patient's house, if a patient will not come to the careprovider?

Coming to a patient's home, even only once, may be enough to enable the patient to succeed. For example, in one instance, members of a care team told a patient, over the phone, that unless he came in, they would *all* come to his home. He pictured the team, he said later, all sitting around him as he lay in bed. He came in. This approach applies equally to other sorts of patients. For example, patients addicted to alcohol may refuse to go to Alcoholics Anonymous, especially initially, on their own, but may be willing to go if someone will pick them up and go with them. A careprovider, in this instance, most likely, should do this.

What Careproviders Might Additionally Consider When Patients Are Suicidal

When patients with a BPD are suicidal, going "the extra mile" may be especially important to try to keep them from suicide. One could say that this is wholly their choice, but this may be mostly self-serving and not quite, entirely, the case. It is true that careproviders are most vulnerable to responding to such patients with fear and anger. I will give three examples of going "the extra mile," of interventions that careproviders might want to consider in such circumstances. Readers might want to imagine the difficulty they might feel in trying to decide whether to go the extra mile in these cases.

Not Hospitalizing Patients

There is a high risk that these patients will become worse if hospitalized, especially for longer periods of time.[21] Careproviders who want to help them may have to be willing to take the risk of not hospitalizing them, even when they feel suicidal. I recall a patient I saw who said that she surely would kill herself if I hospitalized her involuntarily—she had already tried out the knot she would use to hang herself. I arranged with her to not hospitalize her. Instead, I called her several times throughout the day. Luckily, this succeeded. In other situations, similar sharing of decisions with patients

may be optimal, although, likewise, more "risky." An example might be that of a careprovider who does not push to start a patient who has schizophrenia on an antipsychotic medication when the patient opposes it. Some advocates of sharing decisions and not starting a medication under these circumstances believe that this approach preserves and even improves the patient/careprovider relationship, and note, "Some [psychiatrists] believe that . . . paternalism is often necessary. . . . Our bias is to adopt a radically more collaborative style."[22]

Phone Issues

A second set of difficult ethical and clinical issues involves use of the phone: Should a careprovider always be available? What should a careprovider say when a patient, feeling suicidal, calls? How much should a careprovider say in advance about what she or he will say if the patient calls feeling acutely suicidal? For example, a careprovider may not always want to be available by phone; among other reasons, this can be very stressful. Should a careprovider for this reason—as a "tie-breaker" for them—decide to not always be available?[23]

If a careprovider is not always available to patients for this reason, should they tell patients this? How should a careprovider respond when a patient calls, feeling suicidal? Should the careprovider try to "talk the patient down"? Or should the careprovider recommend that the patient go at once to an emergency room? If a careprovider tries to talk a patient down it may fail, and the careprovider, most understandably, may fear this. But if a careprovider won't try to talk the patient down, and tells the patient this ahead of time, the patient may see no reason to call, and the risk that the patient will commit suicide may increase.

Contracting for Safety

Not infrequently, careproviders ask patients with a BPD to agree in writing that they will not try to end their life. This is called "contracting for safety." Hospitals often "require" careproviders to ask patients to sign such an agreement. But some patients respond that they cannot in good faith say they will not attempt suicide in the future, if they experience an overwhelming impulse to do so. This creates two problems. First, careproviders may be asking patients to agree to do something that they don't think they can do. Second, even if patients feel they can do this, being asked to sign an agreement, as if it were a legal contract, may impair their trust. There are no data indicating that these contracts reduce the risk of suicide.[24]

There is anecdotal evidence from careproviders that, if they pressure patients to sign such a document, they will lose the patients' trust. For example, one careprovider asked a patient to sign a contract prior to releasing him as an outpatient, and the patient refused. The careprovider said, "Okay," and the patient did well. The careprovider, however, continues to ask himself, to this day, "What if this patient had killed himself?" Given this, should careproviders ask patients to "contract for safety"? Should they explain that they are asking to meet the "demands" of the hospital? It may be that not pressuring patients or explaining why they are asking for a contract is the best way to maintain a relationship with a patient, but, if they do explain, they may have to do it "in the closet" to avoid later questioning from their hospital.

IMPLICATIONS FOR CAREPROVIDERS

Careproviders may feel fear and anger at patients for many reasons. They may feel fear or anger, for example, because they care very deeply about their patients. Alternatively, careproviders may have such feelings for many other reasons. For instance, they may fear "the law."

This may be one reason careproviders ask patients to sign anti-suicide contracts—they may hope that this will protect them legally. Such fear—as for any fear—may cause careproviders—as all people—to reason wrongly. For example, the cardinal rule for not being sued is, "Always do what is best for your patients." Careproviders may not do this, but instead do what they think will best protect *them*.[25] This may unwittingly leave them at a much higher risk. For example, careproviders may fear disapproval or even censure from colleagues for providing treatment to a patient that is futile or

does not warrant the cost, as the careprovider felt in the case of the patient who swallowed a knife blade.

Careproviders may be able to "erase" a fear, as I noted above, by returning to a fear memory and find a safer meaning in it. Daniela Schiller, a researcher in this area, describes two possible ways to do this: by retelling one's "story" in a way that puts one "more in charge," and through creating artwork.[26] That makes sense. It's what children do when they conquer feelings of fear and anger by retelling their stories using puppets or by making drawings. An adult example of this may be Isabelle Allende, the critically acclaimed author, who says writing helps with her "demons" and "obsessions."[27]

What might careproviders do to try to reduce feelings of fear or anger in response to patients like the one who swallowed a knife blade, when they first occur, and then later, over time? There are many things to try, both with and without the help of others. To consult with colleagues and then document this is the common and probably soundest advice. It has been recommended specifically for careproviders who treat patients with a BPD.[28] There may be other ways that can enable careproviders to acquire the emotional benefits they want—as well as relief—on their own. They might retell their story, as Schiller suggests, as in a diary. The test of whether or not they have succeeded would be how they feel.

Reversal

What might careproviders try on the spot, for example, the first time they are see patients with a BPD? They can try "turning the tables." They can ask themselves what they would feel in the patient's shoes. Doing this is not that unusual. But they could enhance the effect within themselves by imagining sitting in the patient's chair and talking to a careprovider. This approach is one that Raymond Corsini, a therapist for "some 50 years" or so, has used with patients who were "rejecting" him. He asked them to switch chairs and then left the room, saying, "When I return, you will be me and I will be you." He then acts as he would if he were this "client." When this procedure works," he says, it "works well," and, sometimes, he adds, this "reversal" has worked "miracles."[29]

Understanding

Numerous studies have documented that it is easy and common to presume, when we see another person "misbehaving," that the other person's behavior is entirely attributable to who the person *is,* rather than to the person's life circumstances.[30] As careproviders, we can seek to better understand others who seem to be acting badly. Paris, a leader in treating patients with a BPD, exemplifies this in his work to understand why some patients with a BPD are chronically suicidal.[31] He concludes that the patients may want to escape suffering—which may be easy to imagine, thinking about the patient who repeatedly swallowed a knife blade. These patients may feel that careproviders will not sufficiently try to help unless they attempt suicide, and they may want, by doing this, to feel more in control. This last goal is in line with the new research findings that are cited above.

In this context I think of so-called "cutters"—patients who cut themselves. They often report that cutting helps them to feel better, by helping them to feel more in control. Steven Levenkron, a psychotherapist, asks, "What priority exists for the self-mutilator, or cutter, which allows her to bypass her body's own defenses and ignore the pain?" and answers that a cutter must experience her own "necessities, urgencies and dangers" as being as intense and real as the "sight of a drowning child." The cutter then feels the need to rescue the child, even from cold water,[32] "even in ice cold water."

In this regard, I think of how an attempt to understand helped a patient who had been terrified of an in-law. She learned that this in-law had been abandoned by both parents, at separate times, when he was a child. Then, she said, she felt "only compassion" for him. When patients with a BPD are impulsive (or as psychotherapists say, "act out"), it is often, experts believe, in response to what they perceive as another person's "slighting" them. This presents a strong rationale for a careprovider to continue to see such patients after they have tried to take their life or, like the patient above, have swal-

lowed a knife blade—again. A careprovider who is willing to continue to see such patients can explore with them what the patients have experienced as a deep, interpersonal slight—especially since the careprovider may be perceived as the source of the slight! The above patient's threatening her careprovider may be an example of this.

Humor—A "Quick Fix"

There is a possible "quick fix." A careprovider may be able help a patient see how he or she is reacting, or overreacting, by using a different, humorous point of view. This worked miraculously with one of my patients. He came to see me in a panic. He was scheduled to have surgery to replace a knee, but he had just lost confidence in his surgeon, because, he said, she had "mocked" him. I asked him what had happened. He said that while he was sitting in the surgeon's waiting room, another patient coughed "on him," not covering his mouth. My patient said that he feared he could get pneumonia, and told this to the surgeon's receptionist. When he then saw the surgeon, she smiled and then turned her head away and coughed loudly. "But it was a fake cough," he said; "she was mocking me." Then he told me he had also seen patients in the surgeon's waiting room who had tattoos. "Maybe this surgeon isn't so good," he said, "Maybe these patients just can't afford anyone better!"

I asked him to "just bear with me" for a moment. I clicked on a ball point pen, rolled up a sleeve, and started to draw a tattoo on my arm. "I got it," he suddenly said, roaring with laughter. "She was not laughing *at* me. She was laughing *with* me. She was trying to put me at ease." He said he was all better then. Actually, he said, he was "*more* than better." He left, and had the surgery. With, of course, this surgeon.

CONCLUSION

Careproviders may feel fear and anger toward patients, and, as a result, even unwittingly, cause them harm, by distancing themselves, which may make the patients feel worse. A careprovider may do this, unknowingly, by telling him- or herself that treating such patients is futile or not worth it. Careproviders may then rationalize this erroneous conclusion and deny any data that refute it.

Careproviders who are aware of this risk may try to overcome these feelings. New research suggests this may be more possible than previously understood. Careproviders might try to change their feelings of fear and anger as they become aware of them or try to "consult and document" as a response. They could, alternatively, try reversing roles with a patient, or try to understand things that don't make sense to them, or seek to view how they are reacting from a different, possibly even humorous point of view. Most remarkable, and hopeful, in this regard, is the extent to which their trying any of these things may enable them to succeed.

Here is a final example of how this may work, from one of my patients. Her husband has Alzheimer's disease, and was often nasty to her. She retaliated by being nasty back, reasoning, "He's nasty to me on purpose." Over time, I tried to convince her this might not be the case, and she perhaps could give him the benefit of the doubt. She decided she would try it. I saw them both recently. Now he doesn't remember what he has said as soon as he's said it, but still says, smiling, to her, "I love you." When I left them, I said to her, "He is so lucky to have you." She said, "No. *I* am so lucky I have *him*."

MASKING

I have changed details of examples to protect the identity of individuals.

NOTES

1. The "hidden" curriculum, as used here, refers to a cultural process in medical education through which medical students learn value judgments that "enable them to act within a moral economy of care." R.T. Higashi et al., "The Worthy Patient: Rethinking the 'Hidden Curriculum' in Medical Education," *Anthropology & Medicine* 20, no. 1 (2013): 13-23, 14.
2. Ibid., 15.
3. Ibid.
4. Ibid., 22.

5. This diagnosis, as many in psychiatry, is a category made up of many symptoms, as opposed to a proven entity.

6. This may be have occurred, alternatively, because the initial careproviders weren't familiar with the relatively recent findings suggesting that these patients have a much better prognosis than previously believed. This new data is provided in S. Lytle, S.J. Stagno, and B. Daly, "Repetitive Foreign Body Ingestion: Ethical Considerations," in this issue of *JCE.*

7. K.R. Berenson et al., "The Rejection-Rage Contingency in Borderline Personality Disorder," Journal of Abnormal Psychology 120 (2011): 681-90.

8. C. Baum-Baicker and D.A. Sisti, "Clinical Wisdom and Evidence-Based Medicine Are Complementary," *The Journal of Clinical Ethics* 23, no. 1 (Spring 2012): 13-27, 20.

9. J. Paris, "Half in Love with Easeful Death: The Meaning of Chronic Suicidality in Borderline Personality Disorder," *Harvard Review of Psychiatry* 12, no. 1 (2004): 42-8.

10. D. Schiller, "Extinction During Reversal and Reconsolidation of Rear Memories is Different from Standard Extinction," presentation at the 8th Annual Conference on Amygdala, Stress, and PTSD, Uniformed Services University of the Health Sciences, Bethesda, Md., 23 April 2013.

11. In Schiller's presentation, this point concerning uncertainty was underlined in her PowerPoint presentation. This was the only underlining in the presentation. Ibid.

12. See Paris, note 9 above.

13. See Schiller, note 10. "What could we do with such a technique? Mind reading," from D. Schiller, "Affective Neuroscience: Tracing the Trace of Fear," *Current Biology* 21, no. 18 (27 September 2011): R 695-6, R695.

14. J Verwoed et al., " 'If I Feel Disgusted, I Must Be Getting Ill': Emotional Reasoning in the Context of Contamination Fear," *Behaviour Research and Therapy* 51, no. 3 (March 2013): 122-7.

15. V.S. Ramachandran and S. Blakeslee, *Phantoms in the Brain* (New York: Harper Perennial, 1998), 136. Denial is most common in certain kinds of strokes, but it may occur in people who have no brain damage. For example, women, on rare occasions, come into the emergency room, "complaining of" stomach pain, but are delivering a baby and haven't known they are pregnant.

16. Ibid., 134.

17. Ibid., 142.

18. Ibid., 151.

19. Dialectical behavior therapy, a leading treatment for patients with a BPD, requires therapists to meet, often, together, to examine harmful assumptions and unwitting connotations that they may be making, that they may not know they are harboring, and may unwittingly convey to patients. B. Long and S. Witterholt, "An Overview of Dialectical Behavior Therapy," *Psychiatric Annals* 43, no. 3 (April 2013): 152-7, 154.

20. This response may be optimal for patients who have addictions, since their "relapsing" may be triggered by cues that they don't know exist.

21. See Paris, note 9 above.

22. C. Gordon and M. Green, "Shared Decision Making in the Treatment of Psychosis," *Psychiatric Times* 30, no. 4 (April 2013): 33-4, 48, 33.

23. It has recently been reported, anecdotally, that patients may do better if they can always call. See note 19 above, p. 156.

24. M. Goodman et al., "Suicidal Risk and Management in Borderline Personality Disorder," *Current Psychiatry Reports* 14 (2012): 79-85.

25. In one study, for example, 85 percent of careproviders said they had done this. R. Krawitz and M. Batcheler, "Borderline Personality Disorder: A Pilot Survey about Clinician Views on Defensive Practice," *Australas Psychiatry* 14 (2006): 320-2. Careproviders may also believe that if patients make this "promise," they will be more likely to honor it and not take their life.

26. See Schiller, note 10 above.

27. E. Wax, "Love, Liberation, and Achoo!" *Washington Post,* 14 May 2013, C1-4, C4. For example, her daughter, Paula, died, at age 28. Allende wrote a memoir about her.

28. T.G. Gutheil, "Suicide, Suicide Litigation, and Borderline Personality Disorder," *Journal of Personality Disorders* 18 (2004): 248-56.

29. R.J. Corsini, "Turning the Tables on the Client: Making the Client the Counselor, in *Favorite Counseling and Therapy Techniques,* ed. H.G. Rosenthal (New York: Brunner-Routledge, 1998), 55-7.

30. T. Brosch et al., "Neural mechanisms Underlying the Integration of Situational Information into Attribution Outcomes," *Social Cognitive and Affective Neuroscience* (9 May 2013.)

31. See Paris, note 9.

32. S. Levenkron, *Cutting* (New York: Norton, 1998), 41.

Features

Repetitive Foreign Body Ingestion: Ethical Considerations

Sarah Lytle, Susan J. Stagno, and Barb Daly

ABSTRACT

The treatment of persons who frequently present to the healthcare system following repetitive foreign body ingestion has been addressed in the psychiatric literature. However, there has been little exploration of the ethical considerations regarding the treatment of these patients. The complexity of their medical and psychiatric presentation raises fundamental ethical questions regarding the duty to treat, patient autonomy, justice, and futility. Careful ethical analysis is particularly important in this context, since the frustration that medical professionals may feel in response may lead to false assumptions that can negatively impact patient care. A careful exploration of these questions can increase awareness and understanding, which in turn can lead to improved treatment of patients who repetitively ingest foreign bodies. Care for patients who inflict self-harm, particularly by repetitive foreign body ingestion, is not futile. The patients have a right to treatment and are entitled to resources. Efforts should be made to provide a more comprehensive treatment approach to these patients.

Sarah Lytle, MD, MS, is a Fellow at the University Hospitals Case Medical Center Department of Psychiatry in Cleveland, Ohio, *sarah.lytle@uhhospitals.org.*

Susan J. Stagno, MD, is an Associate Professor of Psychiatry and Bioethics at Case Western Reserve School of Medicine in Cleveland.

Barb Daly, PhD, RN, FAAN, is the Gertrude Perkins Oliva Professor in Oncology Nursing and Clinical Ethics Director at University Hospitals of Cleveland at Case Western Reserve University.

BACKGROUND

A 19-year-old female with a history of repetitive foreign body ingestion (RFBI) and removal presented to the emergency room after swallowing the blade of a knife. Following admission, a physician approached the patient and questioned the patient's motives for swallowing objects and implied that she was inappropriately using up valuable resources. The patient became agitated and threatened the physician with bodily harm. The consulting surgeon indicated she did not want to do surgery because she was concerned about her safety and the safety of her staff. Transferring the patient to another hospital was suggested. The perceived futility of providing treatment, since the patient had presented repeatedly after ingesting foreign objects that required multiple expensive interventions, and would likely present again, was also expressed.

The treatment of patients who present with RFBI may involve a variety of healthcare workers including emergency room and security personnel, gastroenterologists, surgeons, anesthesiologists, nursing staff, and psychiatrists. A

recent retrospective case series in an urban hospital reported that 92 percent of ingestions were intentional, 85 percent were in psychiatric patients, and 84 percent of the patients had a history of foreign body ingestion.[1] Of the 33 patients who presented with RFBI, 79 percent had psychiatric diagnoses coded in their medical record.[2] RFBI may be a presentation of various psychiatric disorders including impulse control disorder (ICD), malingering, borderline personality disorder (BPD), pica, or psychosis.[3] Impulse control disorders are characterized by the failure to resist an impulse to perform an act that is harmful to the individual, in this case swallowing a foreign object.[4] An increase in tension may be experienced before committing and relief may be felt following the act. In malingering a patient feigns symptoms intentionally for an external reward.[5] For example, a malingerer might swallow an object with the explicit intention of being hospitalized in order to avoid incarceration. BPD is characterized by impulsivity, and patients may display repetitive self-injurious behavior such as swallowing.[6] Pica involves intentional ingestion of non-nutritive substances. In psychotic disorders, self-harming behavior may occur as a result of disordered thinking or paranoia. Self-injurious behavior most commonly occurs in patients with BPD.[7]

Regardless of the etiology of RFBI, the management of such cases is often complicated. It is not uncommon for patients' characteristics—including anger, impulsivity, entitlement, aggression, repetition, dependency, ingratitude, and manipulation—to elicit strong countertransference reactions in treatment providers.[8] Patients with RFBI combine self-punishment and the punishment of others and essentially force physicians to provide care, placing the patient in a powerful position.[9] Intervening in the actual act of foreign body ingestion is nearly impossible, and, following ingestion, patients have considerable leverage.[10] Countertransference may be manifested as feelings of frustration, anger, futility, foreboding of recurrence, helplessness, vengeance, and apathy by caregivers, with resultant feelings of wanting to blame, punish, and withdraw from care of the patient.[11] This combination of patients' traits and providers' reactions can result in suboptimal treatment and raises questions about the justification for limiting the scope of a duty to provide care for patients who present with RFBI.

This article examines concepts related to the duty to treat, patient autonomy and intentionality, allocation of resources, and futility in regards to patients with RFBI. A careful exploration of these questions can lead to awareness and understanding, which in turn can lead to improved treatment of patients who repetitively ingest foreign objects. Finally, suggestions are made for providing a more comprehensive plan of care for this population.

DUTY TO TREAT

When considering patients who present with repeated acts of self-harm, it is not surprising that the question arises as to whether or not we, as physicians or other healthcare workers, have a duty to continue to treat. However, medical situations in which patients engage in indirect self-harming behavior are not uncommon. Common scenarios might include non-adherent insulin-dependent diabetic patients who repeatedly present in diabetic ketoacidosis or smokers who continue to smoke despite a diagnosis of emphysema. In these cases, patients are engaging in repetitive self-harming behavior, yet they do not elicit strong countertransference reactions like those seen with RFBI. Perhaps patients who present after ingesting a foreign body are more frightening and elicit stronger emotional reactions because their behavior seems so bizarre and they present in the actual act of self-harm (for example, with the blade of a knife in their gastrointestinal tract).[12] Additionally, patients who present with RFBI are often quickly labeled as "psychiatric patients" and may be stigmatized.

A discussion of duty to treat also raises the question of legal requirements to treat. Although we are aware of no court cases involving the duty to treat patients with RFBI, this concept has been addressed in other areas of medicine. The question of duty to treat has been most extensively discussed in the dialysis literature, since non-adherence in patients with end-stage

renal disease can be life threatening and expensive. A number of court cases have centered on the debate over whether or not there is a duty to treat patients who do not engage in their own treatment, are consistently non-adherent, and cause upheaval on dialysis units.[13] The law has upheld that the duty to treat is not absolute and can be foregone in certain cases when a patient becomes threatening, abusive, or disruptive to the care of other patients.[14] Nevertheless, ethically, even under these circumstances, an attempt to resolve conflict is imperative so that a patient can be adequately treated. In addition, if one accepts that psychiatric dysfunction contributes to self-damaging behavior, denying treatment based on a psychiatric disorder is prohibited under the Americans with Disabilities Act, which prohibits, among other things, discrimination on the basis of a disability by healthcare providers.[15] Notwithstanding a legal duty to treat, psychiatric disorders including disorders such as BPD are treatable, and there is an ethical obligation to provide treatment if it will benefit the patient.

The possibility of transferring care to a different physician or facility may arise when interactions become strained between a patient with RFBI and a healthcare provider. Of course, transferring a patient may not be possible if there is an acute risk of serious imminent consequences or death (for example, the ingested knife has perforated the bowel) or if there are no other providers available. Refusing to provide treatment for a patient may be justified if a physician lacks the requisite competence, if there are limited clinical or institutional resources, or if a physician has a strong moral or religious objection to the kind of treatment requested or required.[16] While withdrawal from a patient's care may be acceptable in situations such as these, the prohibition against the abandonment of a patient is relatively absolute. In addition, while an individual clinician may justifiably withdraw from participating in care, institutions have a fiduciary duty to patients. Both individual providers and institutions are obligated to ensure that an alternate source of care is available before withdrawing or discharging a patient.

AUTONOMY AND INTENTIONALITY

In analyzing the duty to treat and the corollary right of a patient to receive treatment, the concepts of autonomy, intentionality, and responsibility are linked, and all play a role. When we assess an individual as lacking autonomy, we are claiming that the person lacks the ability to make reasoned choices consistent with authentic values. While the non-autonomous individual may be physically capable of making a decision and acting on the choice, we would not assign responsibility to that person for the action and its consequences. Further, when caring for a non-autonomous person, duties of beneficence—to promote the "good" or well-being of the person—take precedence. This might include restraining or involuntarily hospitalizing that individual. Thus, consideration of the extent to which we view RBFI as an intentional act of an autonomous person will have implications both for our analysis of the duty to treat and, potentially, for justification of an involuntary hospitalization.

A full exploration of the application of the concept of intentionality would require examination of all of the components of mental states in a causal chain leading to action, including judgment, commitment, volition, as well as intentionality.[17] There are also legal constraints and requirements that would be relevant and possibly determinative. For our purposes, though, we are more concerned with the clinical reasoning that should be brought to bear in directing care decisions.

One potential approach is to consider the behavior of repeated ingestion as a kind of addiction. The literature suggests that patients who are addicted to drugs and alcohol cannot control their use due to their dependency and have lost their autonomy, as it relates to use of the addictive substance.[18] The goal of rehabilitation in this case is to restore the patient's autonomy.[19] Similarly, in self-injurious behavior the patient may not be responsible for his or her actions if these behaviors are a manifestation of the psychiatric or personality disorder. Difficulty controlling and expressing emotion (secondary to traumatic childhood experiences,

for example) may underlie the behavior of RFBI.[20] If a patient has little control over behaviors (the volitional component of action), then it is less appropriate to deny treatment.[21]

As previously mentioned, RFBI may be a manifestation of BPD. One of the prominent features of BPD includes impulsivity that implies acting without adequate rational thought about relevant facts (the judgment component of the action). The expected consequences of an action likely play some role in the patient's decision making and may fulfill a goal (that is, avoiding abandonment or communicating anger). In addition, in BPD it is not clear if an action is irresistible or merely unresisted, with the impulse simply being stronger than any other motivation at that time. People who self-harm may experience dissociated states when under stress, possibly secondary to a history of childhood abuse, trauma, or neglect. Dissociation can cause disturbances in memory and manifest as derealization (a feeling that the external world is unreal), depersonalization (feeling of being detached from oneself) and hallucinations. Impulsivity and mild disassociation do not vitiate the patient's responsibility, since the action (swallowing) in response to powerful emotions and desires is secondary to rational decisions, and the patient is responsible for making the decision to tolerate difficult emotion or act impulsively.[22]

The concepts of responsibility and competency have been explored with regard to patients with BPD, and treatment is generally based on the premise that they are autonomous.[23] "When a patient is able to function competently in the world and then finds herself cutting her wrists and overdosing over some trivial disappointment, she struggles to maintain her dignity, denying the seriousness of her recent behavior and accusing helpers of humiliating her. The only justification for depriving that patient of her liberty is the belief that she has regressed so severely that her adult, functional self could not re-emerge to prevent her from killing herself, or, very rarely, someone else."[24] An inability to control specific self-harming behavior, in and of itself, does not render an individual incompetent. The patient may be autonomous while it is only the act that is non-autonomous. If it is just the decision (or act) that is non-autonomous, then we may have the obligation to try to prevent or interfere with only the act itself, and withholding treatment for a non-autonomous act would be a violation of our ethical duties, as would abandoning the patient. In addition, if we question a patient's autonomy, the goal of treatment should be to restore autonomy, again providing treatment, which in turn would be designed to restore the patient's capacity for responsibility.[25]

ALLOCATION OF RESOURCES AND FUTILITY OF CARE

It is sometimes necessary and morally required to limit care to assure a just distribution of finite resources and non-maleficence to other patients and staff.[26] RFBI tends to be recurrent and resistant to treatment.[27] Of patients who inflict self-harm, 86 percent will repeat a self-harming behavior within one year, and 84 percent of people who present with RFBI have presented previously with similar behavior.[28] Some argue that patients can not claim greater than their "fair share" of resources, and that physicians should disallow futile treatment to conserve and redirect finite resources to those who would most likely benefit.[29]

The repetition of self-harming behavior can instill a sense of futility in healthcare workers involved in their treatment. Clearly, removing a foreign object from a patient's gastrointestinal tract is not physiologically futile, but is the RFBI patient's long-term outcome so poor that it makes sense to not provide treatment? The American Thoracic Society has put forth recommendations that treatment is futile and can be withheld if it will lack medical (physiologic) efficacy and if it will not lead to meaningful survival (as judged by a patient's personal values).[30] No such guidelines exist in the psychiatric world. While there are no studies that specifically follow the long-term outcome of RFBI patients, one study has reported that, over a 16-year period, 78 to 99 percent of patients with BPD had remission of their symptoms (with 10 to 36 percent eventually having a recurrence of

symptoms).[31] Thus, while it can be frustrating and expensive to care for patients with RFBI, there is at least some evidence that treatment is associated with a meaningful chance of recovery. In most cases, then, claims of futility will not provide justification for limiting the duty to treat.

At this time, there is no social consensus about healthcare allocation and we have no way to assess "fair" limits on treatment. This means that we may not pick and choose the patients on whom we will impose limits. If there were a standard way to judge effectiveness or to set limits on how much we spend on any one person, it might be theoretically justifiable to do so in these cases, but until we are willing and able to apply rules of allocation consistently, we have inadequate justification for applying them in these situations.

In addition, in a comprehensive approach to a patient, it is important to differentiate between treatment and care. In psychiatry and other fields, caring for a patient is never futile. The treatment of a patient may involve addressing specific medical or psychiatric issues with behavioral or pharmacologic management that is based on evidence-based approaches. Caring for a patient goes beyond this and encompasses a broader spectrum of investing in the outcome.

CONCLUSION

Thus far we have argued that patients who inflict self-harm, particularly by RFBI, have a right to treatment; they should be regarded as autonomous, at least legally, if not ethically (although the specific act of ingestion may be nonautonomous); they are entitled to resources; and providing care to them is not futile. We are left then with the question of what to do with patients who continue to seek care following repetitive self-harming behaviors such as the ingestion of foreign objects. Unfortunately, there are widespread and significant limitations within the current mental health system.

We suggest that more comprehensive care must be provided for these patients, based on a greater awareness of the complexity of these behaviors and establishment of effective communication. While this patient's primary presentation involves ingestion of a foreign body, her social and medical history is certainly more complicated and thus requires insight on the part of the physician to design a comprehensive approach to treating her. A thorough assessment and attempt to address medical, psychosocial, personal, family, and drug use issues must be made.[32] The use of counseling, pharmacologic treatment, education, utilization of outpatient mental health resources, and social support should all be maximized.

Patients who lack decision-making capacity or are at risk of imminent self-harm may be involuntarily hospitalized to prevent them from harming themselves. Even when it is available, inpatient psychiatric hospitalization actually may have a negative effect due to positive reinforcement of the patients' behavior.[33] Attempts to decrease the swallowing of foreign objects in the future has been mostly unsuccessful, and psychiatric treatment alone is often not effective in preventing future RFBI.[34] Patients who ingest foreign objects may not intend to kill themselves, but unintentional death may occur. A careful assessment of capacity, a determination as to whether the patient was attempting or not attempting suicide, and an evaluation of imminent risk of self-harm (for example, suicide) must be performed. Studies indicate that patients with BPD are at a high risk for completed suicide, with a rate of up to 10 percent.[35] Nearly 50 percent of completed suicides have a history of attempted suicide within the past 12 months, and 25 percent have an episode of deliberate self-harm in the year before death.[36]

If hospitalization is necessary, possible interventions to increase the effectiveness of the hospitalization include:

- outlining and spelling out protocols/approaches that are accessible to the emergency room for the next time the patient presents
- having plans to re-admit the patient to the same division/location each time for consistency of care and assurance that the team won't have to start over
- identifying a consistent and well-informed medical/psychiatric team with whom the

patient will be involved during future admissions
- planning pre-emptive staff meetings with each admission to avoid splitting among the staff (in which different members of the staff develop opposite opinions of the patient) and to deal with the inevitable frustration of the staff.

In addition, improving outpatient care with community-based models that emphasize inclusion of the patient in the treatment plan; regular patient contact through phone calls, home visits, and crisis contacts; limiting inpatient treatment; and increasing education for all personnel involved in treating patients with deliberate self-harm have been reported to be effective in reducing the number of admissions and the patient's length of stay.[37] A greater understanding of ethical issues and their application to patients with RFBI can enhance caregivers' ability to provide optimal care and improve patients' outcomes.

MASKING OF THE CASE

All of the details in the background narrative that might identify any person involved have either been removed or altered so that the substance of the issues related may be presented without infringing privacy or violating confidentiality.

NOTES

1. R. Palta et al., "Foreign-body ingestion: characteristics and outcomes in a lower socioeconomic population with predominantly intentional ingestion," *Gastrointestinal Endoscopy* 69 (2009): 426-33.

2. B.L. Huang et al., "Intentional swallowing of foreign bodies is a recurrent and costly problem that rarely causes endoscopy complications," *Clinical Gastroenterology and Hepatology* 8 (2010): 941-6.

3. D.F. Gitlin et al., "Foreign-body ingestion in patients with personality disorders," *Psychosomatics* 48 (2007): 162-6.

4. *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. (Washington, D.C.: American Psychiatric Association, 2000).

5. See note 4 above.

6. Ibid.

7. J. Gerson and B. Stanley, "Suicidal and self-injurious behavior in personality disorder: controversies and treatment directions," *Current Psychiatry Reports* 4 (2002): 30-8.

8. G. Adler, "The borderline patient in the general hospital," *General Hospital Psychiatry* 3 (1981): 297-300; B.A. Poynter, J.J. Hunter, J.H. Coverdale, and C.A. Kempinsky, "Hard to swallow: a systematic review of deliberate foreign body ingestion," *General Hospital Psychiatry* 33 (2011): 518-24; J.E. Groves, "Management of the borderline patient on a medical or surgical ward: the psychiatric consultant's role," *International Journal of Psychiatry in Medicine* 6 (1975): 337-48.

9. See note 3 above.

10. Ibid.

11. See note 8 above.

12. See note 3 above.

13. D. Orentlicher, "Denying treatment to the noncompliant patient," *Journal of the American Medical Association* 265 (1991): 1579-82.

14. See note 13 above; J. Little and J. Ballarat, "An organizational and community-based approach to deliberate self harm," *Australasian Psychiatry* 17 (2009): 169-70; C.C. Johnson, A.H. Moss, S.A. Clarke, and N.C. Armistead, "Working with noncompliant and abusive dialysis patients: practical strategies based on ethics and the law," *Advances in Renal Replacement Therapy* 3 (1996): 77-86; N.G. Levinsky, E.A. Friedman, and D.Z. Levine, "What is our duty to a 'hateful' patient? Differing approaches to a disruptive dialysis patient," *American Journal of Kidney Disease* 34 (1999): 775-89.

15. 42 *USC* §§12101-12213.

16. V.L. Hood, "Can a physician refuse to help a patient? American perspective," *Polskie Archiwum Medycyny Wewnetrznej* 118 (2008): 368-72.

17. M. Robbins, *Promising, intending and moral autonomy* (New York: Cambridge University Press, 1984).

18. W. Shelton and J.A. Balint, "Fair treatment of alcoholic patients in the context of liver transplantation," *Alcoholism: Clinical and Experimental Research* 21 (1997): 93-100.

19. J. Balint, "There is a duty to treat noncompliant patients," *Seminars in Dialysis* 14 (2001): 28-31.

20. See note 3 above.

21. See note 13 above.

22. A. Bray, "Moral responsibility and borderline personality disorder," *Australian and New Zealand Journal of Psychiatry* 27 (2003): 270-6.

23. J. Little and B. Little, "Borderline personality disorder: exceptions to the concept of responsible and competent," *Australasian Psychiatry* 18

(2010): 445-50.

24. R. Draper, *The Dignity of Risk: Caring in a Different Way*, unpublished course guide, Ballarat Health Service, Ballarat, Vic., Australia, 1999, cited in Little and Little, ibid.

25. See note 18 above.

26. See note 19 above.

27. A.H. James and T.G. Allen-Mersh, "Recognition and management of patients who repeatedly swallow foreign bodies," *Journal of the Royal Society of Medicine* 75 (1982): 107-10; C.V. Soong, C. Harvey, and M. Doherty, "Self-mutilating behaviour and deliberate ingestion of foreign bodies," *Ulster Medical Journal* 59 (1990): 213-6.

28. See note 1 above; C.R. Rodger and A.I. Scott, "Frequent deliberate self-harm: repetition, suicide and cost after three or more years," *Scottish Medical Journal* 40 (1995): 10-2.

29. N. Daniels, "The ideal advocate and limited resources," *Theoretical Medicine* 8 (1987): 69-80; E.H. Loewy and R.A. Carlson, "Futility and its wider implications: A concept in need of further examination," *Archives of Internal Medicine* 153 (1993): 429-31; S.H. Miles, "Informed demand for 'non-beneficial' medical treatment," *New England Journal of Medicine* 325 (1991): 512-5.

30. American Thoracic Society, "Withholding and withdrawing life-sustaining therapy," *Annals of Internal Medicine* 115 (1991): 478-85.

31. M.C. Zanarini, F.R. Frankenburg, D.B. Reich, and G. Fitzmaurice, "Attainment and stability of sustained symptomatic remission and recovery among patients with borderline personality disorder and axis II comparison subjects: a 16-year prospective follow-up study," *American Journal of Psychiatry* 169 (2012): 476-83.

32. See note 19 above.

33. J.G. Gunderson and M.E. Ridolfi, "Borderline personality disorder:Suicidality and self-mutilation," *Annals of the New York Academy of Science* 932 (2001): 61-73; J.P. Paris, "Chronic suicidality among patients with borderline personality disorder," *Psychiatric Services* 53 (2002): 738-42; J.P. Paris, "Is hospitalization useful for suicidal patients with borderline personality disorder?" *Journal of Personality Disorders* 18 (2004): 240-7.

34. Poynter, Hunter, Coverdale, and Kempinsky, see note 8 above.

35. D.W. Black, N. Blum, B. Pfohl, and N. Hale, "Suicidal behavior in borderline personality disorder: Prevalence, risk factors, prediction, and prevention," *Journal of Personality Disorders* 18 (2004): 226-39.

36. T. Foster, K. Gillespie, and R. McClelland, "Mental disorders and suicide in Northern Ireland," British Journal of Psychiatry 170 (1997): 447-52; I.M. Ovenstone and N. Kreitman, "Two syndromes of suicide," *British Journal of Psychiatry* 124 (1974): 336-45.

37. Little and Ballarat, see note 14 above.

The Intensity and Frequency of Moral Distress Among Different Healthcare Disciplines

Susan Houston, Mark A. Casanova, Marygrace Leveille, Kathryn L. Schmidt, Sunni A. Barnes, Kelli R.Trungale, and Robert L. Fine

ABSTRACT

Introduction

The objectives of this study are to assess and compare differences in the intensity, frequency, and overall severity of moral distress among a diverse group of healthcare professionals.

Methods

Participants from within Baylor Health Care System completed an online seven-point Likert scale (range, 0 to 6) moral distress survey containing nine core clinical scenarios and additional scenarios specific to each participant's discipline. Higher scores reflected greater intensity and/or frequency of moral distress.

Results

More than 2,700 healthcare professionals responded to the survey (response rate 18.14 percent); survey respondents represented multiple healthcare disciplines across a variety of settings in a single healthcare system. Intensity of moral distress was high in all disciplines, although the causes of highest intensity varied by discipline. Mean moral distress intensity for the nine core scenarios was higher among physicians than nurses, but the mean moral distress frequency was higher among nurses. Taking into account both intensity and frequency, the difference in mean moral distress score was statistically significant among the various disciplines. Using *post hoc* analysis, differences were greatest between nurses and therapists.

Conclusions

Moral distress has previously been described as a phenomenon predominantly among nursing professionals. This first-of-its-kind multidisciplinary study of moral distress suggests the phenomenon is significant across multiple professional healthcare disciplines. Healthcare professionals should be sensitive to situations that create moral distress

Susan Houston, RN, PhD, FAAN, NEA-BC, is Director of Nursing Research at Baylor Health Care System in Dallas, Texas, *susan.houston@baylorhealth.edu.*
Mark A. Casanova, MD, is Director of the Office of Clinical Ethics and Palliative Care at Baylor University Medical Center.
Marygrace Leveille, PhD, RN, ACNP-BC, is a Nurse Scientist at Baylor University Medical Center.
Kathryn L. Schmidt, MPH, is a Research Associate at the Survery Center at the Baylor Institute for Health Care Research and Improvement.
Sunni A. Barnes, PhD, is Director of the Survey Center at the Baylor Institute for Health Care Research and Improvement.
Kelli R. Trungale, MLS, ELS, is a Medical Writer at the Baylor Institute for Health Care Research and Improvement.
Robert L. Fine, MD, FACP, FAAHPM, is Clinical Director of the Office of Clinical Ethics and Palliative Care at Baylor Health Care System.

for colleagues from other disciplines. Policy makers and administrators should explore options to lessen moral distress and professional burnout that frequently accompanies it.

BACKGROUND

Moral distress in healthcare was first described by Jameton as a phenomenon unique to nursing.[1] He defined moral distress as painful feelings and/or the psychological disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot follow through with that action because of institutional obstacles. Stated more broadly, healthcare professional moral distress may be felt when a professional (who has taken an oath to serve the good of the patient) believes he or she knows the ethically correct action but cannot follow that action because of some constraint, whether interpersonal (with colleagues, patients, or families) institutional, regulatory, or legal.

Most of the research on moral distress has been among nurses, reflecting nurses' feelings about situations of "medical futility" and the overall ethical climate of healthcare delivery.[2] Among nurses, unresolved ethical conflicts and moral distress lessen job satisfaction and cause burnout. In one study, 25 percent of nurses experienced moral distress to the point of wanting to leave a current position; another study revealed that 15 percent of nurses had resigned from a position because of moral distress, and there are other reports that some nurses have left the profession entirely as a result of moral distress.[3]

But what about moral distress among other medical professionals? If one accepts the premise that the best healthcare delivery is provided in a collegial, team-based fashion, it is important that all team members understand not only the technical role of each professional, but also the ethical challenges perceived from different professional standpoints. In the moral life of the healing professions, physicians should better understand how the attitudes they carry or the orders they write affect a nurse, social worker (SW), or other team members; however, other team members should also understand the ethical challenges that physicians perceive.

Although members of multiple healthcare disciplines, including physicians, have privately expressed moral distress to clinical ethics consultants, only one study was found exploring moral distress among physicians,[4] one among SWs,[5] and one among pharmacists.[6] No studies of moral distress among other allied health professionals, including therapists, nutritionists, or hospital chaplains, were found.

With this background in mind, the authors set out to explore differences in the intensity and frequency of moral distress among healthcare professionals (physicians, residents, nurses, SWs, chaplains, therapists, and pharmacists) and how different clinical situations affect moral distress by discipline.

METHODS

Setting

This study was conducted among healthcare professionals working within Baylor Health Care System (BHCS), a nonprofit organization serving approximately 1.4 million patients annually. Based in the Dallas-Fort Worth Metroplex, BHCS comprises 27 hospitals ranging from a 1,000-bed tertiary care referral center to a 50-bed rural hospital, more than 100 primary and specialty care centers, more than 4,500 affiliated physicians, and more than 10,000 employed nurses and allied health professionals.

Instrumentation

Corley and colleagues developed a Moral Distress Scale and documented its validity and reliability in an effort to explore, measure, and better understand nurses' moral distress and its consequences, primarily in the hospital setting.[7] The Baylor University Medical Center Clinical Ethics Committee and BHCS Clinical Ethics and Palliative Care Council modified, adapted, and expanded Corley's Moral Distress Scale to address situations encountered by physicians (attendings), residents (physicians in training), nurses (RNs), pharmacists (RXs), physical therapists (PTs), occupational therapists (OTs), respiratory therapists (RTs), speech therapists

(STs), nutritionists, social workers, and chaplains (see figures 1 and 2). Intensity and frequency were independently scored by respondents on a seven-point Likert scale (range, 0 to 6). Respondents were allowed to score the intensity of each situation item even if they had experienced the situation infrequently or never, because the intensity, rather than the frequency, of certain situations tends to have a lasting effect on one's level of distress. The moral distress survey instrument consists of nine core clinical scenarios that are applicable to all professions, and additional scenarios designed to address the uniqueness of each discipline's potential moral distress encounters, based upon the ethics committee's 25 years of ethics consultation. High scores reflected extreme intensity or frequency of the moral distress situations. The survey took approximately 15 minutes for participants to complete.

An initial cover email described the nature of the moral distress survey and addressed all informed consent criteria via an invitational site link. Informed consent was implied once participants chose to proceed past the cover page. Participants had the option to start the survey, stop, and then return to complete the survey at a later time. The participants could complete the survey only one time, which protected against multiple surveys by a single participant. After two weeks, three weekly reminders requesting participation were sent before the survey was closed.

Only results related to the nine core clinical scenarios that were common to all participants are reported and analyzed in this article. Scores for moral distress intensity and frequency were compiled for each core scenario by an individual respondent. Then the mean moral distress intensity and frequency scores were calculated for each core scenario item by professional job role (see table 1). Composite mean moral distress intensity and frequency ratings for the nine core scenarios were then calculated by professional job role (see table 2). Finally, a total moral distress score was calculated for each of the nine core items by multiplying each respondent's moral distress intensity rating by his or her moral distress frequency rating on each core scenario (maximum score 36). These scores were summed and averaged by professional job role to create a total moral distress score by job role (see table 3).

Data Analysis

Statistically significant differences in mean moral distress score by age, sex, years of service in the system, and years of service in the current job were tested using the Kruskal-Wallis nonparametric test. Statistical significance was defined as $p<.05$ with a two-tailed test. The analysis of variance (ANOVA) procedure was run to test for statistically significant differences in mean moral distress scores by job role and by demographic characteristics within each job role. Finally, Cronbach's *alpha* was estimated to measure the reliability/internal consistency of the moral distress intensity and frequency scales used for the nine core scenarios.

Categorical variables are expressed as percentages and continuous variables as the mean ±SD (standard deviation), unless otherwise stated. SAS statistical analysis software was used for data analysis.[8]

RESULTS

Demographics

A total of 2,271 healthcare professionals responded to the survey, including > 2,000 nurses and > 200 physicians. The survey response rate was 18.14 percent across BHCS (see table 4). Response rates by job role ranged from 5.17 percent (physicians) to 47.92 percent (SWs), with the two largest groups of respondents, nurses, and therapists, comprising approximately 86 percent of all participants. At least one reason for the low response rate by physicians was a previously unrecognized problem with inaccurate email addresses. Although physicians' response rate was low, the total number responding represents the largest number of physician respondents to a moral distress study yet published.

The participants' demographics are reported by job role in table 5. Demographics were not available for MDs and residents, who are not employees of BHCS. Women aged 30 to 49 years

working full time made up the majority of nurses, RXs, SWs, and therapists; men aged 60 years and older, working full time, were the largest demographic among chaplains. Average years of service ranged from 5.9 to 8.4 years; the largest proportion of clinical staff had been in service for one to four years.

Statistical Analysis

Cronbach's *alpha* for both moral distress intensity and frequency scales revealed high internal consistency at *alpha* = 0.88 and 0.91, respectively, thus confirming the nine core scenarios had good internal consistency. The ANOVA revealed statistically significant differ-

Figure 1. BHCS moral distress survey: nine core questions

BHCS Moral Distress Survey

In these times of turmoil within healthcare, your clinical ethics committees across Baylor Health Care System are concerned about levels of moral distress among all healthcare professionals. We are asking physicians, nurses, social workers, chaplains, pharmacists, therapists and others to complete this anonymous survey. The information will be used to help our clinical ethics committees work with medical and administrative leadership to better understand any feelings of moral distress which healthcare professionals may perceive in their work and to lower its intensity if possible.

Moral distress may be felt when a person believes they know the ethically correct action to take but cannot carry out that action because of some constraint. Constraints may be perceived as interpersonal (with colleagues, patients, or families), institutional, regulatory, or legal.

This survey is designed to measure your perception of moral distress related to your work within healthcare in two dimensions:

1. The intensity level of any moral distress you perceive in your work
2. The frequency of the situation(s) causing you moral distress

The following clinical scenarios may or may not cause moral distress for you. Based upon your past two years at Baylor (or whatever amount of time you have been at Baylor if less than 2 years), please respond to each situation by noting:

1. The intensity with which you have experienced moral distress where 0 = no moral distress at all and 6 = a great amount of moral distress
2. The frequency with which you have experienced the particular moral distress causing scenario where 0 = never and 6 = very frequently.

Please note that all persons will be asked to answer certain common scenarios, after which physicians; nurses, pharmacists and other therapists; and social workers/chaplains will each have their own unique sections of the survey to take.

Clinical scenario: all professionals	Intensity of of distress 0 1 2 3 4 5 6	Frequency of distress 0 1 2 3 4 5 6
I follow the patient's wishes for treatment even when I do not think it is the right thing to do.		
I follow the family's wishes for patient treatment when I do not think it is the right thing to do.		
I participate in starting or maintaining life-sustaining treatments when I do not think it is right to start or maintain such treatment.		
I participate in withdrawing or withholding life-sustaining treatments when I do not think it is right to stop such treatment.		
I participate in the discharge of patients who I do not believe are medically ready for discharge.		
I participate in the discharge of patients into circumstances of inadequate social support.		
I provide different treatment for those who can afford to pay or have insurance than for those who lack insurance or cannot pay.		
I provide better treatment for U.S. citizens, regardless of the ability to pay, than I provide for undocumented immigrants.		
I participate in hiding information, especially bad news, from patients because of family requests.		

Figure 2. BHCS moral distress survey: profession-specific questions

Clinical scenario: physicians only	Intensity of of distress 0 1 2 3 4 5 6	Frequency of distress 0 1 2 3 4 5 6
I start or maintain life-sustaining treatment at patient request even when I do not believe it is in the best interest of the patient. I start or maintain life-sustaining treatment at family request even when I do not believe it is in the best interest of the patient. I start or maintain life-sustaining treatment at family request because I fear a lawsuit. I order or participate in CPR in terminally or irreversibly ill patients that I believe won't work. I order or participate in PEG placement in terminally or irreversibly ill patients that I believe will only prolong dying. I order withholding or stopping life-sustaining treatment at patient request. I see that sometimes living wills are ignored. I order withholding or stopping life-sustaining treatment at family request because I fear a lawsuit. I order withholding or stopping life-sustaining treatment because of pressure from fellow physicians. I order withholding or stopping life-sustaining treatment because of pressure from nurses. I order withholding or stopping life-sustaining treatment because of pressure from social workers or care coordination. I order withholding or stopping life-sustaining treatment because of pressure from insurance carriers or patient inability to pay. I order withholding or stopping life-sustaining treatment because of pressure from the ethics committee.		
Clinical scenario: residents only		
I participate in starting or maintaining treatments, including CPR, even when I do not believe such treatments are in the patient's best interest because the attending physician has told me to do so. I participate in withholding or stopping treatments, including CPR, even when I do not believe such withholding or stopping is in the patient's best interest because the attending physician has told me to do so. I carry out work assignments for which I do not feel adequately trained. I practice medical procedures such as intubation or line placementr on the newly deceased without permission from the family. I practice medical procedures such as intubation or line placement on the newly deceased with permission from the family.		
Clinical scenario: RNs and other therapists (PTs, OTs, STs, RTs, nutritionists, pharmacists)		
I carry out orders for tests or treatment that I do not believe are in the interest of the patient. I assist a physician who performs a test or treatment without informed consent. I ignore situations in which patients or families have not been given adequate information to insure informed consent. I carry out work assignments for which I do not feel adequately trained. I work with levels of staffing that I consider unsafe. I observe without taking action when patients have poorly treated pain. I provide treatment that does not relieve the patient's suffering because I fear increasing doses of pain medication will harm the patient. I provide treatment that does not relieve the patient's suffering because the physician fears increasing doses of pain medication will harm the patient. I observe without taking action when healthcare personnel do not respect patient privacy. *(continued next page)*		

ences in the mean moral distress score among job roles, and Tukey's *post hoc* test identified nurses and therapists as the two job roles with significantly different mean moral distress scores (see table 3). Nurses had the highest mean moral distress scores, followed by SWs, residents, MDs, chaplains, RXs, and therapists.

Mean moral distress intensity and frequency ratings for each of the nine core scenarios are displayed by job role in table 1. Respondents in all job roles consistently rated moral distress intensity higher than frequency. The mean moral distress intensity rating across all nine scenarios was both highest and equal among physicians, chaplains, and SWs, and was closely followed by that of nurses and resident physicians (see table 2).

Physicians ranked their source of greatest moral distress intensity as having to follow families' wishes for patients' treatment when the physician did not think it was the right thing to do. Residents and nurses follow physicians' orders and, not surprisingly, rated the item "I participate in starting or maintaining life-sustaining treatment when I do not think it is right" as causing the highest intensity of moral distress. On the other hand, discharging patients into circumstances of inadequate social support caused the greatest moral distress among RXs, SWs, and therapists; chaplains' greatest moral distress surfaced when they participated in the discharge of patients whom they did not believe were medically ready for discharge.

Although intensity of moral distress was similar among physicians and nurses, nurses experienced moral distress more frequently, and mean moral distress scores by job role were highest among nurses, followed by SWs, then residents (see table 3 and figure 3). These professional group differences in mean moral distress scores, however, reached statistical significance only between nurses and therapists. This was due in part to the larger sample sizes available in these subgroups.

Figure 2. *continued*

Clinical scenario: RNs and other therapists (PTs, OTs, STs, RTs, nutritionists, pharmacists)	Intensity of of distress 0 1 2 3 4 5 6	Frequency of distress 0 1 2 3 4 5 6
I follow physician or family orders not to disclose information to patients, even when I believe the patient is competent. I participate in the treatment of demented patients who have had a G-tube inserted that I believe may not have been in the patient's best interest. I participate in the discharge of patients who I do not believe are ready for discharge.		
Clinical scenario: SWs and chaplains		
I observe without taking action when healthcare personnel do not respect patient privacy. I observe without taking action when healthcare personnel are not respectful of a patient's culture or religious faith. I follow physician or family orders not to disclose information to patients, even when I believe the patient is competent. I participate in the treatment of demented patients who have had a G-tube inserted that I believe may not have been in the patient's best interest. I participate in the discharge of patients who I do not believe are ready for discharge. I participate in the discharge of patients to locations that I believe are not safe. I observe without taking action when healthcare personnel are not respectful of a patient's culture or religious faith.		

CPR = cardiopulmonary resuscitation; G-tube = percutaneous endoscopic gastrostomy tube

TABLE 1. Mean moral distress intensity and frequency ratings by core clinical scenarios and job role

Job role	Mean moral distress intensity (0-6)	Mean moral distress frequency (0-6)
Scenario 1: I follow the patient's wishes for treatment even when I do not think it is the right thing to do.		
Chaplain	2.38	2.65
MD	3.48	2.91
Resident	2.91	2.38
Nurse	3.19	2.93
RX	2.47	2.88
SW	2.59	3.33
Therapists	3.13	2.43
Scenario 2: I follow the family's wishes for patient treatment when I do not think it is the right thing to do.		
Chaplain	3.20	3.10
MD	4.19	3.00
Resident	4.24	2.62
Nurse	3.82	3.04
RX	2.81	3.07
SW	3.39	3.23
Therapists	3.61	2.64
Scenario 3: I participate in starting or maintaining life sustaining treatments when I do not think it is right to start or maintain such treatment.		
Chaplain	3.52	2.50
MD	4.18	2.85
Resident	4.09	2.86
Nurse	3.60	3.06
RX	2.75	3.20
SW	3.53	3.57
Therapists	3.32	2.95
Scenario 4: I participate in withdrawing or withholding life-sustaining treatments when I do not think it is right to stop such treatment.		
Chaplain	3.9	2.47
MD	3.82	1.56
Resident	3.42	1.25
Nurse	3.35	1.98
RX	2.39	2.28
SW	2.64	1.71
Therapists	3.08	2.02
Scenario 5: I participate in the discharge of patients who I do not believe are medically ready for discharge.		
Chaplain	4.81	3.06
MD	3.90	1.85
Resident	3.50	1.80
Nurse	3.85	2.43
RX	2.82	3.00
SW	4.26	2.95
Therapists	3.67	2.63
Scenario 6: I participate in the discharge of patients into circumstances of inadequate social support.		
Chaplain	4.36	3.05
MD	3.92	2.72
Resident	3.23	2.76
Nurse	4.02	2.77
RX	3.35	2.80
SW	4.37	3.44
Therapists	4.02	2.73
Scenario 7: I provide different treatment for those who can afford to pay or have insurance than for those who lack insurance or cannot pay.		
Chaplain	4.33	2.58
MD	3.54	1.85
Resident	3.45	2.10

(continued next page)

TABLE 1. *continued*

Job role		Mean moral distress intensity (0-6)	Mean moral distress frequency (0-6)
	Nurse	3.21	1.32
	RX	2.81	2.25
	SW	4.29	1.87
	Therapists	3.19	1.04
Scenario 8:	I provide better treatment for U.S. citizens, regardless of the ability to pay, than I provide for undocumented immigrants.		
	Chaplain	4.50	2.06
	MD	3.14	1.05
	Resident	3.13	1.10
	Nurse	2.93	1.13
	RX	2.48	2.11
	SW	3.75	1.25
	Therapists	2.75	0.84
Scenario 9:	I participate in hiding information, especially bad news, from patients because of family requests.		
	Chaplains	3.89	2.35
	MD	3.67	1.31
	Resident	3.13	1.20
	Nurse	3.91	1.93
	RX	2.85	2.19
	SW	4.50	1.83
	Therapists	3.40	1.79

Nurse = all direct-care employees in nursing department

TABLE 2. Mean moral distress intensity and frequency ratings for nine core scenarios

Job role	Mean moral distress intensity (0 to 6)	Mean moral distress frequency (0-6)
Chaplain	3.79	2.64
MD	3.79	2.18
Resident	3.47	2.02
Nurse	3.58	2.33
RX	2.71	2.64
SW	3.79	2.63
Therapist	3.39	2.12

Nurse = all direct-care employees in nursing department

TABLE 3. Mean moral distress score by job role

Job role	*n*	Mean moral distress score (0-324)*	95% confidence interval
Nurse	1,464	68.00	64.86, 71.14**
SW	41	66.51	53.80, 79.22
Resident	21	64.33	46.10, 82.56
MD	172	62.60	54.77, 70.43
Chaplain	29	60.76	37.64, 83.88
RX	40	53.98	31.50, 76.46
Therapist	239	51.27	45.05, 57.49**

* Range: 0-324.

** Mean score comparisons significantly different at 0.05 level.

Nurse = all direct-care employees in nursing department

DISCUSSION

This study calls attention to three key findings. First, the experience of moral distress is a significant problem across the spectrum of healthcare disciplines, not only among nurses. Although nurses reported the highest overall moral distress scores (taking into account both intensity and frequency of moral distress), the range of mean moral distress scores among several professions was narrow, with the core-scenario mean moral distress score sum for nurses only 5.3 percent higher than that of residents and 7.9 percent higher than that of attending

TABLE 4. Survey response rate

Job role	Survey recipients	Survey respondents	Response rate (%)
Chaplain	79	36	45.57
Nurse	8,558	2,043	23.87
RX	453	57	12.58
SW	96	46	47.92
Therapist	1,474	331	22.46
MD	4,562	236	5.17
Resident	52	22	42.31
Total	15,274	2,771	18.14

Nurse = all direct-care employees in nursing department

TABLE 5. Nonphysician participants' demographics

	Job role (%)				
Demographic	Chaplain	Nurse	RX	SW	Therapist
Gender					
Female	22.22	88.89	71.93	97.83	82.18
Male	77.78	11.11	28.07	2.17	17.82
Age group, years					
<29	5.56	14.80	8.77	15.20	16.31
30-39	13.89	25.10	33.30	39.10	30.82
40-49	19.44	25.60	33.30	28.30	27.49
50-59	25.00	27.20	22.80	10.90	17.82
60+	36.11	7.34	1.75	6.52	7.55
Employment status					
Full time	69.44	91.50	91.20	84.80	82.48
Part time	30.56	8.47	8.77	15.20	17.52
Service in system, years					
<1	11.11	10.80	12.30	15.20	8.76
1-4	33.33	40.80	36.80	41.30	37.76
5-9	30.56	19.60	21.10	30.40	22.66
10+	25.00	28.90	29.80	13.00	30.82
Service in current job, years					
< 1	19.44	66.70	26.30	17.40	20.85
1-3	36.11	14.30	22.80	26.10	32.02
> 3	44.44	19.00	50.90	56.50	47.13

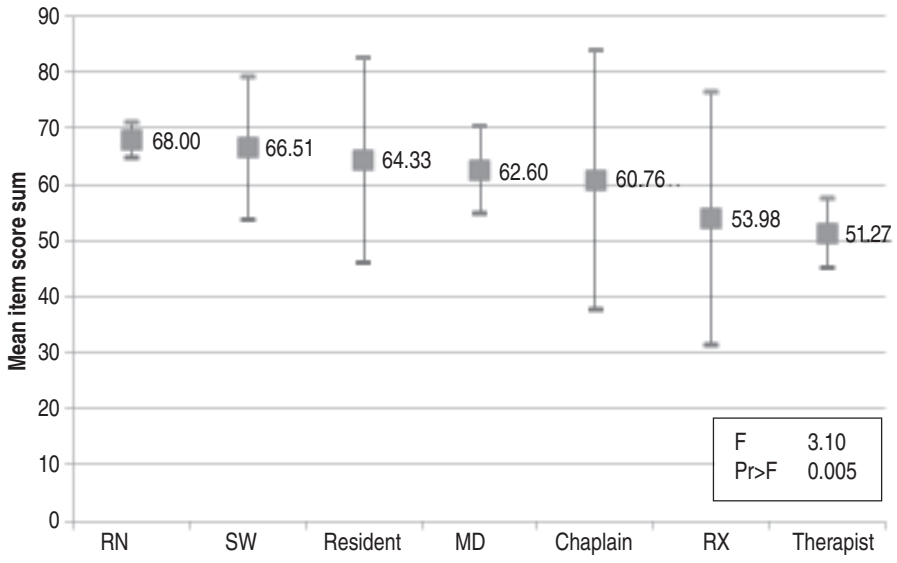
physicians. Second, intensity and frequency of moral distress varied by clinical scenario, across disciplines. Physicians, chaplains, and nurses experienced the highest intensity of moral distress even if they experienced moral distress less frequently. Third, end-of-life clinical scenarios produced the highest intensity of moral distress for physicians (both attending and resident) and nurses, especially when physicians felt constrained to follow the family's wishes when feeling it was not right to do so (see table q, scenario 1) and in the medical futility scenario (see table 1, scenario 3).

Multidisciplinary Experience of Moral Distress

To understand the impact of moral distress on healthcare professionals, it is essential to explore the perspectives of multiple healthcare professionals who must work as a team in caring for patients. The rank order of overall mean moral distress scores are reported in table 3, from highest to lowest, and, as noted elsewhere, nurses reported the highest overall mean moral distress, although it was only 7.9 percent higher than that of attending physicians. However, when evaluating the mean moral distress *intensity* for the nine core items (see table 1), chaplains, physicians, and SWs were tied for first, followed by nurses. Of some interest is that physicians and residents experienced the greatest moral distress related to issues they no doubt perceived as more clinical in nature, such as starting or maintaining a medical treatment they disagreed with, while chaplains and SWs experienced the highest moral distress in areas that might be interpreted as relating to social justice, such as discharging patients into unsafe circumstances (see tables 6 and 7).

Differences in the experience of moral distress may be explained by the different responsibilities of various professional groups. An attending physician may feel obligated to honor the family's requests for maintaining or starting life-sustaining treatment even if the physician believes this is not in the best interest of the patient. This indicates the hierarchical nature of constraints in the field of medicine, in which a doctor perceives the family has power, but is obligated to the patient. Nurses and residents, in turn, may feel obligated to carry out an attending physician's "family-driven" order, even when they feel it is wrong. Meanwhile, SWs who are tasked with post-hospitalization discharge plans experienced the greatest moral distress related to discharging patients into "circumstances of inadequate social support."

Figure 3. Mean moral distress score by job role, with 95 % confidence interval



F=F statistic; Pr=P-value

In reviewing our mean moral distress intensity scores across professions, one group stood out with interest: chaplains. When evaluating the mean moral distress intensity for the nine core items, chaplains, physicians, and SWs were tied for first, followed by nurses. In analyzing the nine core items individually, chaplains scored highest in moral distress intensity in four of nine core items and a close second in two of the items. Of the scenarios in which chaplains had the highest mean intensity, their overall highest mean moral

distress intensity was for the item "I participate in discharge of patients who I do not feel are medically ready for discharge." Following this scenario were the scenarios of "providing better treatment for U.S. citizens regardless of ability to pay, compared to undocumented immigrants" and "providing different treatment for those who can afford to pay, or have insurance than for those who lack insurance, or cannot pay." Chaplains ranked a close second to SWs in terms of moral distress intensity regarding the scenario of "participating in discharging patients into circumstances of inadequate social support."

The common theme of the aforementioned three scenarios is one of social justice. While the exact reason for the high scores among chaplains in these areas may be unclear, one could speculate that there may be an inherent influence from the background of these individuals, from a Judeo-Christian/biblical perspective of societal justice and "loving your neighbor." Another interesting dichotomy was that, for our chaplains, the mean moral distress intensity scores for the scenario involving "participation in withdrawing or withholding life-sustaining treatments when I do not think it is right to stop such treatment" (right-to-die scenario) were the highest, whereas the opposite scenarios, "maintaining life sustaining treatment when I do not feel it is appropriate" and "following family's request for treatment when I do not feel it is right to do so" (futility scenarios), scored much lower. In light of the fact that the frequency of requests to stop treatment when chaplains do not feel it is appropriate is less than the frequency of scenarios of being asked to start or to maintain such treatment, the mean moral distress score is higher for the latter. Therefore, if one were to concentrate on the mean moral distress score alone, one would miss a key issue that is a leading cause of moral distress intensity for this group.

The next question is why the difference in moral distress intensity between a right-to-die scenario and a medical futility scenario. One could speculate that the background of a chaplain would compel him or her to place great value on life (as many practitioners do), which may compel her or him to have greater moral distress intensity for a request to "cut a life short." Perhaps it is, in part, because many chap-

TABLE 6. Mean scores for chaplains by question

Item	Mean item score (0-36)	Mean intensity (0-36)	Mean frequency (0-36)
I participate in the discharge of patients who I do not believe are medically ready for discharge.	19.31	4.81	3.06
I provide better treatment for US citizens, regardless of the ability to pay, than I provide for undocumented immigrants.	14.54	4.50	2.06
I provide different treatment for those who can afford to pay or have insurance than for those who lack insurance or cannot pay.	14.43	4.33	2.58
I participate in the discharge of patients into circumstances of inadequate social support.	13.12	4.36	3.05
I participate in starting or maintaining life-sustaining treatments when I do not think it is right to start or maintain such treatment.	11.19	3.52	2.50
I follow the family's wishes for patient treatment when I do not think it is the right thing to do.	11.00	3.20	3.10
I participate in withdrawing or withholding life-sustaining treatments when I do not think it is right to stop such treatment.	11.00	3.90	2.47
I participate in hiding information, especially bad news, from patients because of family requests.	10.17	3.89	2.35
I follow the patient's wishes for treatment even when I do not think it is the right thing to do.	6.78	2.38	2.65

lains do not have the clinical training to fully evaluate such decisions. Alternatively, in light of their faith background (Christian at our institution), and with an accompanying belief in the afterlife, one could speculate that there may be a certain degree of "solace" or comfort in knowing that, in the end, for a patient who is receiving medically inappropriate treatment/futile interventions, the patient's suffering will cease, and he or she will proceed to a "place devoid of suffering." This is pure speculation, but could serve as an area for further research. Prior research in the nursing literature by Meltzer suggests that nurses who viewed religion as important in their lives experienced less emotional exhaustion than nurses who did not rate religion as important.

Intensity, Frequency, or Both in the Experience of Moral Distress

As mentioned in the methods section, the moral distress score was calculated utilizing both intensity and frequency of moral distress. By examining the intensity of moral distress for particular scenarios, one may gain insight into a comment that many in clinical ethics have heard fellow healthcare professionals make: "To this day, I can still remember that one terrible case." The current study is similar to that conducted by Rice and colleagues, using a Likert scale (0 to 6)-based moral distress score that measured both the intensity and frequency of potentially distressful situations.[9] However, the Rice study included only nurses, whereas this study included participants from seven different healthcare disciplines. Both studies found that cases of futile intervention posed particularly high levels of distress, with high-encounter frequencies noted in the Rice study and high intensity noted in the current study.

This study does not answer the question of whether intensity or frequency of moral distress has a greater impact on the psychological health of healthcare professionals, although mean moral distress intensity was higher than frequency for all professional groups in the study (see table 2). Also, it is not known if higher intensity but less frequent moral distress has the same impact on critical-care nurse burnout as does the overall frequency of moral distress situations perceived as futile as reported by Meltzer and colleagues.[10]

TABLE 7. Mean scores for social workers by question

Item	Mean item score (0-36)	Mean intensity (0-36)	Mean frequency (0-36)
I participate in the discharge of patients into circumstances of inadequate social support.	15.97	4.37	3.44
I participate in starting or maintaining life-sustaining treatments when I do not think it is right to start or maintain such treatment.	15.54	3.53	3.57
I participate in the discharge of patients who I do not believe are medically ready for discharge.	12.54	4.26	2.95
I follow the family's wishes for patient treatment when I do not think it is the right thing to do.	11.56	3.39	3.23
I provide different treatment for those who can afford to pay or have insurance than for those who lack insurance or cannot pay.	11.48	4.29	1.87
I follow the patient's wishes for treatment even when I do not think it is the right thing to do.	9.83	2.59	3.33
I participate in hiding information, especially bad news, from patients because of family requests.	9.36	4.50	1.83
I provide better treatment for U.S. citizens, regardless of the ability to pay, than I provide for undocumented immigrants.	6.55	3.75	1.25
I participate in withdrawing or withholding life-sustaining treatments when I do not think it is right to stop such treatment.	4.40	2.64	1.71

Moral Distress As It Relates to Decisions Near the End of Life

Facing ethical disagreement near the end of a patient's life is a common scenario in which ethics consultants/committees or palliative care teams often assist bedside professionals. In some situations, a surrogate may request withdrawing or withholding interventions, but the treatment team disagrees. Such circumstances are typically referred to as "right-to-die" scenarios by the medical ethics community. Alternatively, there are many more cases in which the treatment team believes that medical interventions should be withheld or withdrawn, but the surrogate disagrees. This scenario is often referred to as "medical futility." Debate over the true meaning of medical futility and the best mechanism for facing the problem clearly exists.[11] However, the present study suggests there should be little debate about the moral distress evoked among healthcare professionals by medical futility cases.

In this study, all professional groups except chaplains found the intensity of moral distress associated with participation in futile interventions to significantly outweigh the intensity of moral distress associated with right-to-die situations. The intensity of such moral distress in the futility scenario was highest among attending physicians and residents, closely followed by that of nurses.

LIMITATIONS

Although this study was conducted in a large healthcare system and had the largest sample size in a moral distress study reported in the literature to date (N=2,771), findings should be generalized cautiously, as this sample was based on a response rate of a bit over 18 percent. Respondents were recruited through the system's intranet via job code; thus, not all participants were in direct patient care positions and potentially may not have been exposed to situations that could cause moral distress and angst. This could result in reduced frequency and intensity scores among nurses, therapists, and pharmacists. After embarking on the study, it was found that the email addresses for physicians affiliated with BHCS were often inaccurate. This may help explain the just over 5 percent response rate of physicians. Nonetheless, the 236 physician respondents represent the largest study of moral distress involving physicians published to date. Lastly, as is the case with many studies, there may have been a component of self-selection bias. There may be individuals who perhaps felt more compelled to answer the survey in light of inherent higher levels of background moral distress, as opposed to individuals who simply did not feel this was an important topic and hence did not participate in the survey.

CONCLUSION

Moral distress is not unique to any one professional discipline within healthcare. However, members of different healthcare professions experience moral distress for different reasons. As long as suffering, mortality, and social inequality remain components of the human condition, those in healthcare must face at least periodic moral distress. The results have provided direction regarding vulnerable healthcare professionals and have moved beyond the previous information regarding the nursing profession. It is hoped that this study will evoke questions such as, Why don't we feel each other's pain? Why don't doctors share nurses' concerns more, and why don't nurses share doctors' concerns more? Does each see needs only from his or her perspective? Is this as it should be, or should we consider whether and how we should change this?

The next question might be, What do we do about it? Two basic options would be to acknowledge the existence of moral distress and focus on efforts to mitigate it to the extent possible, versus a stoic response of "just deal with it" that organized medicine has practiced for decades. When a healthcare organization, or even a major group within medicine (doctors, nurses, therapists) chooses the latter, the results are harmful to the psychological health of individuals, not to mention the end result of burnout. This is not an option the healthcare community can entertain, as there are already short-

ages of healthcare professionals across the spectrum, as well as ever-growing demands on the delivery system. That leaves the first, more "therapeutic" option, starting with the acknowledgment that moral distress is real across the spectrum of healthcare professionals. A simple acknowledgment that another colleague could be struggling with moral distress can offer a starting point for possible mitigation, starting with active listening.

In the authors' clinical ethics consultation experience, it is not uncommon for diverse healthcare professionals to request formal ethics consultation or to simply talk about or seek counseling concerning a particularly distressing clinical scenario. This "counseling" aspect of clinical ethics is one that is often under utilized and under valued. It also happens to be an ethics intervention that requires only active listening and acknowledgment of the moral distress that a colleague is experiencing. Beyond such one-on-one support, structured interventions could include broader education related to medical ethics in general and the promotion of moral confidence through ongoing facilitated dialogue and study. Survey participants were asked about opportunities for further clinical ethics education; the majority answered that they felt adequately educated, but would attend additional education if it were offered (see table 8). Additionally, both formal and informal debriefing sessions following stressful cases may help some team members, as can more in-depth and structured support programs such as Schwartz Center Rounds.[12] Lastly, utilization of palliative care services may mitigate many potentially distressful situations, particularly those involving end-of-life scenarios. In the process of focusing on increasing the intensity of "care" (not necessarily intensity of medical intervention or treatment), palliative care teams may help a primary treatment team at the same time that the patient and family are helped.

Further research is needed to examine the impact of education programs on reducing the intensity of morally distressing situations, as well as the impact of treatment protocols or guidelines related to specific scenarios such as medical futility or discharge into circumstances that are seen as less than optimal.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

NOTES

1. A. Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, N.J.: Prentice-Hall, 1984).

2. B. Pauly et al., "Registered Nurses' Perceptions of Moral Distress and Ethical Climate," *Nursing Ethics* 16, no. 5 (2009): 561-73; E.M. Price et al.,

TABLE 8. Clinical ethics education

Survey participants were asked about further clinical ethics education, and the majority answered they felt adequately educated but would attend additional education, if offered.

		Job role (%)				
	Education Value	Chaplain	RN	RX	SW	Therapist
Adequately educated	Yes	82.76	85.6	83.33	90.24	93.48
	No	17.24	14.4	16.67	9.76	6.52
Would attend additional education	Yes	100.00	84.15	76.19	100.00	83.04
	No	0	15.85	23.81	0	16.96
Future ethics education format						
Lectures	--	3.45	16.87	16.67	2.44	13.04
Case conferences	--	10.34	13.76	11.90	4.88	10.00
Combination	--	86.21	69.37	71.43	92.68	76.96

"Determinants of Moral Distress in Medical and Surgical Nurses at an Adult Acute Care Tertiary Hospital," *Journal of Nursing Management* 16, no. 3 (2008): 360-73; M.J. Mobley et al., "The Relationship between Moral Distress and Perception of Futile Care in the Critical Care Unit," *Critical Care Nursing* 23, no. 5 (2007): 256-63; K.M. Gutierrez, "Critical Care Nurses' Perceptions of and Responses to Moral Distress," *Dimensions in Critical Care Nursing* 24, no. 5 (2005): 229-41; M.C. Corley et al., "Nurse Moral Distress and Ethical Work Environment," *Nursing Ethics* 12, no. 4 (2005): 381-90.

3. C. Ulrich et al., "Ethical Climate, Ethics Stress, and the Job Satisfaction of Nurses and Social Workers in the United States," *Social Science and Medicine* 65, no. 8 (2007): 1708-19; S.K. Sporrong, A.T. Hoglund, and B. Ametz, "Measuring Moral Distress in Pharmacy and Clinical Practice," *Nursing Ethics* 13, no. 4 (2006): 416-27; L.S. Meltzer and L.M. Huckabay, "Critical Care Nurses' Perceptions of Futile Care and Its Effect on Burnout," *American Journal of Critical Care* 13, no. 3 (2004): 202-8.

4. R. Forde and O.G. Aasland, "Moral Distress among Norwegian Doctors," *Journal of Medical Ethics* 34, no. 7 (2008): 521-5.

5. Ulrich et al., see note 3 above.

6. Sporrong, Hoglund, and Ametz, see note 3 above.

7. M.C. Corley et al., "Development and Evaluation of a Moral Distress Scale," *Journal of Advanced Nursing* 33, no. 2 (2001): 250-6.

8. SAS Statistical Analysis Software, version 9.3 (Cary, N.C.: SAS Institute, 2012).

9. Price et al., see note 2 above.

10. Meltzer and Huckabay, see note 3 above.

11. R.L. Fine, "Point: The Texas Advance Directives Act Effectively and Ethically Resolves Disputes about Medical Futility," *Chest* 136, no. 4 (2009): 963-7.

12. *http://www.theschwartzcenter.org,* accessed 22 March 2013.

"He Got His Last Wishes": Ways of Knowing a Loved One's End-of-Life Preferences and Whether those Preferences Were Honored

Angelina R. Wittich, Beverly Rosa Williams, F. Amos Bailey, Lesa L. Woodby, and Kathryn L. Burgio

ABSTRACT

As a patient approaches death, family members often are asked about their loved one's preferences regarding treatment at the end of life. Advance care directives may provide information for families and surrogate decision makers; however, less than one-third of Americans have completed such documents. As the U.S. population continues to age, many surrogate decision makers likely will rely on other means to discern or interpret a loved one's preferences. While many surrogates indicate that they have some knowledge of their loved one's preferences, how surrogates obtain such knowledge is not well understood. Additionally, although research indicates that the emotional burden of end-of-life decision making is diminished when surrogates have knowledge that a loved one's preferences are honored, it remains unclear how surrogates come to know these preferences were carried out. The current study examined the ways that next of kin knew veterans' end-of-life preferences, and their ways of knowing whether those preferences were honored in Veteran Affairs Medical Center (VAMC) inpatient settings.

INTRODUCTION

Confronting end-of-life treatment decisions can be a difficult process for a dying patient's

Angelina R. Wittich, PhD, MPH, is an independent Research Consultant to the Birmingham/Atlanta Geriatric Research, Education, and Clinical Center, Department of Veterans Affairs, in Birmingham, Alabama.
Beverly Rosa Williams, PhD, is a Health Research Scientist at the Birmingham/ Atlanta Geriatric Research, Education, and Clinical Center, Department of Veterans Affairs; and is an Assistant Professor in the Department of Medicine, Division of Gerontology, Geriatrics, and Palliative Care at the University of Alabama at Birmingham.
F. Amos Bailey, MD, is Director of Palliative Care at the Birmingham VA Medical Center, Department of Veterans Affairs; and is a Professor in the Department of Medicine, Division of Gerontology, Geriatrics, and Palliative Care at the University of Alabama at Birmingham,.
Lesa L. Woodby, PhD, MPH, is the Associate Director for Education and Evaluation at the Birmingham/Atlanta Geriatric Research, Education, and Clinical Center, Department of Veterans Affairs; and is an Associate Professor in the Department of Medicine, Division of Gerontology, Geriatrics, and Palliative Care at the University of Alabama at Birmingham.
Kathryn L. Burgio, PhD, is the Associate Director for Research at the Birmingham/Atlanta Geriatric Research, Education, and Clinical Center, Department of Veterans Affairs; and is a Professor in the Department of Medicine, Division of Gerontology, Geriatrics, and Palliative Care at the University of Alabama at Birmingham, *kburgio@uabmc.edu.*

family. As the U.S. population ages, it is likely that a growing number of families will face the challenges of end-of-life decision making. According to a Centers for Disease Control and Prevention (CDC) report on death and dying, nearly 75 percent of all U.S. deaths in 2007 were among individuals aged 65 years or older.[1] Although advance care directives assist families in knowing their loved one's end-of-life preferences, a 2008 report to the U.S. Congress on advance care directives and advance care planning indicated that fewer than one-third of Americans had completed an advance directive.[2] As family members assume the role of surrogate decision maker, they likely will rely on other, less formal means to discern and interpret a loved one's end-of-life preferences. The purpose of the present study was to employ an epistemological framework to examine how veterans' next of kin came to know veterans' preferences for end-of-life care and how the next of kin affirmed that their loved one's wishes were honored in VAMC inpatient settings.

Surrogates' Knowledge and End-of-Life Decision Making

When a gravely ill patient is unable to communicate due to advancing illness, cognitive impairment, or altered mental status, the medical community must rely on a surrogate to convey the patient's preferences for end-of-life care.[3] In cases when a patient has completed an advance directive, family members may rely on that document for assistance in guiding end-of-life treatment choices. Given that only 18 to 36 percent of the adult U.S. population has completed an advance directive, most surrogates must make decisions without the benefit of a patient's documented wishes. In these cases, surrogates are asked to exercise substituted judgment. The substituted judgment standard provides a framework for surrogate decision makers, in that it requires a surrogate to act on behalf of a patient, using *knowledge* of the patient's previously expressed or implied preferences regarding medical treatments.[4] While the substituted judgment standard has been considered the gold standard, some argue that its use is fraught with difficulties. Torke and colleagues delineated three problems with using substituted judgment: (1) an individual's preferences may change over time, (2) there may be a lack of concordance between patient and surrogate, and (3) patients often desire input from family members and physicians.[5]

Inasmuch as the exercise of substituted judgment may pose difficulties for strict adherence to a patient's expressed or implied preferences, the literature suggests a pivotal move toward recognition of the relevance of contributions from patients' family members and physicians to the decision-making process. For example, studies indicate that patients are inclined to defer to a family member's judgment for end-of-life decisions when patients become cognitively impaired,[6] and that patients tend to value a surrogate's decisions over their own previously expressed preferences.[7] In a recent systematic review of the literature on adult end-of-life decision-making goals, Kelly and colleagues found the most common reason for deferring to a surrogate is the belief that a surrogate has *knowledge* of a patient's preferences regarding medical treatment.[8]

Furthermore, studies also report that most patients and surrogates desire physicians' input in end-of-life decision making.[9] Family conferences are typically viewed as an essential vehicle for the optimal delivery of care at the end of life.[10] From a clinical perspective, family conferences are a way to assess family members' understandings of the patient's condition, to inform family members of changes in the patient's status, and to seek input from family members regarding the patient's preferences. Fineberg and colleagues found, however, that both the patient and family members benefited from family conferences because clinicians provided valuable information during the conferences.[11]

Important by-products of social interactions during family conferences are the knowledge that surrogates can acquire regarding the acuity and severity of the patient's condition, as well as knowledge of available treatment options for their loved one.[12] Whereas the influence of social interaction on acquiring new knowledge has been reported in studies across disciplines,[13] an understanding of its influence

on the surrogate decision-making process is lacking. A growing appreciation for the complexities of end-of-life decision making has broadened discourse on decision making[14] and has paved a path for the examination of surrogates' knowledge as a key factor in the decision-making experience and process.

The Emerging Significance of Surrogates' Knowledge

Traditional conceptions of the process of decision making at the end of life are evolving from a purely legal perspective to a broader contextual approach that takes into account the values of both patients and family members.[15] Several studies that used a more contextual approach emphasize that surrogates' knowledge is an operative component in the decisions they make for patients. Boyd and colleagues found that surrogates relied on multiple sources of lay knowledge to estimate the prognosis of a critically ill patient.[16] Only 2 percent of surrogates relied exclusively on prognostic information provided by a physician. In other studies, surrogates' knowledge of a loved one's end-of-life preferences was a key factor in surrogates' positive decision-making experiences.[17]

According to Meeker, having knowledge of the patient as a person is essential for knowing her or his last wishes.[18] Surrogates' knowledge of a patient's attributes and life history are identified as important considerations in designing improved communication practices at the end of the patient's life.[19] Similarly, the literature is beginning to acknowledge the value that a patient's or surrogate's subjective experience and interpretation have for informing the clinical encounter.[20] Such contextual approaches to the study of surrogate decision making highlight the emerging significance of surrogates' knowledge. *Knowing* a patient's end-of-life preferences is viewed as a critical factor in meeting the medical, ethical, and legal thresholds for optimal surrogate decision making,[21] yet the ways in which surrogates acquire knowledge is not well understood. Despite a robust discourse on surrogate decision making, there is virtually no research on the fundamental processes that facilitate knowledge of a loved one's preferences for end-of-life care and whether those preferences were honored.

METHODS

This was a qualitative study within an intervention trial that was designed to evaluate the effectiveness of an educational intervention to improve end-of-life care at VAMCs in the southeastern U.S. The Veterans Affairs (VA) Institutional Review Board granted approval for the study. Patients' next of kin were identified through electronic chart reviews of veterans' deaths at participating VAMCs. Individuals who were listed as next of kin in the patients' charts were invited to participate. A recruitment letter and participant's form were mailed to patients' next of kin three to six months after the date of death. The next of kin who returned a signed participant's form were contacted by phone to discuss the study and to schedule an interview appointment.

Interview Procedures

Between July 2005 and May 2010, face-to-face in-depth interviews were conducted with 78 next of kin by an interviewer experienced in qualitative inquiry. The interviews were conducted at the VAMC where the patient had died. The research service or chaplain service at each VA hospital provided private space for the interviews. Participants were interviewed only once, with the average interview lasting approximately two hours. Each interview was tape recorded and transcribed.

A semi-structured open-ended interview guide was utilized. Existing qualitative instruments[22] and the guidelines of the Center to Advance Palliative Care (CAPC)[23] shaped the development of the interview guide. The guide was designed to facilitate dialogue between the interviewer and the next of kin and to elicit the participant's narrative account. Topic sections in the guide included the next of kin's recollections of the following:

1. the patient's life and final days;
2. interactions with the patient, clinical staff, pastoral staff, and visitors during the patient's final hospitalization;

3. the patient's death experience;
4. the patient's end-of-life preferences and the fulfillment (honoring) of those preferences;
5. the care and treatment provided to the patient and the staff's support of the family during the patient's final hospitalization.

To ensure relevance, clarity, and readability, the guide was reviewed by an interdisciplinary research team comprised of physicians, nurses, a medical sociologist, a clinical psychologist, and a health educator. The guide was pilot tested with the next of kin recruited at the researchers' local VA medical center. Sociodemographic information was obtained by the interviewer at the conclusion of the interview.

Analytical Procedures

As part of the analytical procedure, data coding was an interactive, iterative process. Two coder-analysts simultaneously listened to the taped interviews, and each made notations and wrote memos on the transcriptions.[24] The transcriptions of the interviews were reviewed continuously to confirm, compare, and contrast emerging themes, patterns, and interrelationships. The code book initially was comprised of items specific to the interview guide. As themes emerged, new codes were discussed, negotiated, and added to the code book. Upon thematic saturation, 56 codes had been identified, and 25 codes with relevance to this analysis were employed (see table 1). We constructed a matrix to identify patterns and interrelationships within and between the codes[25] to facilitate regrouping the themes into four categories:
1. factors concerning patients,
2. factors concerning next of kin,
3. factors related to staff, and
4. factors related to the institution (table 1).

The interpretive process for the analysis was guided by an epistemological perspective that explored the nature of knowledge and the ways that individuals acquire knowledge. The following questions were instrumental in informing the process:
1. What do next of kin know about a loved one's end-of-life preferences?
2. How do next of kin come to know their loved one's end-of-life preferences?
3. How do next of kin obtain knowledge about loved one's preferences being honored?

This form of inquiry draws upon the theoretical propositions that social conditions, cultural

TABLE 1. Codes categorized by individual and institutional factors

Patients	Next of kin	Staff	Institution
Medical history	Caregiver role	Physician visits	Location of care and death
Length of final hospital stay	Expectedness of death	Pastoral care visits	Death pronouncement
			Suggestions for improvement in end-of-life care
Cause of death	Presence at time of death	Nursing care to the veteran	--
Mode of death	Presence after death	Staff communication	--
Events surrounding death	Experience of loved one's death	--	--
Interactions with the patient and the family	--	--	--
Pain at time of death	Regrets	--	--
Biography	Bereavement concerns	--	--
Final requests	--	--	--
Expressed last goodbyes	--	--	--
Peace at time of death	--	--	--

practices, and communication are integral to the formation of knowledge.[26] To systematically document the interpretive process, memos were logged regularly and incorporated into the thematic data base. A negotiated approach was used throughout the process to achieve coder agreement and ensure the methodological rigor of the data analysis.

RESULTS

Participants' Characteristics

Next of kin were predominately female (78 percent) and white (60 percent) with a mean age of 61 years (standard deviation=11.4). Relationship status of next of kin included surviving spouse (40 percent), adult child (32 percent), sibling (17 percent), ex-spouse, other relative or significant other (9 percent), and unrelated named caregiver (2 percent).

The Process of Knowing

The process of knowing a loved one's preferences regarding end-of-life care appeared to unfold over time and to be facilitated by hearing about the patient's preferences, seeing the care provided to the patient, and interacting with the patient and the clinical staff. Although prior illness conditions may have precipitated informal discussion of end-of-life issues, at the time of a patient's final hospitalization, the next of kin's need to know their loved one's end-of-life preferences was not their foremost concern. Rather, what took precedence was their need to know their loved one's medical status and life-saving treatment options. As awareness of the patient's dying emerged, the need to know the patient's preferences regarding care at the end of life became more salient. This was comprised of two phases:

1. the patient is sick, and
2. the patient is dying.

Phase 1: the patient is sick. This phase involved seeking information about the patient's current medical condition and obtaining information about treatment options. It was during this phase that the patient entered the hospital. The concerns of the next of kin often focused on what was wrong with the patient and securing the tests that were necessary to determine what plan of care to pursue; 47 percent of patients' next of kin cited the patient's acute illness and treatment options as their primary concerns during the patient's early hospitalization. At this point, awareness of the patient's end-of-life preferences was not at the forefront of the next of kin's consciousness because they did not expect that death might occur during hospitalization: a majority (53 percent) indicated they did not expect the patient would die. Moreover, although 59 percent indicated their loved one had an advance directive, only 6 percent mentioned end-of-life preferences when they described the patient's early days of hospitalization. This does not mean that the next of kin did not have knowledge of their loved one's end-of-life preferences, but only that such knowledge did not appear to be salient at that time.

At the time of intake and during the early hours and days of hospitalization, 35 percent of the next of kin expressed a belief that the patient would be treated and released from the hospital. Among these next of kin, 78 percent had no expectation the patient would die during the hospitalization. If the next of kin believed that the patient would be treated and released, they tended to focus on the patient's illness and recovery rather than on details pertinent to life-sustaining decisions. The following quote exemplifies this thinking: "And I said, 'but he was here to have um, a urinary tract infection and has gone downhill since then.' . . . When they called me and said they were taking him to the hospital with a fever of 104, I never gave up, I kept thinking, 'well they'll get this cured and then we'll go back to the nursing home' " [the patient's wife].

Phase 2: the patient is dying. During hospitalization, patients reached a point that continued pursuit of life-sustaining treatment was not medically indicated. During this second phase, the next of kin became aware that the patient was dying. A majority (78 percent) said they had a discussion with a physician regarding the patient's impending death. At this point, knowl-

edge of a loved one's preferences had salience; 54 percent of the next of kin reported that end-of-life treatment options were part of the discussion. During discussions with medical staff, the next of kin often recalled prior conversations with the patient regarding end-of-life preferences: ". . . I mean there are just so many issues . . . but as far as we know that he was dying, at the end . . . the doctor came and sat down with us and told us that 'look here's, here's where we are, the medicine that he's on right now is pretty much the only thing that's keeping him alive' . . . [the patient] had mentioned to me that he did not want to be on any type of life support" [the patient's brother].

Transition to the "patient is dying" phase also occurred when medical staff discussed a referral to hospice; 19 percent of next of kin indicated having a discussion about hospice with a clinician during the patient's final hospitalization. As the following quote illustrates, these discussions brought to light end-of-life preferences by addressing the patient's end-of-life status: "Then [the doctor] told me, that's the first time I knew that he was in a dying condition. . . . that's when the doctor shared with me that when his muscles wouldn't work with him breathing, his heart would quit. And they were sending him home to hospice on Monday and, so the next day everybody was coming around to talk about hospice, social worker, psychologist . . . " [the patient's wife].

Ways of Knowing

Several ways of knowing a loved one's end-of-life preferences and ways of knowing whether those preferences were honored emerged from our data analysis and interpretation:

1. hearing is knowing,
2. seeing is knowing, and
3. interacting is knowing.

Hearing is knowing involves obtaining knowledge by listening to a loved one as he or she expresses end-of-life preferences or listening to end-of-life conversations between clinical staff and the loved one. *Seeing is knowing* refers to acquiring knowledge via observations of medical staff performing clinical end-of-life medical and nonmedical comfort care activities. The third way of knowing, *interacting is knowing*, refers to knowledge acquired through interactions with clinical staff.

1. Hearing is knowing. Hearing from a loved one about his or her end-of-life preferences takes place via informal discussions and formal advance care planning deliberations. A majority of patient's next of kin (81 percent) recalled conversations in which the patient conveyed both implicit and explicit end-of-life care preferences. The following quotes illustrate both informal and formal discussions between next of kin and a loved one: ". . . he had already told me, and we did talk some about, we discussed it. He said, 'you know what I want done.' 'You know this and this,' you know. And so I knew what everything, what he wanted done. I mean we knew too, down to the last detail how he wanted things . . ." [the patient's ex-wife]. "And [my husband] and I had talked a long time before when we made our living wills and our DNRs and all that we said we did not want, if things happen to get so bad, we didn't want our lives prolonged" [the patient's wife]. "I remember him saying . . . that he did not want to be on, put on a life respirator; you know, stuff like that trying to save him" [the patient's brother].

When patients lost the capacity to participate in making medical decisions or did not have a documented advance directive, the next of kin described conversations in which patients expressed end-of-life care preferences. A majority (59 percent) indicated that their loved one suffered cognitive impairment that included dementia, Alzheimer's disease, posttraumatic stress disorder, delirium, mental illness, or an undefined impairment. Among the 46 cases of cognitive impairment, 80 percent (n=37) of the next of kin claimed they had an informal discussion with their loved one regarding end-of-life preferences: ". . . the Alzheimer's . . . I don't know really how much he really understood, you know, but we talked with him . . . he had already done told us before his mind had ever started going bad. He had already told us he did not want to be on any machines, and he did

not want to be resuscitated. If anything happened to him, he did not want that, and he did not want us to do it" [the patient's son].

One-third (33 percent) of the next of kin stated that the patient did not have an advance directive. Among those patients who did not have an advance directive, however, 77 percent of the next of kin described informal conversations with the patient concerning end-of-life care preferences: "I had already signed my stuff, but I could never get him to sign it. . . . But he didn't want life support, he said 'don't ever put me on life support.' . . . He did not want to be put on life support" [the patient's wife].

Being present during doctor-patient encounters and hearing conversations between a physician and the patient regarding end-of-life treatment decisions provided another way for the next of kin to know their loved one's expressed end-of-life care preferences: ". . . another thing the doctor asked him not only one time but three different times, if his heart stopped if he wanted them to start it back, and he told him, 'No.' And if he stopped breathing, did he want that started back, and he told him, 'No.' 'Cause, I think he had made up his mind that he was ready to go" [the patient's wife]. "He didn't want to be on a respirator . . . the doctor asked him, you know, 'if you have difficulty breathing,' 'cause he was having the lung problems and having to have the oxygen, and he said, 'No,' he did not want to be on a respirator. So I was glad that he was able to talk to the doctor and tell him what he wanted" [the patient's wife].

Nine of the next of kin (11 percent) characterized the conversations they had with physicians as "explaining" the end-of-life process and procedures. Hearing such explanations expanded the knowledge of the next of kin about end-of-life scenarios and the physician's clinical position. The explanations also helped the next of kin to integrate their knowledge of advance directives with their interpretations of a loved one's expressed end-of-life preferences: ". . . when the doctor came . . . I asked, 'what if I'm here and my dad has a heart attack or appears to be having a heart attack, do we try and resuscitate him or is that when you don't?' What I wanted to know is when do you refuse exactly . . . I just wanted him to be really clear with it . . . and [the physician] told me . . . and she also explained to me that because I wasn't sure how he would die. I said, 'what will it be like what should I expect.' . . . You know he didn't want any extreme measures taken. . . . So in that regard he wouldn't have wanted them to pound on his chest and try and revive him" [the patient's daughter].

In four (5 percent) cases, the next of kin perceived end-of-life discussions with clinical staff as lacking. The wife of one patient, for example, said that poor communication with clinical staff compromised her understanding of end-of-life treatment and limited her knowledge of what to expect: ". . . [the patient] did not wish to live in a state of vegetation. . . . I think had he been anywhere else except here a doctor would have sat down and explained things to me . . . and would have quit giving me false hope, 'cause see every time they told me they was gonna try in a day or two to bring him out . . . I looked forward to being able to talk with my husband. . . . All I could see was the hope at the end. . . . I just never expected him to die . . . didn't even entertain the thought of him dying . . . I just don't understand it."

2. Seeing is knowing. When asked if the loved one's end-of-life wishes were honored, 79 percent of the next of kin answered in the affirmative; 73 percent referenced their observations of either medical care comfort care procedures or nonmedical comfort care activities. Of the next of kin who referenced their observations of comfort care, 47 percent (n=27) described witnessing medical procedures such as the delivery of pain medication or removal of intravenous lines, and 46 percent (n=26) described observing staff attending to the nonmedical comfort needs of the patient. The following quotes indicate that observations of the delivery of comfort care seemed to give the next of kin the knowledge that their loved one's wishes were honored at the end of life: ". . . they stopped all of her medicines and were just giving her pain medicines, just making her comfortable . . . I really felt like, you know, they did take good care of her and they made her

comfortable and she didn't suffer . . ." [the patient's daughter]. ". . . I understood what they were going to do and why . . . it seemed like the humane thing to do. . . . So I understood it, very hard to watch them undoing this or undoing that" [the patient's wife]. "All he wanted was to be kept comfortable and out of pain . . . that last day that he lived, the nurse came in . . . she tried to get him to drink. . . . But the only thing that he wanted was Coca-Cola . . . gave that to him every time he wanted it . . . the thing that impressed me so was them keeping him so clean and doing everything to make him comfortable" [the patient's wife].

3. Interacting is knowing. In 11 cases (14 percent), the next of kin learned of a loved one's end-of-life preferences through interacting with clinical staff. The next of kin said they came to know their loved one's wishes were honored during such encounters: "My brother was in that room on the floor . . . he was all out of it. And then that Friday I went to consult with doctor. She told me my brother had requested that he didn't want no machine or nothing . . . the doctor and my brother had talked and then the doctor talked with me about my brother's request. So the doctor and my brother kind of, you know, lift the weight off of me . . . the doctor was in the room when I came and that's when she told me that everything was near the end. So, the request that he didn't want the machine on him . . . a little after 10 . . . my brother had gone" [the patient's sister].

Interactions with staff in the palliative care setting had particular relevance for the next of kin who did not have a long history with the patient (for example, significant others.) Of these, five were not connected to the patient by blood or marriage. The next of kin valued interactions with clinical staff because they were a way to acquire information about the patient's preferences: "The doctors probably told him about his terminal illness, but he didn't mention it to me . . . he came in that Wednesday night and he died the next morning. . . . Now I don't know about the life-support machines because he never talked about that. . . . If they can have a meeting with the patient and the family, especially if they know someone is passing away . . . and sit them down you know and just talk to them and probably that would make the patient open up more . . . 'cause you can come in the hospital and you don't know if you're leaving. . . . So if they could just have a talk with the family together and probably the patient could open up and tell the family members different things that need to be done. . . . 'Cause you don't know, you can come in for one thing and just like him be gone just like that . . . on a quick death like that . . ." [the patient's girlfriend].

In two cases the next of kin characterized their social interactions with clinical staff as a negative. Nonetheless, they acquired knowledge of their loved one's preferences during these encounters. Additionally, despite a negative perception of the interaction, as exemplified in the quote below, the next of kin became aware that their loved one's expressed end-of-life preferences were being honored by clinical staff: ". . . the doctors considered him in sound mind, able to make these decisions . . . I don't know what may have been said between my father and the doctors before hospice was ever brought up to me . . . the doctor brought that up because my father was refusing to eat. . . . It became very ugly between the doctor and I because my father wants to die [that is, to stop dialysis] and the doctor said, 'why would you be trying to keep him alive? This is the man's will' . . . at that board meeting [family conference] . . . they voiced my father's opinion like they're standing up for him and his will" [the patient's son].

In the four instances of interfamily strife, we found that the interactions between family members and clinicians informed surrogates and family members about the medical, legal, and ethical aspects of the patient's preferences. These interactions helped the next of kin to know that the patient's wishes had been honored: "We probably could have pulled the plug sooner . . . a lot of animosity between me and his children from his first marriage . . . when they called us in on Thursday morning, the doctor told them that there was absolutely nothing there, she told them that I would have the final say that that was their father's last wishes.

. . . I was glad we got the living will because he got his last wishes and that's what I told his kids. I said, 'we're doing what he wants, not what I want, not what you all want, we're doing what he wants' " [the patient's fiancée].

DISCUSSION

The findings of this study suggest that surrogates undergo a process of formulating knowledge, wherein they utilize hearing, seeing, and interacting as ways of knowing a loved one's end-of-life preferences and knowing that those preferences were honored. Our analysis revealed two phases in the process of formulating this knowledge. During the first phase, *the patient is sick*, the next of kin focused on the acute illness that necessitated their loved one's hospital admission. Because many next of kin believed their loved one was not seriously ill and would recover, knowledge of the patient's end-of-life preferences was not then their primary concern. Even though a majority of the next of kin said their loved one had an advance directive, very few made mention of the patient's stated preferences when they described the early days of the patient's hospitalization. It was during the second phase, *the patient is dying*, that their knowledge of a loved one's end-of-life preferences became salient to make treatment decisions.

Discussions with physicians regarding a loved one's impending death appeared to play an important role in the transition from the *patient is sick* phase to the *patient is dying* phase. When clinicians raised topics of treatment options and hospice placement, knowledge of a loved one's preferences began to have operative relevance to the next of kin. During this phase, the next of kin articulated recollections of prior conversations when the patient either implicitly or explicitly conveyed her or his end-of-life preferences. Our findings suggest that end-of-life discussions with a clinician were key for the next of kin to transition from the *patient is sick* to the *patient is dying*.

Three ways of knowing a loved one's end-of-life preferences emerged from our analysis: hearing, seeing, and interacting. *Hearing* appeared to be the most prevalent way of knowing, with 81 percent of the next of kin reporting conversations with their loved one about end-of-life preferences. The importance of hearing as a way of knowing about a loved one's preferences was supported by the fact that even when a patient was cognitively impaired, the next of kin indicated they had acquired knowledge of their loved one's preferences during prior conversations. The value of casual or informal conversations about end-of-life preferences is twofold. First, end-of-life conversations impart knowledge of a loved one's preferences. Second, this acquired knowledge was used in a practical way by the next of kin during the difficult process of making decisions at the end of life.

Our analysis further revealed that hearing conversations between the patient and a physician was a way to learn about a loved one's preferences. Obtaining knowledge in this way highlights the significance of end-of-life discussions, even when surrogates were merely observers. Conversations between the next of kin and clinicians were also instrumental for acquiring knowledge, particularly when the next of kin perceived a physician to be "explaining" end-of-life processes. Conversely, our findings indicate that perceptions of poor communication as the patient approached death compromised the next of kin's understanding of end-of-life options.

Seeing as a way of knowing had relevance for affirming that a loved one's wishes were honored. Observing the delivery of medical and nonmedical comfort care provided evidence for the next of kin that their loved one's wishes were being honored. This is important because honoring a loved one's wishes diminishes the stress associated with end-of-life decision making, and so has the potential to reduce the negative impact of making difficult end-of-life decisions on behalf of a loved one.[27]

Social interaction at the end of life informed the next of kin in various ways. For the next of kin who did not have a long history with the patient, interactions with clinicians were an important way to learn about their loved one's preferences. Typically, next of kin who had been in

a long-term relationship with the patient had multiple opportunities to hear the patient discuss end-of-life preferences during visits with a physician or with clinical staff during a hospitalization; but the interactions between clinicians and next of kin who had a limited history with a patient appeared to be uniquely valuable for the next of kin to acquire knowledge about their loved one's end-of-life preferences.

In cases of family strife, interactions with clinicians helped inform the next of kin and other family members of the patient's options. Furthermore, interactions with clinicians afforded the next of kin who had complicated family circumstances the opportunity to know that their loved one's wishes were honored. We found that even negatively perceived interactions with clinicians served as a way to learn about a loved one's preferences and as a way to know whether those preferences were honored, which underscores the significance of social interaction as a way to acquire knowledge.

The formation of knowledge in surrogates at the patient's end of life is not well understood. Employing an epistemological approach, our data described how surrogates in our study came to know their loved one's end-of-life preferences and know whether those preferences were honored. These results extend the literature on ways of knowing. A post-analysis review of the literature indicated similar findings among educational studies. Researchers examining learning strategies found university students and individuals living in communities utilized "speaking," "looking," "hearing," and "seeing" as ways of knowing.[28] Results from these earlier studies provide support for our findings that independently emerged from qualitative analysis.

CONCLUSION

Our study explored how patients' next of kin came to know their loved one's preferences regarding end-of-life treatment and how the next of kin affirmed the honoring of those preferences. As our findings reveal, learning is not a linear process. The next of kin in our study utilized multiple ways of knowing. A broader understanding of how the next of kin come to know about the patient's end-of-life preferences may provide new ways for physicians to initiate conversations about end-of-life care.

Contextualizing the acquisition of knowledge by surrogates as a process can inform the broader discourse on end-of-life decision making. Even though clinicians may determine that a patient's prognosis at the time of hospitalization is dire, it is important to recognize that the patient's next of kin may not have an expectation of death during the early days of a hospitalization. The next of kin may have prior knowledge of a loved one's preferences; however, it is communication at the end of life that may serve as a pivotal juncture in the process of acquiring knowledge for the next of kin. A more informed understanding of how family members acquire and process knowledge may prove helpful to clinicians as they confront difficult encounters around making decisions at the end of a patient's life.

ACKNOWLEDGMENT

This research was supported by a Merit Review grant from the Department of Veterans Affairs, Veterans Health Administration, Health Services Research and Development Service (IIR 03-126 "Intervention to Improve Care at Life's End in VA Medical Centers," PI: K.L. Burgio, Co-PI: F.A. Bailey).

NOTES

1. *Health, United States, 2010: With Special Feature on Death and Dying* (Hyattsville, Md.: National Center for Health Statistics, 2011), 41, *www.cdc.gov/nchs/data/hus/hus10.pdf,* accessed 22 March 2013.

2. N.S. Wenger, L.R. Shugarman, and A. Wilkinson, "Advance directives and advance care planning: Report to Congress," Department of Health and Human Services, 2008, *http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf,* accessed 22 March 2013.

3. A.M. Torke et al., "The physician-surrogate relationship," *Archives of Internal Medicine* 167 (2007): 1117-21; A.M. Torke et al., "Physicians' experience with surrogate decision-making for hospitalized adults," *Journal of General Internal Medicine* 24, no. 9 (2009): 1023-8; I.C. Fineberg et al., "Com-

munication with families facing life-threatening illness: A research-based model for family conferences," *Journal of Palliative Medicine* 14, no. 4 (2011): 421-7.

4. T.L. Beauchamp and J.F. Childress, "A framework of standards for surrogate decision making," in *Principles of Biomedical Ethics*, ed. T.L. Beauchamp and J.F. Childress (New York, N.Y.: Oxford University Press, 2009), 135-40; C.P. Sabatino, "The evolution of health care advance planning law and policy," *Milbank Quarterly* 88, no. 2 (2010): 211-39.

5. A.M. Torke, G.C. Alexander, and J. Lantos, "Substituted judgment: The limitations of autonomy in surrogate decision making," *Journal of General Internal Medicine* 23, no. 9 (2008): 1514-7.

6. K. Pardon et al., "Preferences of patients with advanced lung cancer regarding the involvement of family and others in medical decision-making," *Journal of Palliative Medicine* 13, no. 10 (2010): 1199-203; E.K. Vig et al., "Beyond substituted judgment: How surrogates navigate end-of-life decision-making," *Journal of the American Geriatrics Society* 54 (2006): 1688-93; J.J. Fins et al., "Contracts, covenants and advance care planning: An empirical study of the moral obligations of patient and proxy," *Journal of Pain and Sympton Management* 29, no. 1 (2005): 55-68; C.M. Puchalski et al., "Patients who want their family and physician to make resuscitation decisions for them: Observations from SUPPORT and HELP," *Journal of the American Geriatrics Society* 48 (2000): S84-90.

7. Puchalski et al., see note 6 above; Fins et al., see note 6 above.

8. B. Kelly, A. Rid, and D. Wendler, "Systematic review: Individuals' goals for surrogate decision-making," *Journal of the American Geriatrics Society* 60 (2012): 884-95.

9. L. Apatira et al., "Hope, truth and preparing for death: Perspectives of surrogate decision makers," *Annals of Internal Medicine* 149, no. 12 (2008): 861-8; C.M. Handy et al., "The surrogate's experience in authorizing a do not resuscitate order," *Palliative and Supportive Care* 6 (2008): 13-9; E.K. Vig et al., "Surviving surrogate decision-making: What helps and hampers the experience of making medical decision for others," *Journal of General Internal Medicine* 22 (2007): 1274-9; D.L. Wiegand, "Withdrawal of life-sustaining therapy after sudden, unexpected life-threatening illness or injury: Interactions between patients' families, healthcare providers, and the healthcare system," *American Journal of Critical Care* 15, no. 2 (2006): 178-87; L.R. Evans et al., "Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty," *American Journal of Respiratory and Critical Care Medicine* 179 (2009): 48-53; S.K. Johnson et al., "An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units," *American Journal of Respiratory and Critical Care Medicine* 183, no. 7 (2011): 915-21.

10. Fineberg et al., see note 3 above.

11. Ibid.

12. Ibid.

13. M.C. Green and T.C. Brock, "Organizational membership versus informal interaction: Contributions to skills and perceptions that build social capital," *Political Psychology* 26, no. 1 (2005): 1-25; A. Chua, "The influence of social interaction on knowledge creation," *Journal of Intellectual Capital* 3 (2002): 375-92; M. Handzic and D. Tolhurst, "The role of personal experience and social interaction in knowledge creation and utilisation," *Proceedings of the 15th Annual Conference of the International Academy for Information Management* (Brisbane, Australia: International Academy for Information Management, 2000), 37-48.

14. K. Pardon et al., see note 6 above; K.E. Rosenfeld, N.S. Wenger, and M.Kagawa-Singer, "End-of-life decision making: A qualitative study of elderly individuals," *Journal of General Internal Medicine* 15 (2000): 620-5; C. Frank et al., "Determining resuscitation preferences of olderly inpatients: A review of the literature," *Canadian Medical Association Journal* 169, no. 8 (2003): 795-9; Fins et al., see note 6 above.

15. Puchalski et al., see note 6 above; Fins et al., see note 6 above; Sabatino, see note 4 above; T.L. Mills and J.M. Wilmoth, "Intergenerational differences and similarities in life-sustaining treatment attitudes and decision factors," *Family Relations* 51, no. 1 (2002): 46-54; Torke, Alexander, and Lantos, see note 5 above; G.S. Winzelberg, L.C. Hanson, and J.A. Tulsky, "Beyond autonomy: Diversifying end-of-life decision-making approaches to serve patients and families," *Journal of the American Geriatrics Society* 53, no. 6 (2005): 1046-50; J.T. Berger, E.G. DeRenzo, and J. Schwartz, "Surrogate decision making: Reconciling ethical theory and clinical practice," *Annals of Internal Medicine* 149 (2008): 48-53.

16. E.A. Boyd et al., "It's not just what the doctor tells me: Factors that influence surrogate decision-makers' perceptions of prognosis," *Critical Care Medicine* 38, no.5 (2010): 1270-5.

17. Vig et al., see note 6 above; Vig et al., see note 9 above; V.P. Tilden et al., "Family decision-making to withdraw life-sustaining treatment from

hospitalized patients," *Nursing Research* 50, no. 2 (2001): 105-15; M.A. Meeker, "Family surrogate decision making at the end of life: Seeing them through with care and respect," *Qualitative Health Research,* 14, no. 2 (2004): 204-25.

18. Meeker, see note 17 above.

19. I. Tuffrey-Wijne, "A new model for breaking bad news to people with intellectual disabilities," *Palliative Medicine* 27, no. 1 (2012): 5-12; L.S. Zier et al., "Surrogate decision maker's interpretation of prognostic information: A mixed-methods study," *Annals of Internal Medicine* 156 (2012): 360-6.

20. G. Elwyn, "Arriving at the postmodern medical consultation," *Primary Care* 5 (2005): 287-9; J.H. Danovitch and F.C. Keil, "Should you ask a fisherman or a biologist?: Developmental shifts in ways of clustering knowledge," *Child Development* 75 no. 3 (2004): 918-31; K. Malterud, "The art and science of clinical knowledge: Evidence beyond measures and numbers," *Lancet* 358 (2001): 397-400.

21. D.R. Brush, C.E. Brown, and G. C. Alexander, "Critical care physicians' approaches to negotiating with surrogate decision makers: A qualitative study," *Critical Care Medicine* 40, no. 4 (2012): 1-8; M.B. Kapp, "Medical decision-making for incapacitated elders: A 'therapeutic interests' standard," *International Journal of Law and Psychiatry* 33 (2010): 369-74; A.M. Torke et al., "Physicians' views on the importance of patient preferences in surrogate decision-making," *Journal of the American Geriatrics Society* 58 (2010): 533-8; J.W. Jones and L.B. McCullough, "Dominions of surrogate opinions: Who is in charge?" *Journal of Vascular Surgery* 49 (2009): 249-50.

22. J.R. Curtis et al., "A measure of the quality of dying and death. Initial validation using after-death interviews with family members," *Journal of Pain and Symptom Management* 24, no. 1 (2002): 17-31; K. Rosenfeld and J. Rasmussen, "Palliative care management A Veterans Administration demonstration project," *Journal of Palliative Medicine* 6, no. 5 (2003): 831-9; J.M. Teno et al., "Validation of Toolkit After-Death Bereaved Family Member Interview," *Journal of Pain and Symptom Management* 22, no. 3 (2001): 752-8.

23. D.E. Meier, *A Guide to Building a Hospital-Based Palliative Program* (New York: Center to Advance Palliative Care, 2004).

24. L.L. Woodby et al., "Expanding the notion of researcher distress: The cumulative effects of coding," *Qualitative Health Research* 21, no. 6 (2011): 830-8.

25. M.B. Miles and A.M. Huberman, "Qualitative data analysis," 2nd ed. (Newbury Park, Calif.: Sage Publications, 1994); J.B. Averill, "Matrix analysis as a complementary analytic strategy in qualitative inquiry," *Qualitative Health Research* 12, no. 6 (2002): 855-66.

26. J.R. Hall, "Epistemology and sociohistorical inquiry," *Annual Review of Sociology* 16 (1990): 329-51; J. Habermas, *Theory of Communicative Action*, trans. T. McCarthy(Boston: Beacon Press, 1984); ; M. Foucault, *Power/knowledge: selected interviews and other writings, 1972-1977,* ed. C. Gordon, trans. C. Gordon et al. (New York: Pantheon, 1980).

27. K.M. Detering et al., "The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial," *British Medical Journal* (2010): 340:c1345; D. Wendler and A. Rid, Systematic review: The effect on surrogates of making treatment decisions for others," *Annals of Internal Medicine* 154 (2011): 336-46; Meeker, see note 17 above; Tilden et al., see note 17 above.

28. W.G. Perry, *Forms of Intellectual and Ethical Development in the College Years: A Scheme* (New York: Holt, Rinehart, and Winston, 1970); M.F. Belenky, B.M. Clinchy, N.R. Goldberger, J.M. Tarule, *Women's Ways of Knowing: The Development of Self, Voice, and Mind, 10th Anniversary Edition* (New York: Basic Books, 1997); K. Taylor, C. Marienau, and M. Fiddler, "Women's ways of knowing," in *Developing Adult Learners: Strategies for Teachers and Trainers* (San Francisco, Calif.: Jossey-Bass, 2000), 345-9.

Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates

Jenna Fritsch, Sandra Petronio, Paul R. Helft, and Alexia M. Torke

ABSTRACT

Background

Hospitalized older adults frequently have impaired cognition and must rely on surrogates to make major medical decisions. Ethical standards for surrogate decision making are well delineated, but little is known about what factors surrogates actually consider when making decisions.

Objectives

To determine factors surrogate decision makers consider when making major medical decisions for hospitalized older adults, and whether or not they adhere to established ethical standards.

Design

Semi-structured interview study of the experience and process of decision making.

Setting

A public safety-net hospital and a tertiary referral hospital in a large city in the Midwest United States.

Participants

The study included 35 surrogates with a recent decision-making experience for an inpatient aged 65 or older.

Measurements

The key factors that surrogates considered when making decisions. Interview transcripts were coded and analyzed using the grounded theory method of qualitative analysis.

Results

Surrogates considered patient-centered factors and surrogate-centered factors. Patient-centered factors included: (1) respecting the patient's input, (2) using past knowledge of the patient to infer the patient's wishes, and (3) consider-

Jenna Fritsch, BS, is a Medical Student at Indiana University School of Medicine in Indianapolis, Indiana.
Sandra Petronio, PhD, is Senior Affiliate Faculty at the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health and is a Professor at Indiana University-Purdue University Department of Communication Studies.
Paul R. Helft, MD, is Director of the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health; is an Associate Professor of Medicine at Indiana University; and is an Oncologist at the Indiana University Melvin and Bren Simon Cancer Center.
Alexia M. Torke, MD, MS, is a Scientist at the Indiana University Center for Aging Research at the Regenstrief Institute; is Senior Affiliate Faculty and Fellowship Director at the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health; and is an Associate Professor of Medicine in the Division of General medicine and Geriatrics at the Indiana University School of Medicine, *atorke@iupui.edu.*

ing what is in the patient's best interests. Some surrogates expressed a desire for more information about the patient's prior wishes. Surrogate-centered factors included: (1) surrogate's wishes as a guide, (2) surrogate's religious beliefs and/or spirituality, (3) surrogate's interests, and (4) family consensus.

Conclusion

Our study indicates that surrogate decision making is more complex than the standard ethical models, which are limited to considerations of the patient's autonomy and beneficence. Because surrogates also imagine what they would want under the circumstances and consider their own needs and preferences, models of surrogate decision making must account for these additional considerations. Surrogates' desire for more information about patients' preferences suggests a need for greater advance care planning.

INTRODUCTION

Approximately 40 percent of hospitalized patients lack decision-making capacity due to cognitive impairment,[1] and, in such cases, physicians must work with surrogate decision makers to determine an appropriate course of care. This need for surrogate decision making is likely to grow as life-sustaining technology expands, the population ages, and the prevalence of diseases like Alzheimer's and other forms of dementia increase.[2]

Bioethical standards for surrogate decision making have advocated basing decisions on the patient's previous autonomous wishes as well as on the patients' best interests.[3] Surrogates should first honor the patient's wishes by following the patient's advance directive or relying on substituted judgment. If a patient's wishes are unknown, a surrogate should then advocate for the patient's best interests. Courts have similarly argued that surrogate decisions should be based on prior knowledge of the patient's wishes or on the patient's best interests.[4] This emphasis on the patient's wishes is further supported by the U.S. Patient Self-Determination Act and by statutory documents for advance directives that allow patients to specify their desired care and decision makers.

There are, however, problems in the application of these standards.[5] These include the fact that the majority of patients do not have advance directives[6] and that surrogates frequently make inaccurate predictions of the patient's wishes[7] or make decisions that clinicians do not think are in the patients' best interests.[8] Additionally, advance care planning and surrogate decision making often require that decisions be made about life situations that the decision makers themselves have not experienced.[9] Studies report that despite advance care planning, chronically ill patients change their mind about their medical treatment over time and as their health status dissipates.[10] This instability in patients' wishes adds to surrogates' challenge to respect patients' autonomy.

Making decisions is clearly complex for family members and other surrogates, yet there is little data about how surrogates go about making decisions. A qualitative study in Norway reported that relatives acting as surrogate decision makers for nursing home patients used the patients' preferences and patients' best interests as well as other factors, such as surrogates' preferences, fear of loss of a loved one, and feelings of guilt for not trying everything possible when making decisions.[11] Another study examining surrogates for patients with advanced Alzheimer's disease, in a suburban long-term care facility as well as in a subspecialty clinic in the U.S., found that reaching a family consensus, determining a patient's quality of life, and advice from healthcare authorities are major contributors to the surrogate decision-making process.[12] A study of surrogates considering past and future decisions for veterans found that surrogates consider patients' preferences, values that the surrogates shared with patients, surrogates' own beliefs, and input from others.[13]

Surrogates for hospitalized older adults often face life-threatening decisions and sometimes must make decisions under significant time pressure. However, we have little information about surrogates' approaches to decision making in this setting. To gain better insight into the ethical factors considered by surrogates during their decision-making process, we interviewed the surrogates of hospitalized older adults during or soon after the surrogates had made a major medical decision.

METHODS

Study Design and Population

Semi-structured, in-depth interviews were conducted with surrogate decision makers from two urban hospitals: a public safety-net hospital and a tertiary referral hospital, both part of an urban, university-affiliated, academic health center. Patients were recruited for this study as part of a larger observational study of surrogate decision making. For the present investigation, surrogates of inpatients aged 65 or older who were admitted to an internal medicine or medical intensive care unit who had considered at least one major decision in the first 48 hours of hospitalization were eligible. Eligible surrogate decision makers were identified by briefly interviewing the patients' primary inpatient physician or advanced practice nurse to determine whether the medical team had considered a major intervention for a patient during the current hospital admission and whether there was surrogate involvement in decision making. For purposes of this study, major medical decisions included: (1) decisions regarding procedures and surgeries; (2) decisions regarding life-sustaining care such as code status, intubation, artificial nutrition, et cetera; and (3) decisions about hospital discharge to a nursing facility or similar institution. Eligible procedures were any that required signed informed consent based on hospital policy. The study was approved by the Indiana University Institutional Review Board, and informed consent was obtained from each surrogate prior to the interview.

Data Collection

Semi-structured, in-depth interviews were conducted by two investigators using an interview guide (see figure 1). Open-ended questions were asked of the surrogates, followed by optional prompts, which were included in the interview guide in order to maintain consistency in the interviews. Surrogates were interviewed within one month of having made a major medical decision for an inpatient. This was done to minimize recall bias. In the case of a patient's death, surrogates were interviewed between two and five months later, to allow time for acute grieving prior to the interview. Interviews were audiotaped and transcribed verbatim.

Data Analysis

After the first five interviews had been conducted, two investigators (AMT and SP) reviewed the transcripts to identify themes or topics that merited further attention in successive interviews, with particular attention to those we considered to have ethical dimensions. The investigators continued to meet after approximately every five interviews to discuss emerging themes and determine whether theme saturation had been achieved. For the current analysis, all of the interviews were read and coded independently by two researchers (AMT and JF) using methods of grounded theory.[14] Segments of the transcripts pertaining to the surrogate's justification for their decisions and the decision-making factors they relied on were identified and coded. The two researchers met weekly to review coding and to identify overarching themes that described the factors surrogates relied upon to make decisions. Discrepancies in coding were discussed and consensus was reached. This reoccurring process allowed for ideas and themes to be refined and clarified throughout the data collection process in accordance with standard qualitative methods.[15] The two coders met with a third member of the research team (SP) to discuss the codes and emerging themes.

In addition to two investigators independently coding the interviews, other measures were taken to ensure the credibility and trustworthiness of the data. The three researchers were familiar with all of the interviews, each of whom offered a unique disciplinary perspective to the qualitative analysis; they included a practicing physician with bioethics training (AMT), a medical student with a biology and business background (JF), and an expert in the fields of health and family communication (SP). The interview process continued until theme saturation was reached (that is, the point at which no new themes emerged). Finally, our findings were presented to a group of physicians who practice inpatient or geriatric medicine to confirm the validity of our conclusions.

RESULTS

Subjects

A total of 35 surrogates were interviewed (see table 1). At the public hospital, 87 surrogates were enrolled in a larger observational study, of whom 30 consented to an interview. At the tertiary referral center, 13 surrogates were enrolled in an observational study, and five completed an interview. We found that 68 percent of the surrogates interviewed made a decision on the patient's behalf about life-sustaining therapy; 80 percent made a decision about a procedure or surgery; and 40 percent made a decision about where the patient would go upon discharge from the hospital. All of the surrogates except one were relatives of the patient (see table 1). Surrogate/patient relationships prior to the patient's acute illness varied in their intimacy, from surrogates who only saw the patient occasionally to relatives who lived with or served as the primary in-home caregiver for the patient. Below we describe primary and secondary themes related to the surrogate's decision-making factors, the process of decision making, and the outcomes of the decisions.

Decision-Making Factors

We found that decision-making factors could be grouped into two primary themes: patient-centered factors and surrogate-centered factors. We also found that many surrogates incorporated several decision-making factors into their reasoning for a single decision.

Figure 1. Interview guide

1. **Introduction**
   Tell me about [patient] and what brought [him/her] to the hospital.
2. **Information disclosure**
   During the time [patient] was/has been in the hospital, how did you find out what was happening to him/her?
3. **Relationship building**
   What was your first impression of the hospital staff? Was there anyone at the hospital you could rely on? Why or why not? Tell me a little about how things have been for you since [patient] was in the hospital? Sometimes people have both positive and less positive experiences when they are in the hospital. In the time that [patient] was most recently in the hospital, could you tell me a little about the positive experiences?
4. **Decision making [repeat questions 4 through 6 for up to three decisions]**
   One decision that [patient's] physicians have considered is [target decision]. What, if any, conversations with the doctors or other hospital staff can you recall about this decision? What part did you play in making the decision? How did you decide what to do? In the end, did you think the right decision was made? Why or why not?
5. **Possible interventions**
   Can you think of anything that could have been done to help you make this decision for [patient]?
6. **Decision-making outcomes**
   When you look back on this decision, what do you think would be the best possible outcome for [patient]? What about for you? Do you think [patient] was fully able to make the decision for him/herself, partially able to make the decision, or not at all able to make the decision?
7. **General outcomes**
   When you look back on [patient's] time in the hospital, what seems most important to you?
8. **General interventions**
   Can you think of anything that could have been done to make the hospital experience better for you or [patient]?
9. **Additional information**
   Is there anything else you would like to tell me about your experience when [patient] was in the hospital?

Patient-Centered Factors

The primary theme of patient-centered surrogate decision making is represented by three secondary themes: (1) respecting the patient's input, (2) using past knowledge of the patient to infer the patient's wishes, and (3) considering what is in the patient's best interests.

The patient's input. We identified two ways that surrogates respected patients' wishes through the use of the patients' input. First, surrogates often actively shared in decision making with the patient by discussing options with the patient and reaching an agreement. Second, several surrogates left the entire decision up to the patient, even though, in the opinion of the treating physician, the patient was not fully capable of decision making. For example, one surrogate noted, "I was just really in the background to support her decision when she made it so she didn't feel like she was by herself and really just support her." In some cases, surrogates acknowledged that the patient may have been unable to fully understand the decision, but still they honored the patient's decision.

TABLE 1. Subjects' characteristics (*N* = 35)

Characteristic	Number of surrogates	%
Race		
African American	18	51.4
White	17	48.6
Gender		
Female	28	80.0
Education		
9 to 12 years	20	57.1
13 to 16 years	11	31.4
17+ years	4	11.4
Religion		
Protestant	29	82.9
Roman Catholic	3	8.6
Spiritual	1	2.9
None	2	5.7
Relationship of surrogate to patient		
Daughter	21	60.0
Son	5	14.3
Sister	2	5.7
Spouse	2	5.7
Other*	2	14.3

* "Other" includes nephew, niece, grandson, cousin, and friend (one each).

Knowledge of the patient's prior wishes. Some surrogates based their decisions on statements of preference made by the patient some time in the past or by using their knowledge of the patient's values and interests to determine what the patient would have wanted. To demonstrate, one surrogate stated, "She always told us, even when we were younger, that she never wanted to be a burden on anybody, where, um, she was just like a vegetable laying there hooked up to machines and really wasn't productive or . . . or couldn't live a life, she doesn't want that." Additionally, surrogates based their decisions on the patients' stated wishes through the use of an advance directive.

On many occasions, surrogates who lacked knowledge of a patient's preferences expressed a desire to have more information so they could better decide in accordance with the patient's wishes. This lack of knowledge tended to add stress and difficulty to the decision-making process. "Um . . . it was difficult in the emergency room to have to make that decision for someone. When they are not able to tell you, you know, how they feel or what they want done," explained one surrogate.

The patient's best interests. Surrogates often considered what was in a patient's best interest when making decisions. Their emphasis on the patient's best interests was displayed in four different ways. First, surrogates often considered what decision would most help to improve the patient's health. When asked, "When looking back on [the patient's] time in the hospital, what seems most important to you?" surrogates frequently gave a response such as the patient's receiving the best possible care or the patient's getting healthy. Sometimes surrogates viewed specific procedures or undertakings as necessary or the only way to improve the patient's health, and so did not consider the choice to be an actual decision. For instance, one surrogate stated, "There was no decision with us . . . I mean they thought hey . . . . she needs it."

Second, surrogates viewed the patient's best interest in terms of the patient's suffering or

quality of life. Surrogates would often note that they did not want the patient to suffer any longer and thus refused life-sustaining therapies. For example, one surrogate explained, "To me, she's suffering because she can't see. She can't walk. . . . So, I made that decision based on that and that way she don't have to suffer. I don't want her to go through the pain that will be put on her with them trying to resuscitate her." In other instances, surrogates noted that the use of life-sustaining therapies simply maintained a body, but not a life, and therefore opted against using such therapies. This reasoning was also applied in other types of decisions, such as surgeries and resuscitation code status.

Third, some surrogates would weigh the risks and benefits of procedures when trying to make a decision in the patient's best interests. This often included gathering information from clinicians or from another source, such as the internet. Some surrogates reported feeling uneasy about making decisions when they felt they did not have adequate information.

Finally, surrogates often sought the advice of a physician or other professional when making decisions. Surrogates reported that they valued a clinician's opinion because they trusted the clinician to place the patient's best interest first and foremost. However, surrogates seemed to only consider the clinician's advice when they trusted the clinician. One surrogate stated, "The belief that you folks [medical professionals] have our wellness and goodness first and utmost in, you know, that has to be a belief. We are in a huge trust factor here." Trust and consideration of a clinician's opinion tended to be mentioned hand in hand.

Surrogate-Centered Factors

The primary theme of surrogate-centered decision making is represented by four secondary themes that include: (1) the surrogate's wishes as a guide, (2) the surrogate's religious beliefs and/or spirituality, (3) the surrogate's interests, and (4) family consensus.

The surrogate's wishes as a guide. In addition to patient-centered considerations, surrogates often relied on their own wishes, or what they themselves would want if they were the patient. Sometimes the surrogates used this notion as a primary means to reach a decision, while, in other instances, surrogates used their own wishes as a backup guide when a patient's wishes or interests were unknown. One sister who described her relationship with the patient as somewhat distant stated, "I said, 'I can only tell you what I would want. I cannot tell you what she would want because I don't know.' And, of course, my choices are that no heroic measure be taken if I'm in that bad of shape. It's just time to let go."

The surrogate's religious beliefs/spirituality. At times surrogates based their decisions on their own religious beliefs and/or spirituality. Several surrogates explained that the patient's situation was part of God's plan. In some cases, this deterred the surrogate from making a decision that might, in the surrogate's view, interfere with God's plan, and, in other instances, a surrogate made a decision based on other factors, but acknowledged that the outcome of that decision was in God's hands. One surrogate justified her decision to sign a do-not-resuscitate (DNR) order because she did not want to interfere with God's plan. She stated, ". . . I feel that will be the best decision for her and if her heart was to stop beating, I feel like that God was calling her home. . . . To me, that's God's doing so I wouldn't want to mess with God's plan."

The surrogate's interests. Beyond the surrogate's wishes, the surrogate's interests played a role in decision making. The surrogate's interests included considerations of how decisions might affect the surrogate's lifestyle and the impact of a decision or outcome on the surrogate and/or family. In several cases, surrogates expressed their inability or discontent with taking care of the patient themselves, when considering the patient's discharge placement or code status. In one interview, a surrogate who lived with a patient and served as his caregiver explained that the patient did not want to go to a nursing home, but, despite the patient's wishes, the surrogate still made the decision to put the patient in a nursing home following discharge. The surrogate explained: "I could never tell if he was hungry, if he didn't want this, if he had to go to the bathroom, so I had no choice,

. . . there's nothing I can do about that. I couldn't take care of him no more. Not with no communication I can't. There's nothing I can do except clean up constantly, and I don't want to do that." This surrogate expressed a limit to the obligations he was willing to take on with respect to the patient.

Another common consideration when determining discharge placement was how close or accessible a nursing home or similar type of facility was to the patient's family. Many surrogates discussed trying to find an institution in a specific region or radius of the family. Convenience appeared to play little role in other major medical decisions made by the surrogates.

Family consensus. Surrogates often felt compelled to reach family consensus on decisions or have the support of their family behind the decisions they made. Surrogates used family consensus as a means to reach what they considered to be the best decision or as a way to remove responsibility from themselves. One surrogate recounted, "I can't make that decision on my own when I got five sisters. . . . They have to be there too . . . I'm not taking responsibility to say, well you should have did everything and they should have did this and they should have did that, and I said no, I'm not taking that responsibility. We either all make the decision or none make the decision."

DISCUSSION

Our qualitative study of surrogates' approaches to decision making found that, in addition to the patient's wishes and best interests, surrogates considered other factors such as their own wishes, interests, emotional needs, religious beliefs, and past experiences with healthcare. Surrogates' decision making is therefore more complex than standard ethical models, which are limited to the patient-centered principles of autonomy and beneficence. In prior research we found that physicians considered surrogate-centered factors and other ethical factors when making decisions for hospitalized patients.[16] We conclude that the standard patient-centered model does not provide a complete framework for surrogate decision making. Further theoretical work is needed to consider the appropriate role of surrogate-centered factors in decision making.

Patients' preferences were a major consideration for surrogates. Surrogates relied on information about patients' preferences when they were present through the use of advance directives, substituted judgment, or patients' input, but surrogates often expressed the need for more information about what the patient would have wanted when the patient's wishes were not known. Without such information, surrogates struggled to feel confident in their decisions. This study provides further support for the important potential role of advance care planning in preparing surrogates for decision making and mitigating distress in the decision-making role.[17]

Our study highlights the value that surrogates placed on family consensus in decision making. Many surrogates favored consensus because it distributed the responsibility of decision among several individuals, or because it may have lessened the guilt felt by the surrogate when making decisions such as ending life support, and there are other potential benefits to consensus. Consensus helped to maintain family cohesion through the distress, and made surrogates more comfortable in their role. Most importantly, family consensus might align with a patient's wishes for the decision-making process.[18] Not only do patients want family and caregivers to reach consensus regarding their care,[19] guidelines also advocate working towards consensus in surrogate decision making.[20]

We found that when surrogates lacked information about the patient's preferences, some employed other means to make decisions in addition to considerations of what was in the patient's best interests. Specifically, some surrogates considered what they themselves would have wanted if they were the patient. Using one's own beliefs as a guide to make decisions for another does not appear in the ethical standards for surrogate decision making, although there is evidence that surrogates do rely on their own beliefs to make decisions in other clinical settings.[21] Two additional studies that used hypothetical cases found that surrogates' decisions for patients were more closely aligned with pref-

erences for themselves than with the patient's preferences. The authors regarded this finding and an example of the surrogates' "projection" and noted that this process was conceptually different from substituted judgment, in which a surrogate might imagine what a patient would want, rather than what the surrogate wants.[22] In the present study, surrogates' reliance on what they would want for themselves does seem to be consistent with the golden rule, a fundamental concept in Judeo-Christian ethics. The normative role of a "golden rule" approach is worthy of further study and theoretical consideration, as it may constitute an alternative approach to surrogate decision making that is ethically acceptable.

Consistent with other studies,[23] we found surrogates consider their own needs and preferences when making decisions for patients. This raises the question of whether it is ethically acceptable for surrogates to base decisions on their own needs or whether the traditional model that relies entirely on patient-centered factors should be maintained. Studies report that patients are concerned with burdening their loved ones,[24] recognize that surrogates must live with the decisions they make,[25] and do not perceive deviations from patients' preferences as infractions of their autonomy.[26] Patients therefore give surrogates some leeway when making decisions.[27]

The emotional needs of surrogates, particularly the understandable drive to avoid guilt, also swayed their decisions. Surrogates often made decisions that gave patients every possible chance at recovery, in an effort to avoid feelings of guilt for not trying everything possible, or to fulfill their perceived obligations towards the patients. This highlights the need to reassure surrogates that decisions to refuse life-sustaining therapy do not indicate that surrogates have given up on or are personally responsible for negative outcomes or a patient's death.

Our study had several weaknesses. First, we had a low response rate of 35 percent. This could introduce bias into our results. Our largely female sample may have underrepresented the views of male surrogates. However, our sample is consistent with other studies that have found that hospital surrogates and family caregivers for older adults are at least 70 percent female.[28] Additionally, we chose to delay interviews when a patient had recently died to allow time for acute grieving. The responses of the subjects whose interviews were delayed due to the death of a patient may have differed from subjects who were interviewed sooner and may be a source of bias.

In conclusion, surrogate decision makers for hospitalized older adults relied heavily on the standard ethical concepts of the patient's preferences and best interests, but also considered other factors such as their own preferences, interests, emotions, experiences, and religious beliefs, factors that are not traditionally included in ethical models of surrogate decision making. Surrogates' desire for more information about the patient's preferences points to a need for more advance care planning. When such information is not known, surrogates may use their own wishes as a decision-making guide, but they may also consider their own beliefs and interests. More work is needed to understand the implications of expanding the ethical models of surrogate decision making, including how to better address these important issues and to consider how they ought to be weighed in the decision-making process.

ACKNOWLEDGMENTS

Jenna Fritch was supported through the Medical Student Training in Aging Research (MSTAR) program, administered by the American Federation for Aging Research and the National Institute on Aging. Alexia Torke was supported by a career development award from the National Institute on Aging of the National Institutes of Health under Award Number K23AG031323. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

NOTES

1. V. Raymont et al., "Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study," *Lancet* 364 (October 2004): 1421-7.

2. F.G. Reamer, "Review," *Social Service Review*

65, no. 4 (1991): 640-3; A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1990); Alzheimer's Association, *Alzhiemer's Disease Facts and Figures* (Washington, D.C., Alzheimer's Assocation, 2011).

3. Buchanan and Brock, see note 2 above; E.J. Emanuel and L.L. Emanuel, "Proxy decision making for incompetent patients: An ethical and empirical analysis," *Journal of the American Medical Association* 267, no. 15 (15 April 1992): 2067-71.

4. R. Dresser, "Precommitment: a misguided strategy for securing death with dignity," *Texas Law Review* 81, no. 7 (June 2003): 1823-47.

5. Dresser, see note 4 above; A. Fagerlin and C.E. Schneider, "Enough: The failure of the living will," *Hastings Center Report* 34, no. 2 (March-April 2004): 30-42; J.V. Welie, "Living wills and substituted judgments: a critical analysis," *Medicine, Health Care, and Philosophy* 4, no. 2 (2001): 169-83; K.B. Hirschman, J.M. Kapo, and J.H. Karlawish, "Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person?" *American Journal of Geriatric Psychiatry* 14, no. 8 (August 2006): 659-67.

6. S.H. Miles, R. Koepp, and E.P. Weber, "Advance end-of-life treatment planning: A research review," *Archives of Internal Medicine* 156, no. 10 (27 May 1996): 1062-8; J.M. Teno et al., "Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment," *Journal of the American Geriatric Society* 45, no. 4 (April 1997): 508-12.

7. D.I. Shalowitz, E. Garrett-Mayer, and D. Wendler, "The accuracy of surrogate decision makers: a systematic review," *Archives of Internal Medicine* 166, no. 5 (13 March 2006): 493-7.

8. A. Dreyer, R. Forde, and P. Nortvedt, "Autonomy at the end of life: life-prolonging treatment in nursing homes—relatives' role in the decision-making process," *Journal of Medical Ethics* 35, no. 11 (November 2009): 672-7; L.C. Kaldjian, L.A. Shinkunas, M. Bern-Klug, and S.K. Schultz, "Dementia, goals of care, and personhood: a study of surrogate decision makers' beliefs and values," *American Journal of Hospice & Palliative Care* 27, no 6 (September 2010): 387-97.

9. Dresser, see note 4 above.

10. S. Carmel and E.J. Mutran, "Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments," *Social Science & Medicine* 49, no. 3 (August 1999): 303-11; L.L. Emanuel et al., "Advance directives: Stability of patients' treatment choices," *Archives of Internal Medicine* 154, no. 2 (24 January 1994): 209-17; M. Danis, J. Garrett, R. Harris, and D.L. Patrick, "Stability of choices about life-sustaining treatments," *Annals of Internal Medicine* 120, no. 7 (1 April 1994): 567-73; M.N. Wittink et al., "Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study," *Archives of Internal Medicine* 168, no. 19 (27 October 2008): 2125-30; V.C. Martin and K.A. Roberto, "Assessing the stability of values and health care preferences of older adults: A long-term comparison." *Journal of Gerontological Nursing* 32, no. 11 (November 2006): 23-31, quiz 32-23; P.H. Ditto et al., "Stability of older adults' preferences for life-sustaining medical treatment," *Health Psychology* 22, no. 6 (November 2003): 605-15.

11. Dreyer, Forde, and Nortvedt, see note 9 above.

12. Hirschman, Kapo, and Karlawish, see note 6 above.

13. E.K. Vig et al., "Beyond substituted judgment: How surrogates navigate end-of-life decision-making," *Journal of the American Geriatrics Society* 54, no. 11 (November 2006): 1688-93.

14. A. Strauss and J. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory,* 2nd ed. (Thousand Oaks, Calif.: Sage, 1998).

15. M.K. Giacomini and D.J. Cook, "Users' guides to the medical literature: XXIII. Qualitative research in health care A: Are the results of the study valid? Evidence-Based Medicine Working Group," *Journal of the American Medical Association* 284, no. 3 (19 July 2000): 357-62.

16. A.M. Torke et al., "Rethinking the Ethical Framework for Surrogate Decision Making: A Qualitative Study of Physicians," *The Journal of Clinical Ethics* 19, no. 2 (Summer 2008): 110-9; A.M. Torke et al., "Physicians' experience with surrogate decision making for hospitalized adults," *Journal of General Internal Medicine* 24, no. 9 (September 2009): 1023-8.

17. P.H. Ditto et al., "Advance directives as acts of communication: a randomized controlled trial," *Archives of Internal Medicine* 161, no. 3 (12 February 2001): 421-430; V.P. Tilden, S.W. Tolle, C.A. Nelson, and J. Fields, "Family decision-making to withdraw life-sustaining treatments from hospitalized patients," *Nursing Research* 50, no. 2 (March-April 2001): 105-15; R.L. Sudore and T.R. Fried, "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making," *Annals of Internal Medicine* 153, no. 4 (August 2010): 256-61.

18. Hirschman, Kapo, and Karlawish, see note 6

above.

19. N.A. Hawkins, P.H. Ditto, J.H. Danks, and W.D. Smucker, "Micromanaging death: process preferences, values, and goals in end-of-life medical decision making," *Gerontologist* 45, no. 1 (Febrary 2005): 107-17.

20. J.H. Karlawish, T. Quill, and D.E. Meier, "A consensus-based approach to providing palliative care to patients who lack decision-making capacity: ACP-ASIM End-of-Life Care Consensus Panel: American College of Physicians—American Society of Internal Medicine," *Annals of Internal Medicine* 130, no. 10 (18 May 1999): 835-40.

21. Dreyer, Forde, and Nortvedt, see note 9 above; Vig et al., see note 14 above.

22. A. Fagerlin et al., "Projection in surrogate decisions about life-sustaining medical treatments," *Health Psychology* 20, no. 3 (May 2001): 166-75.

23. Dreyer, Forde, and Nortvedt, see note 9 above; Vig et al., see note 14 above.

24. P.A. Singer et al., "Reconceptualizing advance care planning from the patient's perspective," *Archives of Internal Medicine* 158, no. 8 (27 April 1998): 879-84.

25. D.W. Brock, "What is the moral basis of the authority of family members to act as surrogates for incompetent patients?" *The Journal of Clinical Ethics* 3, no. 2 (Summer 1992): 121-3; J. Hardwig, "The problem of proxies with interests of their own: toward a better theory of proxy decisions," *The Journal of Clinical Ethics* 4, no. 1 (Spring 1993): 20-7.

26. J.J. Fins et al., "Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy," *Journal of Pain and Symptom Management* 29, no. 1 (January 2005): 55-68.

27. C.M. Puchalski et al., "Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment: Hospitalized Elderly Longitudinal Project," *Journal of the American Geriatric Society* 48, supp. no. 5 (May 2000):S84-90; A. Sehgal et al., "How strictly do dialysis patients want their advance directives followed?" *Journal of the American Medical Association* 267, no. 1 (1 January 1992): 59-63.

28. L. Apatira et al., "Hope, truth, and preparing for death: Perspectives of surrogate decision makers," *Annals of Internal Medicine* 149, no. 12 (December 2008): 861-8; S. Diwan, G. W. Hougham, and G. A. Sachs, "Strain experienced by caregivers of dementia patents receiving paliative care: Findings from the palliative Excellence in Alzhimer care efforts (PEACE) Program," *Journal of Palliative Medicine* 7, no. 6 (December 2004): 797-807.

Clinical Ethics Consultation

The Threshold Moment: Ethical Tensions Surrounding Decision Making on Tracheostomy for Patients in the Intensive Care Unit

Arvind Venkat

ABSTRACT

With the aging of the general population and the ability of intensivists to support patients using ventilator support, tracheostomy has become a vital tool in the medical management of critically ill patients. While much of the medical literature on tracheostomy has focused on the optimal timing of and indications for performing this procedure, little is written on the ethical tensions that can revolve around decisions by patients, surrogates, and physicians on its use. This article will elucidate the ethical dilemmas that can arise surrounding the use of tracheostomy in critically ill patients and how ethics consultants and committees can approach these cases to allow resolution.

INTRODUCTION

The aging of the general population and the ability of healthcare providers to support patients through critical illness has raised the demand for intensive care resources. In the United States, it is estimated that, annually, patients receive more than 18 million days of care in the intensive care unit (ICU) setting, accounting for 1 percent of the gross domestic product. This demand is only expected to rise in the next two decades, as the portion of the U.S. population over the age of 65 increases, and disease processes that cause critical illness in this population, such as sepsis, become more prevalent.[1]

One of the key modalities for providing critical care is ventilator support. Whether it is provided due to acute illness or is planned postoperatively, ventilator use is viewed as a means to support patients temporarily until the underlying disease process has resolved. However, it is increasingly recognized that patients who require a ventilator acutely may require longer term management to allow recovery. To allow that recovery process, tracheostomies are commonly used. Tracheostomy involves a short surgical procedure that places an artificial airway through the neck into the airway (trachea). A tracheostomy allows patients to be more easily weaned off ventilator support over the medium (six to eight weeks) and long term and to be transferred to rehabilitation facilities for medical management. From the perspective of in-

Arvind Venkat, MD, FACEP, is Vice Chair for Research and Faculty Academic Affairs in the Department of Emergency Medicine at West Penn Allegheny Health System and is an Ethics Consultant and Chair of the Ethics Committee at Allegheny General Hospital in Pittsburgh; and is an Associate Professor of Emergency Medicine at Drexel University College of Medicine at Temple University School of Medicine in Philadelphia, Pennsylvania, *avenkat@wpahs.org*.

tensivists and hospitals, this is a necessity to free up badly needed ICU beds and resources for new acutely ill patients.

For patients and families, however, the perception of a tracheostomy is often quite different. Tracheostomy has a known association with patients' perception of decreased quality of life and self-image.[2] The transfer of a patient to a rehabilitation facility can be viewed as the first step to longer term dependency on medical care, with a loss of quality of life and personal autonomy. Although this perception may be misguided or based on a poor understanding of prognosis, it is well recognized in the physical medicine and rehabilitation literature that issues of goal setting and patients' expectations are common causes of ethical conflict in long-term care facilities.[3] In this context, the desire of critical care physicians to advance a patient's care by performing a tracheostomy and to transfer the patient to a rehabilitation setting can create an impasse, resulting in a request for an ethics consultation.

Conversely, a tracheostomy can be viewed by surrogate decision makers as a simple step to maintain a chronically ill or persistently vegetative patient in the long term. For these family members, a tracheostomy is another tool to preserve the life of a loved one when the value held most dear is the sanctity of life. Physicians who are asked to perform this surgical procedure in these circumstances may view a tracheostomy as a futile intervention that only prolongs the dying process of an end-stage patient, creating the potential for moral distress. This distress derives from the a professional's perception that his or her expertise in performing the procedure is to no beneficial end, creating an impasse that may require an ethics consultation.

When the competing perspectives of the physician, patient, and family clash, a decision of whether to offer or consent to a tracheostomy can be viewed as a *threshold moment*, when the differing ethical perspectives of the patient, family, and healthcare provider may crystallize and come into conflict. This threshold moment arises from the transition of a patient who receives a tracheostomy from an acute to a more chronic management state. The performance of the procedure, as cited above, can be viewed by a patient or family members as a moment when the loss of personal autonomy and long-term quality of life is at heightened risk, in comparison to standard critical care. Alternatively, offering the procedure can be viewed by physicians or surgeons as a futile gesture that is against their better medical and ethical judgment. Using case examples, this article will elucidate the ethical dilemmas that can surround the use of tracheostomy in critically ill patients and how ethics consultants and committees can approach such cases to allow resolution.

CURRENT MEDICAL INDICATIONS AND EVIDENCE FOR TRACHEOSTOMY USE

Prior to exploring the ethical tensions that can arise in decision making regarding the use of tracheostomy, it is necessary to delineate the current state of medical evidence in support of its use. In the pulmonary and critical care literature, the commonly discussed indications for tracheostomy are avoidance of airway damage, ease of ventilator weaning, patient comfort, and anticipated medium- or long-term need for ventilator support.[4] Prolonged translaryngeal intubation can place patients at risk for airway stenosis, which is avoided by direct airway placement via tracheostomy into the trachea. Tracheostomy also reduces the physiological "dead space" of an artificial airway that may allow easier weaning of a patient from a ventilator. An analogy is that an endotracheal tube is equivalent to breathing through a straw, and the resultant difficulty in respiration requires an easier means to connect a ventilator that does not tax the energy of an already debilitated patient. Tracheostomy allows easier suctioning of patients, and, with modification, vocalization by individuals who are ventilator dependent, as the device is placed below the larynx.[5]

There is evidence to support early tracheostomy placement in patients with traumatic brain injury, stroke, and after cardiac surgery, reducing the number of days on a ventilator and the incidence of ventilator-associated complications such as pneumonia.[6] However, no study

has clearly shown a mortality benefit or reduction in hospital or ICU stay from immediate tracheostomy. As a result, it is generally recommended that a judgment be made that a patient will require longer than 10 days of ventilator management before a tracheostomy is performed.[7] On this basis, most rehabilitation facilities require that a tracheostomy be performed prior to the transfer of patients for medium- or long-term ventilator management.

Tracheostomy can also be used to maintain patients whose disease process will leave them chronically dependent on a ventilator. However, unlike the literature on the use of gastrostomies in patients who are chronically debilitated or in a persistent vegetative state,[8] there is little discussion on whether the use of tracheostomy as a means to maintain a terminally ill patient who lacks decision-making capacity is medically or ethically appropriate. One article on this topic focused exclusively on the use of tracheostomy in patients when a decision had already been made to withdraw ventilator support. This article framed the use of a tracheostomy as a palliative care measure to allow suctioning of the patient and to reassure the family regarding the patient's comfort without the use of a ventilator.[9] For patients who are conscious but debilitated, such as in the case of a patient with amyotrophic lateral sclerosis (Lou Gehrig's disease), it is common to explore the benefits and consequences of long-term maintenance by tracheostomy and ventilator early in the disease process with the patient, with his or her wishes generally being accepted. In contrast, the use of tracheostomy with ventilator support in patients who lack decision-making capacity, who are progressively ill with a degenerative or terminal condition, is largely unexplored in the current medical literature.

Overall, the evidence supporting the current medical indications and use of tracheostomy is based on expert consensus rather than on empirical study. It is standard to perform the procedure after approximately 10 days of ventilator support, with the expectation that such support will be required for a medium or longer period of rehabilitation (six to eight weeks or beyond). In the case of a terminally ill patient who lacks decision-making capacity and requires ventilator care to sustain life, as in the case of neurodegenerative disorders, there is little evidence beyond anecdotal case discussions to guide medical practitioners in the use of tracheostomy.

CASE DISCUSSIONS OF ETHICAL TENSIONS SURROUNDING THE USE OF TRACHEOSTOMY

Given the increased use of tracheostomy in the ICU and rehabilitation settings, it is reasonable to expect that the dilemmas surrounding decision making in this context will arise to a greater degree. Legally, tracheostomy is a surgical procedure, and therefore requires informed consent from a patient or surrogate decision maker to be performed in this context. While the above medical evidence might suggest that tracheostomy should not be viewed as an escalation of critical care interventions, but rather as a continuation of ventilator support by another means, there is no common statutory basis for presumed consent for this intervention.[10] As a result, ethics consultants and committees can be expected to be called to mediate between patients, families, and physicians when their ethical and medical perspectives on the performance of a tracheostomy conflict. Three cases will be presented that exemplify the ethical tensions surrounding tracheostomy in the critical care setting.

In these three cases, it will be clear that decision making on tracheostomy in the ICU represents a threshold moment that can crystallize the ethical tensions that may arise in this healthcare setting. There are important areas that should be given consideration by ethics consultants and committees when they consider cases that involve decision making on the subject of tracheostomy.

The Medical Versus the Personal

Medically, the performance of a tracheostomy is a relatively minor procedure, literally the exchanging of one means of connection to a ventilator or airway protection for another. The tracheostomy, if anything, is lower profile,

likely more comfortable to a patient, and may, in some cases, allow a quicker removal of a patient from ventilator support. However, on a personal level, tracheostomy may be seen as a step that crosses a line from an acute intervention to one in which a patient may perceive himself or herself as a semipermanent resident of the healthcare system, dependent on artificial support for survival. This fear of a loss of personal autonomy stands in contrast to the prototypical physician's view that a tracheostomy is a medical intervention that should be judged on its physiologic benefit to a patient or the lack thereof. For ethics consultants and committees, there is a need to bridge these differing perspectives to allow resolution of the impasses that may arise from the ethical viewpoints of the patient and the physician.

Tracheostomy as a Tool to Resolve Ethical Impasses

Tracheostomy is not merely a prism through which the ethical values of a patient and physician can come into conflict. The decision to perform a tracheostomy can allow patients and physicians to come to a consensus on how far the healthcare system should go to rehabilitate an individual who might have a prolonged course of recovery. A tracheostomy can be a valid ethical option for allowing a trial of therapy to better establish whether a patient would recover from a profound pulmonary insult and to reconcile the ethical positions of a patient's surrogate decision maker and a physician. For ethics consultants and committees, a detailed understanding of the medical facts of a case may allow the proposed use of a tracheostomy as a vehicle to resolve ethical conflict.

The Escalation or Paralysis of Care

One of the more common resolutions in clinical ethics consultation is a decision to neither withdraw nor escalate care. Tracheostomy does not neatly fall into either category. It can serve a palliative, curative, or stabilization purpose. However, the necessity for informed consent to perform this surgical procedure means that the presenting physician and the patient or surrogate need to share an understanding of the purpose of placing the tracheostomy. Without this unity, treatment of the patient is paralyzed. There may be a role, from the perspective of preventive ethics, to establish early in the communication with a patient or surrogate decision maker that a tracheostomy may be required, and how that should be viewed by both sides of the doctor-patient relationship. Ethics consultants and committees have an important role in elucidating the various roles of tracheostomy in aiding surgeons, intensivists, patients, and healthcare organizations in communications that may prevent a decision to perform the procedure from becoming an impediment to a patient's care.

Case Example: The Conscious Patient with Involved Family Members

An 84-year-old African American male presented to this center for resection of a nonmetastatic lung tumor. Pre-operatively, the surgeon felt that the patient would likely have a cure from the procedure and should not require prolonged ventilator support. Over a 10-day period, however, attempts to remove the patient from ventilator support failed. He was extubated twice, but both times required re-intubation for respiratory distress. The patient was alert and able to communicate via written notes, and it was the opinion of his attending physician that the patient had intact decision-making capacity to consent or refuse further critical care interventions. The attending physician felt that the patient would benefit from medium-term rehabilitation to wean him off the ventilator, and that it was premature to presume that the patient would have long-term dependence on ventilator support or require permanent residence in a nursing home. The patient did not have other signs of organ failure and had been quite functional at home prior to diagnosis and surgery.

The patient, when presented the option of tracheostomy with transfer to a rehabilitation facility for care, was wary and deferred to his daughter. The daughter stated that her father had repeatedly stated that he never wanted to be in a "nursing home" and feared above all else dependency on the healthcare system for

his care. Her discussion with her father and his physicians led to a request for ethics consultation to aid in establishing how the values of the patient could be reconciled with his medical situation.

In considering this case, all three areas of focus for ethics consultation with regard to decision making around tracheostomy are relevant. The source of ethical conflict in this case had its roots in the patient's pre-operative perception on what it would mean to have complications that required intermediate or long-term rehabilitation in an inpatient setting. For the surgeon, tracheostomy would be simply a continuation of a slightly altered postoperative recovery course that was likely to be successful with more time. For the patient and his daughter, there was no pre-operative expectation that further interventions might be required to facilitate his recovery. To the patient and his daughter, placement of a tracheostomy was not a continuation of recovery, but a further step in the loss of personal autonomy and subsequent increased dependency on medical care through inpatient rehabilitation.

To resolve this case, it was necessary to facilitate an understanding among the surgeon, patient, and family on how a decision about tracheostomy was a threshold moment requiring empathy on both sides. Accepting that the patient viewed tracheostomy as an escalation of care, from a sense of loss of personal autonomy, allowed the surgeon to communicate more clearly that there was no requirement to go further than a tracheostomy in the rehabilitation process. The surgeon, patient, and family agreed that if the patient suffered more complications in his recovery, no further aggressive intervention (cardiopulmonary resuscitation, dialysis) would be pursued. They agreed that the rehabilitation process would be revisited after six to eight weeks, with a strong presumption that if the patient was not improving, the tracheostomy would be decannulated. The patient and family learned there was limited but real evidence that a tracheostomy might allow more aggressive rehabilitation and rapid removal of ventilator support, providing guidance on how the procedure was medically beneficent, and not performed solely to maintain the *status quo.*

Similarly, it was useful for the patient to learn that the tracheostomy might allow better communication, since he had intact decision-making capacity, and, with training, a tracheostomy would allow easier vocal interaction. It was a relief to the daughter to know that a tracheostomy would allow her father to more clearly communicate for himself what he would want in his medical care, as it removed personal stress in having to serve as a substitute decision maker. Her father could communicate before a tracheostomy, but to a limited extent, and so he had deferred decisions on the next step in his care to her. The resolution of performing the tracheostomy, but limiting further escalation of care, did not require either side to compromise their perception of the situation. Rather, knowledge of the evidence for tracheostomy, and the limitations of that evidence, allowed the ethics committee to facilitate an outcome that respected the medical and personal values of the parties to the consultation.

Case Example: The Unconscious Post-Operative Patient

A 75-year-old Caucasian male patient presented to this institution for surgical resection of an esophageal cancer. He had been diagnosed with this condition four months prior to his presentation to the surgeon and undergone neoadjuvant chemotherapy as a means to determine his responsiveness to treatment. He had shown enough of a response to chemotherapy, based on clinical and radiographic evaluation, that he was a candidate for definitive surgical resection. The characteristics of his tumor response suggested that his five-year survival might approach 40 percent. After a long discussion with the surgeon regarding the extensive nature of the resection operation, the patient consented to the procedure in the presence of his son, who held his healthcare power of attorney.

In the intervening three weeks between the appointment when informed consent was given and the date of surgery, however, the patient refused to eat and told his son that if he were to develop complications postoperatively, he did not want to undergo a prolonged rehabilitation

process. Unfortunately, this was not conveyed to the cardiothoracic and general surgeons scheduled to perform his resection operation.

The patient underwent his operation, and, by all indications, including final pathology evaluation of the tumor resected, it was a success with no residual malignancy. Postoperatively, the patient could not be removed from the ventilator and then developed a significant lung injury that was thought to be due to acute respiratory distress syndrome. He required escalating ventilator support and maneuvers to maintain oxygenation and ventilation, including prone positioning. But over a 10-day period he showed improvement in his pulmonary health, although not enough to be extubated.

On the second postoperative day, the son began to request that the patient be allowed to die under palliative care, based on his understanding of his father's wishes. The thoracic surgeon had multiple discussions with the son and other family members, who initially agreed to a short period to determine whether the patient would require medium- or long-term ventilator support. After a week, the consensus from the family was that the trial had been long enough and that the patient would not want more extensive critical care efforts to maintain his life.

The thoracic surgeon expressed her position that the patient was still in the immediate postoperative period, and that it was therefore premature to conclude that the patient's wishes would be to forego life-sustaining treatment. Had she known about the patient's actions and statements after the consent process but before surgery, she said, she would have revisited the consent process and likely would have recommended against surgery. She noted that the patient had elected for a curative procedure, and that his recovery process, while more prolonged than anticipated, was progressing. With further rehabilitation, the patient might be able to be extubated or conscious enough to express what he would want under the circumstances. At this point, an ethics consultation was requested.

This case highlights the importance of clear communication and the establishment of realistic expectations in the informed consent process. As the surgeon noted, she had explained how extensive the surgery would be. The patient and his son, however, either did not perceive that recovery might include the possibility of prolonged ventilator support, or presumed that, if complications did arise, the surgeon would agree to initiate palliative care measures. These issues are not unique to cases when a tracheostomy might be required. As seen in this case, tracheostomy, as an invasive procedure and as a means to facilitate medium- or long-term inpatient rehabilitation, is a threshold moment in which the expectations and perceptions of surgical and critical care come to the forefront. In such cases, when a prolonged recovery course may be more likely, the informed consent process should include some of the potential complications and where they might lead. This should be done delicately, so as not to engender unnecessary fear in the patient, nor be falsely reassuring. It is appropriate for surgeons and ethics committees to devise templates for communicating these risks in the informed consent process for high-risk procedures. Examples might include prolonged surgeries in the elderly, surgeries with a high likelihood of significant blood loss, and surgeries in patients with significant underlying medical, especially pulmonary, conditions.

To resolve this case, one pathway suggested by the ethics service was to view a tracheostomy as simultaneously a trial of therapy and a palliative care measure. As noted above, there is some evidence that tracheostomy can accelerate pulmonary rehabilitation in a ventilated patient, and a presumption that it is more comfortable than endotracheal intubation. In this context, it was communicated that it might be appropriate to perform a tracheostomy and set a limited period of aggressive attempts at ventilator weaning over a seven to 10 day period of time. The son, who was the patient's healthcare power of attorney, did not feel this would reflect the patient's wishes in this circumstance. The thoracic surgeon was offered the opportunity to transfer the patient to another physician's care so as not to compromise her professional ethical values, but she chose to comply with the wishes of the patient's son. The pa-

tient was extubated and died surrounded by his family two days later.

Case Example: The Ventilator-Dependent End-Stage Patient

A 50-year-old African American male patient with Creutzfeldt-Jakob disease (a rapidly progressing degenerative brain disorder) was hospitalized in the ICU with respiratory failure. He had shown a marked deterioration in his level of consciousness over a six-month period and had been admitted twice in the past two months because his family had not been able to care for him at home. During this hospitalization, he had been intubated due to an aspiration event with respiratory failure. He had improved and was breathing comfortably during trials of minimal ventilator support. While he technically was a candidate for extubation, it was widely anticipated that his continued neurologic deterioration would result in the risk of aspiration and a potential need for ventilator support again. The assessment of the neurology service was that the patient had an end-stage illness, but that he might survive six months to a year with aggressive care, including airway protection via tracheostomy and nutritional support via gastrostomy. During the remainder of his life, he would be completely dependent on artificial medical technologies after having deteriorated to a persistent vegetative state.

When this information was presented to the patient's wife, she stated that the patient had never discussed with her what his wishes would be under these circumstances. She did say that the patient knew he was dying and valued the time he had left, but he would not want to suffer pain or discomfort. In this context, she expressed a desire to not escalate care, but also to maintain the patient by the ventilator and with a gastrostomy tube for the time he had left. She did agree that the patient should have do-not-resuscitate status if he were to deteriorate under these conditions. The intensivists did present the wife with the medical evidence that, in the patient's condition, he would not communicate or otherwise interact meaningfully with his environment. She understood this, but felt the patient would view the continuance of his life and the comfort that his survival would provide his family members as the values he held most dear.

In this context, a surgical consult was requested for the placement of a tracheostomy and gastrostomy to facilitate the patient's transfer out of the ICU to a skilled nursing facility for ongoing care. During this consultation, the attending surgeon expressed ethical reservations about performing these procedures. She stated that, given the marked deterioration of the patient and the desire of his wife to not escalate care, it was inappropriate to offer a tracheostomy and gastrostomy. She believed these procedures would be an escalation of care and that, instead, the patient should be extubated and allowed to survive (or not) without artificial technological support. In her view, even if the tracheostomy and gastrostomy were simply new conduits for providing existing life-sustaining treatment, they represented a shift from acute to more long-term support that violated the patient's wife's stated wish to avoid treatment escalation.

On a practical level, the surgeon expressed a concern that to perform the tracheostomy and gastrostomy would place herself and her surgical team at risk, as the exact mechanism of transmission of Creutzfeldt-Jakob disease is unclear. She noted that there were reports of potential infection of healthcare providers in the care of patients with this condition.[11] Standard decontamination protocols of operative instruments were ineffective,[12] and the performance of the tracheostomy and gastronomy would require the shuttering and cleaning of the relevant operative suite for a day. Finally, she questioned whether performance of the procedures would allow the patient to be transferred out of the hospital. While the patient might leave the ICU, the likelihood that he could be placed in a skilled nursing facility was unlikely, as he lacked a payer for the high level of care he would need to survive. As a result, the performance of these procedures, in the opinion of the surgeon, was ethically fraught. Instead, a more appropriate ethical option would be to more forcefully express to the wife the termi-

nal nature of the patient's condition and advocate for palliative care without surgical intervention.

A palliative care consult was requested to allow the wife to hear the full range of treatment options in the context of how she understood the patient's wishes. She refused to accept palliative care, and again requested that the tracheostomy and gastrostomy be placed. At this point, to assist with the resolution of this clinical and ethical impasse, an ethics consult was requested.

In contrast to the other two cases, the ethical objection to performing the tracheostomy was expressed by the surgeon, not the patient or surrogate. The surgeon's objection was based on her medical and subsequent ethical judgment regarding the condition of the patient, and the potential risk posed to her team in the context of the lack of perceived benefit to the patient. The patient's wife, however, took a less medical view of the situation. Rather, her judgment was based on her perception of her husband's personal values in his dying process. As noted above, the decision regarding the use of a tracheostomy is the threshold moment when conflicting views of further medical care (the medical versus the personal, whether tracheostomy is an escalation of care or not) can come to the fore. The question for the ethics consultants was whether there was a way to reconcile the conflicting value hierarchies. If there was not, the logical next question was whether the patient's view, as expressed by his wife, should take precedence over the physician's view, or whether the healthcare organization had an obligation to find an alternative provider to facilitate the maintenance of the patient in this progressive debilitated state. It is beyond the purview of this article to define organizational ethical policy. This case does exemplify, however, how decision making on tracheostomy can create conflict between providers and patients/surrogates that deserves consideration by ethics committees in defining how their organization will respond.

In this case, a second surgical opinion was obtained, which concurred with the first opinion, that it was medically and ethically inappropriate to perform a tracheostomy. However, the second surgeon did not concur that refusal should be based on the communicable disease risk, given the common circumstance of physicians and surgeons caring for patients with infectious conditions. In discussion with the patient's wife and after presenting the concerns of the physicians involved, it was agreed that the patient would be extubated. To maintain the patient on a ventilator, whether by tracheostomy or endotracheal tube, would not be to his benefit, since he was stable for removal of this support. Continuation of the ventilator might subject the patient to iatrogenic complications such as pneumonia. It was also agreed that aggressive pulmonary suctioning and non-invasive support would be used to avoid aspiration as much as possible, and that the patient would not be re-intubated based on his expected clinical course. Assuming that he survived extubation, the surgeons agreed to revisit with the family other forms of support, such as a gastrostomy.

This resolution was accepted reluctantly by all of the parties involved. It was viewed as a compromise by the surgeons, who did not believe that a desire for comfort measures should include artificial life-prolonging measures of any kind, tracheostomy or gastrostomy. Similarly, the wife felt that the surgeons and facility were forcing her towards a particular course of action, but she agreed that it was not beneficial to transfer her husband elsewhere to have a tracheostomy and gastrostomy performed. This case suggests that healthcare organizations should have plans in place regarding the resolution of such impasses, when ethical obligations may move beyond that of the individual practitioner, a prime example of preventive ethics.

CONCLUSION

With the aging of the population and the increased use of intensive care resources, the utilization of tracheostomy will become more common in clinical practice. This article indicates how a decision to perform this procedure can raise profound ethical tensions that have

the potential to paralyze the care of a patient. Ethics consultants and committees have an obligation to examine how such threshold moments can be met in a way that balances the values of healthcare organizations, physicians, family members, and patients.

MASKING OF THE CASES

Identifying details of patients and their cases in this article have been altered or fictionalized to protect the privacy of the individuals involved.

NOTES

1. *Report to Congress: The Critical Care Workforce: A Study of the Supply and Demand for Critical Care Physicians* (Rockville, Md.: Health Resources and Services Administration, U.S. Department of Health and Human Services, May 2006), 1-43, *http://bhpr.hrsa.gov/healthworkforce/reports/studycriticalcarephys.pdf,* accessed 3 April 2013.

2. D. Gilony et al., "Effects of Tracheostomy on Well-Being and Body-Image Perceptions," Otolaryngologyy—Head and Neck Surgery, 133, no. 3 (September 2005): 366-71; N.K. Hashmi et al., "Quality of Life and Self-Image in Patients Undergoing Tracheostomy," *Laryngoscope* 120, supp. 4 (2010): s196.

3. K.L. Kirschner et al., "Ethical Issues Identified by Rehabilitation Clinicians," *Archives of Physical Medicine and Rehabilitation* 82, no. 12, supp. 2 (December 2001): s2-8.

4. N.R. MacIntyre et al., "Evidence-Based Guidelines for Weaning and Discontinuing Ventilatory Support," *Ches*t 120, no. 6 (December 2001): 375S-95.

5. Ibid., 385S.

6. M.A. Bouderka et al., "Early Tracheostomy versus Prolonged Endotracheal Intubation in Severe Head Injury," *Journal of Trauma* 57, no. 2 (August 2004): 251-4; J. LeBlanc et al., "Outcome in Tracheostomized Patients with Severe Traumatic Brain Injury Following Implementation of a Specialized Multidisciplinary Tracheostomy Team," *Journal of Head Trauma Rehabilitation* 25, no. 5 (October 2010): 362-5; B.D. Freeman and P.E. Morris, "Tracheostomy Practice in Adults with Acute Respiratory Failure," *Critical Care Medicine* 40, no. 10 (2012): 1-7; J. Devarajan et al., "Early Tracheostomy Is Associated With Improved Outcomes In Patients Who Require Prolonged Mechanical Ventilation After Cardiac Surgery," *Journal of the American College of Surgeons* 214, no. 6 (June 2012): 1008-16.

7. Freeman and Morris, see note 4 above.

8. A. Kruse et al., "Recommendations of the ESGE Workshop on the Ethics of Percutaneous Endoscopic Gastrostomy (PEG) Placement for Nutritional Support," *Endoscopy* 35 (2003): 778-80; L.D. Scott, "The PEG 'Consult,' " *American Journal of Gastroenterology* 100 (2005): 740-73.

9. S.H. Chotirmall et al., "Extubation versus Tracheostomy in Withdrawal Treatment—Ethical, Clinical and Legal Perspectives," *Journal of Critical Care* 25 (2010): 360.e1-e8.

10. A. Venkat, and J. Becker, "The Effect of Statutory Limitations on the Authority of Substitute Decision Makers on the Care of Patients in the Intensive Care Unit: Case Examples and Review of State Laws Affecting Withdrawing or Withholding Life-Sustaining Treatment," *Journal of Intensive Care Medicine* (17 January 2012), epub ahead of print.

11. E. Alcalde-Cabero et al., "Health Professions and Risk of Creutzfeldt-Jakob Disease, 1965-2010," *Euro Surveillance* 17, no. 15 (2012): pii:20144.

12. R. Hervé, T.J. Secker, and C.W. Keevil, "Current Risk of Iatrogenic Creutzfeldt-Jakob Disease in the UK: Efficacy of Available Cleaning Chemistries and Reusability of Neurosurgical Instruments," *Journal of Hospital Infection* 75 (2010): 309-313.

Commentary

A Response to Dubler's Commentary on "Surmounting Elusive Barriers: The Case for Bioethics Mediation"

Edward J. Bergman

ABSTRACT

Dubler's commentary[1] focuses on knowledge of clinical medicine and "institutional savvy" as pieces of the skill set required of bioethics mediators. Here, I describe why, as a practical matter, such requirements are unlikely to be achieved by a meaningful number of aspirants. Simultaneously, I examine the reasons why Dubler's criteria are inherently risk-laden and would be better addressed as a dialogue among experienced practitioners regarding the merits of alternative stylistic approaches, rather than as universal threshold criteria for the practice of bioethics mediation.

Nancy Dubler's commentary on my article, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," in the spring 2013 issue of this journal, invites a response. While we are both zealous advocates for bioethics mediation, Dubler's piece summarizes important distinctions in our views of the future of its practice and the skills required of its practitioners.

Dubler places substantial emphasis on the mediator's working knowledge of clinical medicine and the mediator's possession of "institutional savvy."[2] There are five reasons for my skepticism regarding these baseline criteria.

First, economics militates against a likelihood that aspiring bioethics mediators will acquire the levels of training and expertise needed to fulfill Dubler's requirements as a precondition to practice. The scope of these wide-ranging competencies would require hospitals to compensate practitioners at a level commensurate with such erudition—an unlikely prospect.

Second, while the knowledge of clinical medicine prescribed by Dubler is available in the case of practicing clinicians, such individuals must still be persuaded to acquire substantial mediation training, not as a superficial gloss on their existing professional competencies, but in recognition of the demanding, independent discipline of mediation. The clinician may already be functioning as a clinical ethics con-

Edward J. Bergman, JD, is Founding Faculty and Principal Mediator, Penn Clinical Ethics Mediation Program, Department of Medical Ethics and Health Policy, Perelman School of Medicine, University of Pennsylvania, and Affiliated Faculty, Department of Legal Studies and Business Ethics, Wharton School of Business, University of Pennsylvania, *ejb@gear3.net.*

sultant, employing a traditional, juridical approach. Dubler has previously lamented a woeful absence of mediation training in spite of the theoretical embrace of mediation reflected in the literature.[3] What Dubler apparently has not concluded is that clinical ethics consultants—entrenched in positions for which they have long been deemed qualified, and facing a threat to their very relevance—will not only decline such training but are likely to resist its legitimacy. Such resistance will bear little relationship to objective assessment of the virtues of clinical mediation. The majority of nonclinicians seeking to acquire knowledge of clinical medicine will primarily be relegated to the methodology described in the next paragraph.

Third, much of the medical knowledge for which Dubler advocates can be acquired by hospital mediators in the form of on-the-job training. A mediator focused on the management of conflict in a clinical context will be exposed to a vast array of clinical information. Mediators are notoriously quick studies, evidenced by their frequent capacity to manage dispute resolution across diverse subject matter areas. Mediators learn to acquire complex information necessary for the understanding of their tasks, a different order from the level of knowledge required of a practicing clinician.

Fourth, the institutional savvy mandated by Dubler can *only* be acquired by the mediator having been embedded in an institution and, consequently, cannot be posited as a precondition to the practice of bioethics mediation. Additionally, asymmetrical familiarity of the mediator with hospital staff risks displacement of a perception of mediator neutrality with a perception of bias, even cronyism.

Fifth, knowledge of clinical medicine and the acquisition of institutional savvy are themselves double-edged swords. Belief in one's substantive medical knowledge can create unintended bias stemming from intrinsically questionable expertise. Physicians, even specialists in a field, will frequently reach opposing conclusions on diagnoses, prognoses, and treatment choices. Prevailing medical uncertainty calls into question a mediator's substantive medical guidance. Some conversance with clinical medicine can facilitate a mediator's ability to formulate probative questions. This is precisely the kind of information that can be gained from extended exposure to the clinical environment. Such familiarity, as opposed to expertise, is unlikely to result in a perception that the mediator claims subject matter mastery that may be viewed as in competition with, or in support of, a disputant. While the knowledge that Dubler prescribes may prove helpful in particular cases, the medical activist portrayal of a bioethics mediator painted by Dubler in her "vignettes"[4] risks a redefinition of the mediator as a quasi-party to the conflict, rather than the manager of a process. While a mediator's role includes identification of information for the parties' consideration, the mediator as a primary source of subject matter expertise has, understandably, been viewed as a threat to her or his presumed neutrality.[5] It is difficult (although not impossible) to become the source of an option without being viewed as a proponent of that option. While the interventions that Dubler describes are admirable, these approaches are dependent upon mediator competencies that are only attainable in rare contexts.

Dubler's perspective on the foregoing issues is unique. Embedded in one medical institution—Montefiore Medical Center—for some 40 years, Dubler embodies an experience few, if any, have shared. Dubler's accomplishments constitute a legacy of immeasurable importance to the field of bioethics mediation. We would be wise, nonetheless, to consider that Dubler is likely *sui generis* and that, an attempt to "clone the leader,"[6] rather than to define viable pathways for the widespread adoption of bioethics mediation, will be fraught with peril. We should resist the temptation, and the naiveté, to believe we can train a cadre of institutional gurus, foolishly thought to possess the skill and wisdom accumulated by Dubler as the by-product of a life's commitment.

Setting the bar for the training of bioethics mediators at ambiguous and/or unrealistic levels presages two likely outcomes. Aspiring mediators may enter the practice with substantial breadth of knowledge that is skin deep and difficult to apply. Alternatively, prospective bio-

ethics mediators will be deterred by a perception that its range of mandatory competencies is practically unattainable.

Perhaps the foregoing dilemma is soluble, in part, by drawing a distinction between preconditions to the practice of bioethics mediation and aspirational considerations for the experienced practitioner. Such a distinction would help clarify, and render attainable, baseline requirements, leaving open to debate a multiplicity of tactical and stylistic approaches to the craft. After all, debate over distinct mediation styles has always been lively outside the realm of clinical healthcare conflict.[7] One might also question the advisability of a doctrinaire approach to a process that encompasses elements of artistry, emanating from unique personal attributes of its practitioners.

On a specific point, Dubler's dismissiveness of the concept of moral *aporia*, as referenced in my article,[8] was a surprise. Dubler's suggestion that "arcane" and "unfamiliar" words intrinsically confound elusive concepts[9] is an unusual assertion in the framework of scholarly discourse, where discovery of useful analogies or nuanced language to describe complex phenomena is highly valued. Dubler may mistakenly believe that I am advocating the use of arcane phrases in the *practice* of bioethics mediation. I learned about moral *aporia* simultaneously, but independently, from the work of Fiester[10] and Solbaak.[11] I have found that term of art a powerful tool for understanding and teaching the virtues of bioethics mediation—a process suited to conflict management in situations that involve competing, yet legitimate, moral claims.

Paradoxically, Dubler authored a commentary to Fiester's earlier article in this journal, "Ill-Placed Democracy: Ethics Consultations and the Moral Status of Voting."[12] In that commentary, Dubler quotes Fiester: " 'The term *aporia* comes from the Greek meaning "a state of perplexity." In a clinical ethics case it is a helpful term to use to describe ethical ambiguity in a case in which there is a sharp clash between disparate moral considerations, values, or principles, or significant disagreement about which moral consideration ought to trump the others in the case.' "[13]

Dubler goes on to state, in support of mediation as the antithesis of ill-conceived adjudication between legitimate moral claims: "Fiester says it eloquently: 'Mediation as a process honors the validity of both sides in a dispute . . . because it takes no stand on which moral principles or claims ought to trump in a disputed case. It does not claim moral authority when there is none to be had.'"[14] Far from asserting its inutility, Dubler lauded the relevance of moral *aporia* to clinical ethics cases, much in the way I applied the concept. While, as Dubler notes, bioethics mediation is not limited to aporetic conflict,[15] the significance of such disputes in a healthcare setting is a signature component of clinical ethics conflict.

CONCLUSION

While I agree with Dubler that the literature referenced herein is part of "a vital current conversation,"[16] I am conflicted about my own contribution to a dialogue that may be interpreted by naysayers to bioethics mediation as more divisive than is actually the case. I would be saddened if that perception provided solace to those who oppose widespread adoption of a mediation model for the management of clinical conflict.

Advocates of bioethics mediation should move forward, in concert, agreeing to disagree, without compromising our capacity to nurture a clinical dispute resolution model that reflects the inclusive, collaborative, patient-centered healthcare enterprise of the 21st century.

NOTES

1. N.N. Dubler, "Commentary on Bergman: 'Yes . . . But," *The Journal of Clinical Ethics* 24, no. 1 (Spring 2013): 25-31, commentary on E.J. Bergman, "Surmounting Elusive Barriers: The Case for Bioethics Mediation," *The Journal of Clinical Ethics* 24, no. 1 (Spring 2013): 11-24.

2. Dubler, see note 1 above, p. 26.

3 N.N. Dubler and C.B. Liebman, *Bioethics Mediation,* 2d ed. (Nashville, Tenn: Vanderbilt University Press, 2011), xiii.

4. Dubler, see note 1 above, pp. 27-30.

5. C. W. Moore, *The Mediation Process: Practi-*

cal Strategy for Resolving Conflict, 3d ed. (San Francisco, Calif.: Jossey-Bass, 2003), 288.

6. W. Allen and M. Brickman, *Sleeper* (Beverly Hills, Calif.: United Artists, 1973).

7. Bergman, see note 1 above, pp. 11-2.

8. Ibid., 13-4.

9. Dubler, see note 1 above, p. 26.

10. A. Fiester, "Mediation and Moral Aporia," *The Journal of Clinical Ethics* 18, no. 4 (Winter 2007): 355-6.

11. J. Solbaak, "Therapeutic Doubt and Moral Dialogue," *Journal of Medicine and Philosophy* 29, no. 1 (2004): 97; J. Solbaak, "Catharsis and Moral Theory I: A Platonic Account," M*edicine, Health Care and Philosophy* 9 (2006): 63.

12. N.N. Dubler, "Commentary on Fiester's 'Ill-Placed Democracy: Ethics Consultations and the Moral Status of Voting,'" *The Journal of Clinical Ethics* 22, no. 4 (Winter 2011): 373-9, commentary on Fiester, see note 10 above.

13. Dubler, see note 12 above, p. 373.

14. Ibid., 379.

15. Dubler, see note 1 above, p. 26.

16. Ibid., 25.

The Art of the Chart Note in Clinical Ethics Consultation and Bioethics Mediation: Conveying Information that Can Be Understood and Evaluated

Nancy Neveloff Dubler

ABSTRACT

Unlike bioethics mediators who are employed by healthcare organizations as outside consultants, mediators who are embedded in an institution must be authorized to chronicle a clinical ethics consultation (CEC) or a mediation in a patient's medical chart. This is an important privilege, as the chart is a legal document. In this article I discuss this important part of a bioethics mediator's tool kit in my presentation of a case illustrating how bioethics mediation may proceed, and what this approach using both bioethics and mediation may add.

THE CASE AND THE SETTING: WHY MEDIATE?

There is, generally, little mention of bioethics principles in bioethics mediation. Mediation exists in stark contrast to the structured intellectual work of a bioethics committee. The mediation is designed to manage or resolve conflict. It seeks to level the playing field and empower all of the participants to search for acceptable solutions that they can all agree on.

The principles and practices of bioethics matter to mediators as they struggle to keep in mind the ethical, legal, and medical literature that sets the boundaries for the agreement they seek. Because bioethics mediation is focused on solving a problem within the confines of a "principled resolution,"[1] and not just applying abstract bioethics principles, it self-consciously eschews abstract discussions that may alienate and silence patients, family, friends, and even staff. But staff, who both participate in the mediation and become involved while working subsequent shifts, must be brought along through notes in the patient's chart.

Some bioethics mediators act as outside consultants to healthcare institutions. They see this role as a benefit to the patient and family, who may feel that a mediator who is embedded in an institution has a stake in the outcome. I have argued previously that insider status allows bioethics mediators knowledge, status, and power within an institution that outsiders cannot har-

Nancy Neveloff Dubler, LLB, is a Consultant for Ethics at the New York City Health and Hospitals Corporation, *Nancy.Dubler@nyhhc.org.*

ness. As members of the clinical staff, yet neutral to any particular case, bioethics mediators must have the authority to include a report of the mediation in a patient's chart. This functions as part of the chart—a legal document—and is an important privilege not granted to outside consultants. Equally important, the chart note facilitates peer review and quality improvement initiatives. In this article I discuss this important part of a bioethics mediator's tool kit in my presentation of a case illustrating how bioethics mediation may proceed and what this approach using both bioethics and mediation may add.

I had come to the Canadian workshop[2] with a prepared presentation on bioethics mediation. However, in attending the faculty meeting on the morning of the conference, and understanding the proposed structure of the day, I made the suggestion to amend my part of the program. The day had been designed to begin with a clinical ethics (CE) consultant directing a hospital ethics committee discussion on a difficult and troubling case. I suggested that I mediate the very same case, with the same role-players, that evening.

The case involved a patient, Joseph,[3] with end-stage multiple sclerosis (MS). He had cared for his mom, who also had MS, until he was unable to manage; she had died insensate in a nursing home. That was the particular end that he feared above all. Joseph had been living at home with shifts of attendants, was deteriorating rapidly, and had managed to save barbiturates, planning to take his life. His attempt was interrupted by an unanticipated visit by the postman who summoned emergency medical services (EMS). Joseph was taken to the local intensive care unit (ICU) and intubated. It was unclear how long he had been without respiration and oxygen.

Two close friends and three former physicians, the primary care physician, a neurologist, and a neuropsychiatrist arrived at the ICU almost immediately and urged removing the patient from the ventilator. All stated that he was not depressed, had assessed his options carefully, and had left explicit advance directives about his care that stated unambiguously that he never wanted ventilation. The ICU attending was reluctant to remove the ventilator as long as the opiates Joseph had ingested continued to diminish his ability to breathe on his own. One day after admission, the ICU attending contacted the ethics committee for help in resolving the growing dispute between herself and the friends and prior physicians of the patient. This case was discussed at the faculty meeting and would be presented to a mock ethics committee that morning.

The ethics committee discussion was directed skillfully[4] and addressed the ethical issues comprehensively. The CE consultant had invited the patient's closest friends, the primary care physician, a neurologist, and a neuropsychiatrist to the meeting. The CE consultant began by sketching out the case and asking the two physicians, who had known the patient over time, and one who had recently completed a depression evaluation, to explain to the committee their assessment of the patient's history, diagnosis, prognosis, and emotional and neurological status before the suicide attempt. All reported that he was not depressed, was, other than his underlying disability, quite healthy, and was realistic about his future inevitable deterioration.

The CE consultant then asked the friends to speak about the patient's values and preferences. They reported a dear and determined man who was a great friend, but who did not want to face his slow deterioration into death. He had been clear and unambiguous with his friends and his physicians about his fear of his future and his desire to end his life.

Finally, the ICU attending was asked to explain her position. She admitted that the reports of both friends and physicians were extremely powerful, but felt that she would be assisting in a suicide if she removed the ventilator while opiates were still present in the patient's system. The approximately 20 members of the ethics committee then discussed the case.

The committee discussion was impressively scholarly and analytical. It addressed the case in the context of relevant ethical principles including autonomy, beneficence, non-malfeasance, and justice. The ethics committee mem-

bers sympathized with Joseph's friends and physicians, but agreed that the ICU physician was correct in interpreting contemporary philosophical and legal norms as prohibiting the removal of the ventilator while opiates were operative in the patient's system. They offered the opinion, and recommended to the ICU attending, that removing the ventilator would be assisting the suicide.

In the evening, the three physicians and the two friends met with me as the bioethics mediator. I shaped the mediation using the acronym STADA: **S**—Sit down; **T**—Tell me about Mama (let the family speak from their knowledge and experience); **A**—Admire the family for coming to help with the difficult decision; **D**—Discuss the medical facts, diagnosis, and prognosis; **A**sk—what should be the recommendation on the outcome.[5] We **sat** together in a small group. I began, as I always do, with the nonmedical narrators: "**Tell** me about Joseph." I begin this way because physicians are the experts on medicine, but the family, or in this case the friends, are the experts on the patient. One of the basic tasks of bioethics mediation is to "level the playing field" between medical staff and family/friends. By providing the opening remarks, they become privileged commentators bringing important matters to the discussion.

They spoke movingly about his steady and accelerating medical decline. One of the friends related that Joseph had been sexually abused as a child, and that every time his diapers were changed he re-experienced that terrible trauma. They explained that he loved life and was not depressed, but judged that his quality of life was simply no longer, in his eyes, sufficiently robust to counterbalance his indignity, pain, suffering, and ongoing fear and anxiety about the future. The friends feared, reflecting the patient's deepest concerns, that if this case were to proceed without immediate removal of the ventilator, the patient might emerge in a permanent vegetative state, but able to breathe, which would send him to a nursing home for months or years as a "lump" of a person—his very worst fear.

I thanked (**admired**) the friends for being willing to come and help us with this difficult decision about Joseph, whom they knew so well and cherished. The physicians then **discussed** the diagnosis, prognosis, history, and most recent depression assessment; all agreed that he was not clinically depressed. Finally, when asked to explain her position, the ICU physician addressed her fears about violating the law by removing the ventilator. But after an hour and a half of discussion, when the ICU physician was again **asked** for a decision, she explained that she was so moved by the discussion and the picture of the patient that it presented that she was willing to remove the respirator. The mediator then urged caution until the ICU physician, with the assistance of the mediator, if she desired, could discuss her decision with the hospital authorities and be certain that they supported her reasoning and decision.

The mediator then briefly explained the "principled resolution"[6] that she had kept in mind for this case: a "consensus that identifies a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts, and that facilitates a clear plan for future intervention."[7] She discussed the central position of autonomy in the taxonomy of relevant ethical principles and cited this commitment as the basis for endorsing the conscious choice of a decisionally capable patient over opposing notions of beneficence and a commitment to extending life. She also discussed the possibly relevant U.S. Supreme Court cases (admitting that she did not know the Canadian law), especially noting the existence of the doctrine of "double intent" lurking in the case regarding physician-assisted suicide.

THE CHART NOTE: PROVIDING THE ETHICS FOR BIOETHICS MEDIATION

When the mediation ended, the audience appeared genuinely agitated in their opening responses, critiques, questions, and attacks. Primary among the responses was: Where is the bioethics in this process? Where are the principles? Where is "do no harm," beneficence, and non-maleficence? What does this process have

to do with bioethics? Why did the ICU physician present such a diametrically opposite position from the one articulated in the morning? Why didn't the friends tell the same stories in the morning, especially about the history of abuse?

The panel members first responded, addressing the difference in feeling between the intimate evening meeting and the open, and very public, ethics committee meeting. The discussion of the ethics committee seemed exposed, even though it opened with a promise of confidentiality, but the numbers of the ethics committee already constituted the sort of wide sharing that real confidentiality precludes. The physicians and friends stated that they felt extraneous to the gathered experts. The ethics committee members all greeted each other as friends, as insiders; the physicians and friends felt as though they were outsiders. The morning was, by its nature, public. In contrast, the mediation was quiet and shielded.

Clearly the evening meeting did not have the crisp, organized structure of the bioethics committee. It meandered, especially at the beginning, as the friends shared stories and associations. It sharpened its focus when the physicians discussed the medical facts of the case and strongly shared perceptions that the patient was, without question, decisionally capable and not depressed. The physicians concluded that Joseph was not depressed when he attempted to end his life and saw his action as advancing his self-identified interests. Finally, the ICU physician said that her objections to following the patient's advance directives were overwhelmed by the tone and content of the discussion, offering the portrait of this strong and determined patient.

The clamor of the audience was correct. There is, generally, little mention of bioethics principles in bioethics mediation. Mediation exists in stark contrast to the structured intellectual work of a bioethics committee. The mediator did comment, in the course of the mediation, on the notion of autonomy and on the principle of "do no harm." She queried whether only a vitalist notion of life would demand continuing ventilatory support? Is the length of a patient's life the only relevant measure? Or could the patient's own self-described notion of value be relevant?

The mediation is designed to manage or resolve conflict. It seeks to empower the nonmedical persons as the experts on the patient and to search for solutions within the medical facts and the patient's described commitments. The principles and practices matter to mediators as they struggle to keep in mind the "principled resolution." Mediators need to keep in mind the ethical, legal, and medical literature that sets the boundaries for the agreement they seek.

CREATING THE CHART NOTE: WRITING TO THE TEST

Because bioethics mediation is focused on solving a problem, within the confines of the principled resolution, and not on just applying abstract bioethics principles, it self-consciously eschews abstract discussions that may alienate and silence patients, family, friends, and even staff. But staff, both participants in the mediation and in subsequent shifts, who we can assume are familiar with the bioethical language, must be brought along in the chart note. Chart notes are critically important as they:

- Reflect the support of the administration, which approves the particular consultant's interventions and facilitates a bioethics note in the chart—the legal record of the patient's care;
- Provide the only reliable basis for engaging in peer review and quality improvement of the CE consultation process;
- Communicate the consensus reached and explain the ethical bases for that agreement, couched in a recommendation that reflects the nature of the principled resolution;
- Explain the resolution/consensus in terms of commonly agreed upon ethical concepts;
- Elucidate the process and the product of the bioethics mediation so that staff members who were not present will be able to understand and implement the agreement;
- Offer the basis for a completely transparent process as the note, once entered into the chart, can be sent to administrative authori-

ties as a record of the actions that were recommended.

The use of a chart note evaluation document, such as shown in figure 1, permits the CE consultant to "write to the test" and include all of the elements that count in the evaluation. If any of these major elements is missing, it may constitute a "deal breaker" and call into question not only the validity of the note, but of the consultation itself. Consider the following as the body of the chart note for this case.

The Chart Note

Relevant social and medical history. Joseph was brought to the hospital by EMS, called by the postman who discovered him unresponsive in his home. He was intubated in the ICU. Thereafter, his close friends, his primary care physician, a neurologist, and a neuropsychiatrist who had recently examined him, came to the hospital to try and convince the ICU attending to disconnect ventilator. They argued that Joseph, in the last stages of MS, had decided to end his life rather than suffer slow and inevitable decline. All of the physicians stated that he was decisionally capable at the time of his decision and it was not caused by a clinical depression. All argued that his autonomous decision was to control his dying while he could before total physical incapacity intervened. To that end, he saved barbiturates and took, what he thought to be, and what would have been—but for the accident of his being found—a lethal dose.

The ICU attending was uncomfortable disconnecting the ventilator while barbiturates were still in the patient's system and likely suppressing respiration. Once these medications had been excreted, then the residual respiration would be evident. The friends argued that it might be that he would be able to breathe on his own, but given the likely anoxic brain damage (he was not breathing when discovered), he might end up in long-term care in a persistent vegetative state, which was his greatest fear. He had cared for his mom as she had died of MS in a nursing home, and he clearly, in all of his directives, did not want to repeat that voyage for himself. [This discussion could be augmented by the facts described above in this article.]

The process of the CE consultation. This CE consultation consisted of a mediation among the patient's primary care physician, a neurologist, a neuropsychiatrist who had recently seen the patient to assess his disease and to evaluate his possible depression, the ICU attending, and two close friends of the patient's. First, all of the participants visited the patient. Then they moved to another room for discussion.

Ethical issues and analysis. Advance directives contain two sorts of documents: living wills and the appointment of a proxy or healthcare agent. This patient had executed both. A living will is a document that explains what the patient would want in the future if she or he could no longer discuss the decision and provide contemporaneous informed consent. Living wills are value neutral, and could be used to prospectively request or refuse care. Most living wills, however, are structured to refuse interventions like surgery, ventilators, and antibiotics. Healthcare proxy appointments give the person appointed general ability to make decisions for the patient based on the standards of what the patient has said she or he would want (explicit directive), what one could surmise she or he would want from her or his behavior and pattern of life (substituted judgment), and, absent both of these, what is in her or his best interest. Healthcare proxy appointments are generally more flexible and more responsive to the nuances of medical conditions than are living wills. Proxy appointments permit the team, with the proxy, to begin an intervention, to assess its success, and then to continue or withdraw it as the condition of the patient requires. Living wills tend to make absolute rather than nuanced statements, and as such are less appropriate to the art of medicine.[8]

However, in this case, the patient's advance directives consisted of a living will and the appointment of his two best friends as alternate proxies: Ms. A was first and Mr. B was to act if Ms. A were unavailable. Both advance directives were unambiguous. Joseph had expressed his wishes never to be on a ventilator and never

Figure 1. Clinical ethics consultation quality improvement review

Patient name _____ Age _____ MR # _____
Hospital _____ Unit or clinic _____
Clinical ethics consultant _____ Date of consult _____
Reason given for consult _____
Clinical ethics reviewer _____ Date of review _____

Question	Yes	+/-	No	N/A	Comment
Is it clear who requested the consult?					
Did the consultant meet with the clinicians?					
Are the positions of the clinicians clear?					
Did the consultant visit the patient?					
Is the patient's voice heard?					
Did the consultant meet with one or more surrogates?					
Are surrogates' voices heard?					
Is it clear who is making decisions on the patient's behalf?					
Did mediation, facilitation, explanation or other intervention achieve consensus?					
Is ethically relevant medical history included in the chart note?					
Is ethically relevant social history included in the chart note?					
Are the ethics issues identified (indicate in the list below)?					
Is relevant bioethical knowledge and analysis included in the chart note?					
Is the chart note sufficient for educational purposes?					

✓	Ethics issues identified	✓	Ethics issues identified
	Advance directive interpretation		Benefit/burden analysis
	Best interest of the patient		Confidentiality
	Cultural values and treatment		Capacity (decision specific)
	Disputes among clinicians		Disputes among surrogates
	Disputes clinicians versus surrogates		DNR/DNI
	Double effect		End of life decision making
	False choices		Fair allocation of resources
	Informed consent		Medical futility
	Palliative versus curative treatments		Patient autonomy
	Refusal of treatment		Religious values and treatment
	Responsibility dumping		Setting limits for care
	Substituted judgment		Truth telling
	Withdrawing/withholding of life-sustaining treatment		

This particular iteration of the chart note review form was composed by James Zisfein, Chief of Neurology, Lincoln Hospital, New York City Health and Hospitals Corporation, for use as an evaluation form for the Ethics Council, which he chairs.
MR = medical record; DNR = do not resuscitate; DNI = do not intubate

to be in a nursing home. He had written documents and engaged in conversations to these ends with all of his physicians and friends.

The ethical problems in this case lie both in the law and in long-standing physician objections to assisted suicide.[9] In 1997, the U.S. Supreme Court upheld two state laws that absolutely prohibit assisted suicide. The Court found that Washington State's law did not violate constitutional guarantees of liberty (*Washington v. Glucksberg*[10]) and that New York State's similar law did not violate constitutional guarantees of equal protection (*Vacco v. Quill*[11]). However, in 2006, this same Court upheld the Oregon Physician Assisted Suicide Act over the attempts of the Bush administration's Attorney General to trump the state's power with the federal government's ability to regulate physicians' use of opiates. Thus, it is possible that the legal norm is evolving and favoring a more nuanced interpretation of patient rights.

It is, in this legal context, especially important to note Justice O'Connor's concurrence in *Washington v. Glucksberg*. Implicitly incorporating the doctrine of double effect, she wrote: "In sum, there is no need to address the question whether suffering patients have a constitutionally cognizable interest in obtaining relief from the suffering that they may experience in the last days of their lives. There is no dispute that dying patients in Washington and New York can obtain palliative care, even when doing so would hasten their deaths."[12]

In the same vein, in the shadow of the doctrine of double effect, the ICU attending was choosing to respect the prior direct wishes of a decisionally capable and nondepressed patient, so well documented by his physicians and friends, even when doing so might hasten his death. The goal of her actions was to support the patient's autonomy in the face of a likely horrible outcome. This consensus reflected the clear dictates of the patient that he "never wanted to be on a ventilator."

Recommendation. The consensus of the group was to recommend respecting the wishes of the patient by removing the ventilator in response to his clear and unambiguous prior wishes. Both his friends and his physicians stated that he was unambivalent about his wish to end his life in light of his inevitable deterioration and death.

CONCLUSION

Bioethics mediation is a useful tool for resolving conflicts in medicine. It does not focus directly on the bioethical and legal issues, although knowledge about these is critical in setting the boundaries for possible agreements that could be reached. The analysis of the relevant issues is explored directly in the chart note, which must review the social and medical facts, analyze the dynamic of the intervention, review the bioethics arguments and literature, and state the recommendation reached as part of the consensus.

Not only does the chart note record an event that is a critically important part of the planning for the care of this patient, but it permits the intervention to be reviewed for the purposes of peer review and quality improvement. If CEC (and bioethics mediation as a powerful tool) is to take its place as a part of medicine, it must be subject to review, assessment, and quality improvement initiatives, for which the chart note is the basis.

NOTES

1. I discuss the concept of "principled resolution" in N.N. Dubler, " 'A Principled Resolution': The Fulcrum for Bioethics Mediation," *Duke Law School Journal of Law and Contemporary Problems* 74 (Summer 2011): 170-200; N.N. Dubler and C.B. Liebman, *Bioethics Mediation: A Guide to Shaping Shared Solutions,* rev. and exp. ed. (Nashville, Tenn.: Vanderbilt University Press, 2011) 14-15, 302.

2. Ethics Consultation Boot Camp, Provincial Health Ethics Network of Alberta, Banff, Canada, 3 November 2011.

3. Details of this case have been changed to mask the identity of the patient and family.

4. By Susan B. Ruben, PhD.

5. Dubler and Liebman, *Bioethics Mediation,* see note 1 above, 74-5.

6. Ibid.

7. Ibid.

8. There is some debate regarding this sort of

generic paragraph. For those who see chart notes as educating the staff, it is useful to explain the concepts. This paragraph and other useful discussions were written by Jeffrey Blustein, Professor or Philosophy and Zitrin Professor of Bioethics, City College, City University of New York. Dubler and Liebman, *Bioethics Mediation,* see note 1 above pp. 11-130.

9. L.O. Gostin, "Physician-Assisted Suicide: A Legitimate Medical Practice?" *Journal of the American Medical Association* 295, no. 16 (2006): 1941-43, doi:10.1001/jama.295.16.1941; P. J. van der Maas et al., "Special Report: Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," New England Journal of Medicine 225 (28 November 1996): 1699-1705; D.E. Meier et al., "Special Article: A National Survey of Physician-Assisted Suicide and Euthanasia in the United States," *New England Journal of Medicine* 338 (23 April 1998): 1193-1201, doi: 10.1056/NEJM199804233381706.

10. *Washington v. Glucksberg,* 521 US 702—Supreme Court 1997.

11. *Vacco v. Quill,* 521 US 793—Supreme Court 1997.

12. This is the last paragraph of O'Connor's concurrence, see note 10 above.

Law

Legal Briefing: The New Patient Self-Determination Act

Thaddeus Mason Pope

ABSTRACT

This issue's "Legal Briefing" column covers recent legal developments involving the Patient Self-Determination Act (PSDA). Enacted in the wake of the U.S. Supreme Court's *Cruzan* decision in 1990, the PSDA remains a seminal event in the development of U.S. bioethics public policy, but the PSDA has long been criticized as inadequate and ineffective. Finally, recent legislative and regulatory changes promise to revitalize and rejuvenate it. The PSDA has been the subject of recent articles in *The Journal of Clinical Ethics*.[1]

I categorize new legal developments concerning the PSDA into the following eight sections:

1. Background and History
2. Rules and Requirements
3. Criticism and Challenges
4. Failed Efforts to Amend the PSDA
5. Personalize Your Care Act of 2013
6. New Regulations
7. New Regulatory Guidance
8. Expanded Enforcement

Thaddeus Mason Pope, JD, PhD, is Director of the Health Law Institute and Associate Professor of Law at Hamline University School of Law, in Saint Paul, Minnesota *tpope01@hamline.edu.*

1. BACKGROUND AND HISTORY

By the late 1980s, it was clear that individuals had an indisputable right to refuse treatment. But it was also clear that patients often lost that right when they lost capacity to make healthcare decisions. Even the U.S. Congress recognized that healthcare providers often subjected people to "unwanted and sometimes unnecessary treatment, treatment that unnaturally prolongs the dying process." The healthcare system had "become obsessed with extending life, at times neglecting the caring component of medicine and trampling on the rights of patients." Advance directives were seen as a key part of the solution. Without an advance directive, "doctors and families often just don't know a patient's wishes and fear the awesome responsibility of guessing what the patient would have thought was best."[2]

To encourage people to complete advance directives, Senator John Danforth (R-Missouri) introduced the "Patient Self-Determination Act of 1989" in the U.S. Senate in October 1989.[3] The bill had a simple goal: require Medicare and Medicaid providers to inform patients of the rights that they already have under state law to complete an advance directive. The Subcom-

mittee on Medicare and Long-Term Care of the Senate Committee on Finance held hearings.[4] But Danforth's bill died in committee. In April 1990, Representative Sander Levin (D-Michigan) introduced the Patient Self-Determination Act of 1990.[5] This bill also failed to advance.[6] But it is important to note that these early versions of the PSDA were more ambitious than the version later enacted. For example, they would have required facilities to "periodically review" advance directives and to establish "institutional ethics committees."[7] Compliance would have been burdensome and expensive.

Then, on 25 June 1990, the U.S. Supreme Court issued its opinion in *Cruzan v. Director, Missouri Department of Health*.[8] As readers of this journal are well aware, Nancy Cruzan was in a persistent vegetative state. Her family wanted to withdraw her clinically assisted nutrition and hydration.[9] But the Missouri Supreme Court denied the family's petition because they failed to present clear and convincing evidence that this treatment plan was consistent with Cruzan's wishes.[10] The Supreme Court affirmed, holding that the Constitution does not prohibit a state from requiring a family to present "clear and convincing evidence" of a patient's wishes before having authority to withdraw life-sustaining medical treatment.

The *Cruzan* case shined a bright spotlight on the importance of advance care planning.[11] This salience was apparently sufficient to reinvigorate the PSDA. Representative Levin introduced a new PSDA bill the same week.[12] While Levin's bill did not advance on its own, all of its provisions were included in the 400-page Omnibus Budget Reconciliation Act of 1990 (OBRA). Introduced on 15 October 1990, OBRA was signed into law just 20 days later, on 5 November 1990, by President George H.W. Bush.[13] OBRA did not refer to the PSDA provisions as the "Patient Self-Determination Act."[14] But the name stuck.[15] The PSDA went into effect on 1 December 1991.

2. RULES AND REQUIREMENTS

The PSDA applies to a range of healthcare facilities that participate in Medicare and Medicaid, including hospitals, nursing facilities, home health agencies, and hospice.[16] The PSDA spans fewer than 500 words in a more than 8,000-word list of requirements for participation in Medicare and Medicaid. But while it is short, the PSDA imposes five distinct duties on participating careproviders.[17]

First and most famously, the PSDA requires providers to:

1. "maintain written policies and procedures" to provide written information to each adult individual receiving medical care concerning both
   a. the individual's rights under state law to make decisions concerning medical care, including the right to formulate advance directives, and
   b. the provider's written policies respecting the implementation of such rights.[18]

The PSDA further requires providers to:

2. document in the individual's medical record whether the individual has executed an advance directive,
3. not condition the provision of care or otherwise discriminate against an individual based on whether the individual has executed an advance directive,
4. ensure compliance with requirements of state law respecting advance directives, and
5. provide education for both staff and the community on issues concerning advance directives.[19]

As it does with most other federal Medicare and Medicaid legislation, the U.S. Department of Health and Human Services (DHHS) quickly implemented the PSDA through regulations.[20] The requirements were included as Medicare "Conditions of Participation" relating to "Patient Rights."[21] While the regulations largely parrot the statutory text, they interpret and expand the statute in several places. For example, if a provider cannot implement an advance directive on the basis of conscience, the regulations specify the elements of a valid "statement of limitation."[22] At a minimum, it must:

1. clarify any differences between institution-wide conscience objections and those that

may be raised by individual physicians,
2. identify the state legal authority permitting such objection, and
3. describe the range of medical conditions or procedures affected by the conscience objection.

Congress has never amended the PSDA itself.[23] But, in 1997, Congress clarified the scope of the PSDA when it enacted the Assisted Suicide Funding Restriction Act of 1997. This statute mandated that the PSDA must not be construed to require any provider "to inform or counsel any individual regarding any right to obtain an item or service furnished for the purpose of causing, or the purpose of assisting in causing, the death of the individual, such as by assisted suicide, euthanasia, or mercy killing." The Assisted Suicide Funding Restriction Act further mandated that the PSDA not be construed to "apply to or to affect any requirement with respect to a portion of an advance directive that directs the purposeful causing of, or the purposeful assisting in causing, the death of any individual, such as by assisted suicide, euthanasia, or mercy killing."[24]

3. CRITICISM AND CHALLENGES

For decades, a significant volume of medical and legal literature has criticized the PSDA. Commentators began expressing concerns during the first few years of the PSDA.[25] And the criticism has continued for the next 20 years.[26] Much of it has focused on the PSDA's failure to more ambitiously and expansively address problems in end-of-life healthcare decision making. For example, some had hoped that the PSDA would have fixed or pre-empted inadequate patient rights protections under state law.[27] Others have criticized the PSDA on a number of other grounds, such as failing to meet the needs of patients with limited English proficiency.[28] In 1999, I joined this growing chorus.[29] I argued that the PSDA "has promoted the execution of uninformed and under-informed advance directives, and has undermined, not protected, self-determination." I concluded that the PSDA "looks like an utter failure."

I may have been too strong. To be fair, facilities have generally complied with the law.[30] But the outcome has been simply increased documentation of advance directives. The PSDA has not increased the completion of either advance directives or advance care planning.[31] Some commentators have argued that this was an inevitable organizational failure.[32] After all, the PSDA mandates advance care planning information at the wrong place, at the wrong time, by the wrong person, and through the wrong mechanism. In short, most agree that the PSDA has been, at most, a "modest success."[33]

In just the past year, major legal and medical professional associations have urged Congress to expand and update the PSDA. For example, in August 2012, the American Bar Association House of Delegates passed a resolution calling on Congress to amend the PSDA to require that:

1. Every patient or patient's authorized representative be given an opportunity to discuss issues relating to advance care planning with an appropriately trained professional representative of the provider organization within a reasonable time after the patient's admission to a facility covered by the PSDA,
2. Health insurance exchanges developed pursuant to the Patient Protection and Affordable Care Act of 2010 be required under the PSDA to provide advance care planning information and resource options for follow-up assistance,
3. In the absence of a validly executed advance directive, any clear, undisputed expression of a person's healthcare wishes with respect to healthcare should be honored, as long as consistent with applicable law.[34]

Similarly, in 2013, the American Academy of Nursing (AAN) called for the PSDA to be "updated and expanded" beyond its mere "clerical function" of providing advance directive forms to patients on hospital admission.[35] The AAN urged that the PSDA's requirements be expanded to include conversations about advance care planning in outpatient settings, primary care clinics, long-term care facilities, and com-

munity based home care and acute care settings. The AAN also called for information on the planning process to be provided to both patients and significant others.

4. FAILED EFFORTS TO AMEND THE PSDA

So far, these calls for changes to the PSDA have not met with success. Bills to amend the PSDA were first introduced within two years of its enactment. For example, the National Organ Donor Awareness Campaign Act of 1992 would have required that the provision of information under the PSDA "be coordinated with the provision of organ donation information."[36] A 1994 bill introduced by the PSDA's original proponent, Senator Danforth, would have provided for the "portability" of advance directives by specifying that "an advance directive validly executed outside the state in which such directive is presented must be given effect to the same extent as an advance directive validly executed under the law of the State in which presented." The same bill also would have extended the PSDA to dialysis centers.[37]

Since the early 1990s, dozens more bills have been introduced to expand and strengthen the PSDA. For example, in the 112th Congress, the Senior Navigation and Planning Act of 2012 would have mandated advance care planning education campaigns, an information phone line, and a clearinghouse. It also would have required the inclusion of advance care planning materials in the *Medicare and You* handbook.[38] In the 111th Congress, nearly 10 separate bills, like the Advance Directive Promotion Act of 2009,[39] called for similar measures.[40] One bill would have even required student loan lenders to discuss advance directives.[41] But none of this legislation was enacted.

In the United States, much of the public debate over end-of-life issues has occurred in the courts rather than in the legislature.[42] The legislature is better positioned to deliberate about how to balance the competing interests at stake. For example, legislatures can conduct more extensive, resource-intensive hearings. But the lack of legislative movement suggests that end-of-life medicine is "too hot" for the political branch of government, especially in the wake of the highly charged public rhetoric regarding "death panels." A Pennsylvania court hearing a right to die case summarized this sentiment as follows: "Legislatures are often slow to act, and where the legislature has failed to act, the courts must respond to protect individual rights."[43]

5. PERSONALIZE YOUR CARE ACT OF 2013

The PSDA requires that patients be apprised, at the time of admission, of their right to complete an advance directive. It also requires providers to do some community education. But it neither requires providers to engage patients, nor compensates them for engaging patients, in early advance care planning, particularly in community and clinical practices. The PSDA takes only a last chance, safety net approach to advance directive completion.

Other legislation has tried to complement the PSDA in this respect. For example, Medicare has long covered an "initial preventive physical examination" (IPPE), also known as the "Welcome to Medicare Preventive Visit."[44] The IPPE includes physicians' services consisting of a physical examination with the goal of health promotion and disease detection. In 2008, the Medicare Improvements for Patients and Providers Act of 2008 expanded the definition of the IPPE to include education, counseling, and referral with respect to screening and other preventive services as well as end-of-life planning.[45] The required "end-of-life planning" means verbal or written information regarding "(A) an individual's ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and (B) whether or not the physician is willing to follow the individual's wishes as expressed in an advance directive."[46]

While useful, including end-of-life planning only at the IPPE is limited in the same way that the PSDA is limited. Just as the PSDA is limited to disclosure on facility admission, the IPPE is limited to disclosure on Medicare "admission." In response, the bill that would become

the Affordable Care Act (ACA) was, at one time, intended to more directly offer incentives for the use of tools for early end-of-life decision making.[47] Earlier drafts of the bill contained a provision that would have reimbursed physicians under Medicare for periodically consulting with patients about advance care planning and discussing POLST (physician orders for life-sustaining treatment, an important complement to advance directives for persons with advanced illness), when available and applicable.[48] In contrast to an advance directive, which must be interpreted to be implemented, a POLST form translates the patient's wishes into immediately actionable medical orders. Moreover, POLST is transportable from one care setting to another, and is authoritative in hospitals, nursing homes, and ambulances. A growing body of evidence demonstrates that POLST is an important complement to advance directives for persons with advanced illness. But political backlash (involving talk of "death panels") ultimately forced the removal of this provision.[49]

Still, the March 2010 enacted version of the ACA did authorize "annual wellness visits" under Medicare.[50] So, through regulations in late 2010, the DHHS authorized Medicare coverage of advance care planning conversations as an element of this "annual wellness visit."[51] But this also proved controversial,[52] and the regulation was rescinded just six weeks later.[53] In 2011, Representative Earl Blumenauer (D-Oregon), the proponent of the (ultimately eliminated) "voluntary advance care planning" language in the original ACA, introduced new legislation that would have provided Medicare and Medicaid coverage for advance care planning conversations and would have provided grants to develop POLST programs.[54] But his bill died.

In March 2013, Representative Blumenauer introduced a new version of his bill, titled the Personalize Your Care Act of 2013.[55] The bill supports advance care planning in five ways. First, it provides Medicare and Medicaid coverage for a "voluntary advance care planning consultation" every five years or in the event of a major change in health status.[56] This periodic revisiting of advance care documents and goals of care recognizes that an individual's preferences can change over time. It also recognizes that the advance care plan should be updated if an individual develops a serious or chronic illness, if additional curative and palliative treatment options become available, and to consistently reflect the individual's current circumstances and preferences. On the other hand, particularly with sudden conditions like quadriplegia, the updated plan might reflect only transient and not settled long-term preferences.

Second, the Personalize Your Care Act of 2013 expands the definition of "advance directive" to also include any "other statement that is recorded and completed in a manner recognized under State law by an individual with capacity to make health care decisions and that indicates the individual's wishes regarding medical treatment in the event of future incapacity of the individual to make health care decisions." Most notably, this would expand the PSDA, requiring facilities to provide information and education about POLST in addition to traditional advance directives.[57]

Third, the Personalize Your Care Act of 2013 helps make advance care planning documents accessible wherever care is provided. The legislation ensures that an individual's electronic health record is able to display his or her current advance directive and/or POLST, so that his or her wishes are easily accessible and respected.

Fourth, under the Personalize Your Care Act of 2013, advance directives would be portable, that is, that advance directives completed in one state are honored in another state. The states have taken at least four different approaches to portability. First, some states will honor the originating state's advance directive so long as it complies with the law of the receiving state. Second, some states will honor the originating state's advance directive so long as it just reasonably or substantially complies with the law of the receiving state. Third, some states honor the originating state's advance directive so long as it complies with the law of the originating state. Fourth, some states will honor the originating state's advance directive so long as it complies with either the law of the receiving state or the law of the originating state.

In light of this variation, portability is clearly an area in which federal law is needed and could be very effective. The Personalize Your Care Act of 2013 provides: "an advance directive validly executed outside the State in which such directive is presented must be given effect by a provider of services or organization to the same extent as an advance directive validly executed under the law of the State in which it is presented." The bill has an express pre-emption clause that would pre-empt any state law with inconsistent portability provisions.

Finally, the Personalize Your Care Act of 2013 provides grants to states to establish or expand POLST programs. For instance, the National POLST Paradigm Program Task Force provides consultation, guidance, and mentorship to developing states for program and form development, recognizing the uniqueness of each state.[58] These programs have a track record of promoting patient autonomy through:

a. documenting and coordinating a person's treatment preferences,
b. clarifying treatment intentions and minimizing confusion,
c. reducing repetitive activities in complying with the PSDA, and
d. facilitating appropriate treatment by emergency personnel.

Representative Blumenauer's Personalize Your Care Act of 2013 has been referred both to the House Committee on Energy and Commerce, and to the House Committee on Ways and Means. Each committee will consider those provisions of the bill that fall within its jurisdiction. Unfortunately, the measure is not expected to pass.

6. NEW REGULATIONS

Furthering the objectives of the PSDA are new re-imbursement carrots in the electronic health records (EHR) incentive program.[59] To spread the use of EHRs to improve healthcare quality, the Centers for Medicare and Medicaid Services (CMS) issued "meaningful use" standards.[60] These relate to having complete and accurate information, to ensuring access to the information, and to assuring the empowerment of patients. By satisfying specific criteria, providers can earn incentive payments. One of these measures is "whether more than 50% of unique patients 65 years old or older admitted to a hospital's inpatient place of service have an indication of an advance directive status recorded as structured data."[61] CMS has already paid more than $8 billion in incentive payments, and advance directive documentation has presumably increased. But these significant financial incentives could increase the already documented risk that clinicians will badger or coerce patients into completing advance directives or POLSTs. A significant population of individuals are reluctant to complete advance directives. Some may distrust how clinicians will use them. Some find it too painful to imagine future states of critical illness. Others are simply not ready, because they have not yet reflected and discussed their preferences.

7. NEW REGULATORY GUIDANCE

On 15 April 2010, President Obama issued a Memorandum on Hospital Visitation to the Secretary of DHHS.[62] While largely focused on visitors for lesbian, gay, bisexual, and transgender patients, in this memorandum, the President asked that DHHS "ensure that all hospitals participating in Medicare or Medicaid are in full compliance with regulations . . . promulgated to guarantee that all patients' advance directives . . . are respected." The President further requested that DHHS "issue new guidelines . . . and provide technical assistance on how hospitals . . . can best comply with the regulations and take any additional appropriate measures to fully enforce the regulations."

By May 2010, CMS, the relevant DHHS agency, promulgated a proposed rule.[63] After receiving and reviewing comments, CMS promulgated a final rule in November 2010.[64] But perhaps more significantly, CMS revised two section of its State Operations Manual (SOM).[65] This manual contains interpretive guidelines that elaborate on the regulations. And it contains instructions for surveyors on how to monitor compliance.[66]

In September 2011, CMS first revised SOM Appendices A and W.[67] Appendix A relates to hospitals. Appendix W relates to critical access hospitals. CMS published a further update in December 2011.[68] The revisions provide additional guidance to surveyors on how to assess compliance with advance directive requirements. For example, they provide tips on conducting patient and family interviews and directions for performing document review.

In September 2012, CMS revised Appendix PP, the section focusing on long-term care facilities. CMS published a further update in March 2013.[69] Federal regulations have long provided that a nursing home resident "has the right to refuse treatment. . . ." But in its SOM update, CMS strengthened the implementation of this standard by better clarifying that "the resident may not be treated against his/her wishes."[70] Specifically, CMS issued detailed guidance for surveyors, helping them to identify noncompliant practices, policies, and procedures.

Surveyors conduct observations, interviews, and record reviews to assess compliance at two different levels. First, they determine whether "orders are consistent with the resident's documented choices and goals." Second, they determine whether "any treatment or interventions have been ordered . . . that are inconsistent with the resident's documented acceptance or refusal of treatment or with an existing advance directive." In short, the new CMS guidance directs surveyors to ensure (1) orders match wishes and (2) treatment matches orders.

Furthermore, the new guidance not only strengthens the rigor of the inspection process relative to life-sustaining treatment, but it also increases the penalties for noncompliance. The new guidance provides that "failure to obtain and implement medical orders related to life-sustaining treatments" is the highest level deficiency: "Level 4: Immediate Jeopardy to Resident Health or Safety."

7. EXPANDED ENFORCEMENT

In the past 20 years, a number of individuals have brought lawsuits against healthcare providers, alleging violations of the PSDA. But these claims have been uniformly dismissed. The courts have consistently held that the PSDA affords individuals no private cause of action.[71] Indeed, Congress specifically avoided changing this when, in March 2005, it enacted the infamous "Act for the Relief of the Parents of Theresa Marie Schiavo." This law gave jurisdiction to the United States District Court for the Middle District of Florida "to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo for the alleged violation of any right . . . relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life." Some legislators may have been concerned that this law might imply that other patients were entitled to litigate PSDA violations. Accordingly, the Schiavo Act specifically provides that "nothing in this Act shall affect the rights of any person under the Patient Self-Determination Act of 1990."[72]

Since patients and families cannot themselves enforce the PSDA, enforcement authority rests with CMS.[73] CMS, in turn, contracts with the states to monitor healthcare facilities that want to be eligible to provide care to Medicare and Medicaid beneficiaries.[74] So the state, usually through its health department or department of human services, has the responsibility to certify a facility's compliance or noncompliance with quality and performance standards in Medicare and Medicaid regulations.

My own preliminary investigation suggests that surveyors are stepping up enforcement of the PSDA. For example, my examination of a new hospital inspection database created by the Association of Health Care Journalists indicates there were twice as many inspections relating to advance directives in 2012 compared to 2011.[75] My research in a DHHS database reveals the same thing. When providers dispute imposed sanctions, they can appeal to an administrative law judge and then to the DHHS Departmental Appeals Board.[76] A search for Departmental Appeals Board cases concerning advance directives found there were as many cases (11) concerning advance directives since 2010 as in the previous 10 years combined.[77]

Right to Refuse

One type of PSDA obligation that surveyors have been aggressively enforcing is the right to refuse treatment. For example, the Kentucky Cabinet for Health and Family Services Office of Inspector General (OIG) is Kentucky's regulatory agency for licensing all long-term care facilities.[78] To monitor and enforce the rights of residents in Kentucky long-term care facilities, the OIG conducts unannounced inspections.[79] For example, according to the South Carolina Nursing Home Blog, in March 2008, the OIG issued a citation to Green Meadows Health Care for trying to revive a resident who had signed a do-not-resuscitate (DNR) order.[80] And, according to the *Independent Online*, in March 2009 the OIG cited Louisville's Jefferson Manor after staff resuscitated 95-year-old Eva Karem, despite a DNR order.[81]

Other states have similarly sanctioned facilities for resuscitating residents contrary to their instructions. For example, in June 2012, a Florida facility was cited for initiating CPR on a resident "who had stated on admission that he did not want to be resuscitated."[82] Many additional cases concerning PSDA rights are included in ProPublica's Nursing Home Inspect database.[83]

Furthermore, the states have been sanctioning facilities not only for inappropriate resuscitation, but also for improperly or inadequately recording residents' preferences not to be resuscitated. For example, one facility "failed to place the signed DNRs in the patient's records," placing them "at risk for their [DNR] wishes not being followed."[84] Another facility lacked "necessary policies and procedures for assuring that residents' advance directives would be honored."[85]

Right to Futility Policies

Surveyors have also been enforcing other PSDA requirements. One of these requirements is to "provide written information" to all admitted patients concerning "the written policies of the provider or organization respecting the implementation of . . . an individual's rights . . . to make decisions concerning such medical care."[86] Several hospitals have recently been penalized for failing to disclose their medical futility policies. To be clear, the PSDA does not restrict a hospital's ability to adopt or implement a medical futility policy. It simply requires disclosure of the policy.

For example, according to reports by the Association of Health Care Journalists (AHCJ), based on information from CMS, in January 2012, clinicians at Milwaukee's Froedtert Hospital had an actively dying patient who had 21 hospitalizations in the past year and had received 20 units of blood in the past month. Clinicians concluded that this patient had no capacity to benefit either from nearly daily transfusions or from being a full code. But the family would not consent to the proposed treatment plan. So, pursuant to the institution's futility policy, clinicians wrote a DNR order over the objections of the patient's family. Surveyors found that Froedtert violated the patient's rights under the PSDA because the "hospital failed to notify patient of the hospital's Medical Futility Policy prior to implementing the policy."[87]

Surveyors reached a similar conclusion, in February 2012, at Botsford Hospital in Farmington Hills, Michigan, according to AHCJ. Surveyors found that there was no information in the "Patient Folder" informing patients of the hospital's "Medical Futility" and "Resuscitation Not Indicated" policies, even though those policies may limit a patient's rights to formulate advance directives and have them honored by the facility. Furthermore, surveyors found that patients and surrogate decision makers were not provided with written information on facility policies when a physician determines medical futility and writes an order for "no CPR" (cardiopulmonary resuscitation.)[88]

CONCLUSION

The legislative history of the PSDA indicates that its proponents had six clearly distinguishable goals for the act.[89] These were:

1. to empower people,
2. to produce more advance directives,
3. to ensure the honoring of advance directives,
4. to spur more state advance directive statutes,

5. to reduce overtreatment, and
6. to control medical costs.

But the PSDA has substantially failed to achieve most of these goals. Its main outcome has been just the routine distribution of information about advance directives and patients' rights to accept or refuse medical treatment.

This should not be surprising. The PSDA's mandates are too modest to produce broader change. Recognizing this, recent legislative and regulatory efforts have focused not only on enforcing the PSDA but also on expanding and supplementing the reach of the PSDA. Still, even this is not enough. CMS alone cannot achieve the PSDA's original goals, due to limitations imposed by the PSDA itself. The agency has repeatedly confirmed that the PSDA "defers to State law to govern advance directive issues."[90] Consequently, to achieve the original objectives of the PSDA, state legislatures and health agencies must strengthen state laws concerning informed consent, advance directives, POLST, and surrogate decision making.

NOTES

1. T.M. Pope, "Legal Briefing: Advance Care Planning," *The Journal of Clinical Ethics* 20, no. 4 (Winter 2009): 289-96.

2. Sen. Danforth, "Patient Self-Determination Act," 35 *Cong. Rec.* S13,564 (17 October 1989).

3. S.1766, 101st Cong., 1st Sess. (1989) (Danforth).

4. Senate Hearing 101-1168 (20 July 1990).

5. H.R. 4449, 101st Cong., 2nd Sess. (1990) (Levin).

6. The bill was referred to the Subcommittee on Health and the Environment of the House Committee on Energy and Commerce.

7. An exhaustive legislative history is provided in E.J. Larson and T.A. Eaton, "The Limits of Advance Directives: A History and Assessment of the PSDA," *Wake Forest Law Review* 32, no. 1 (1997): 249-93.

8. 497 *U.S.* 261 (1990).

9. W. Colby, *Long Goodbye: The Deaths of Nancy Cruzan* (Hay House, Carlsbad, Calif.: 2002).

10. *Cruzan v. Harmon,* 760 S.W.2d 408 (Mo. 1989).

11. Rep. Levin, "Introduction of the Patient Self-Determination Act," 136 *Cong. Rec.* H4222 (27 June 1990); Rep. Levin, "Patient Self-Determination," 136 *Cong. Rec.* E2190 (28 June 1990).

12. H.R. 5067, 101st Cong., 2nd Sess. (1990) (Levin).

13. H.R. 5835, 101st Cong., 2nd Sess. (1990) (Panetta), enacted as Pub. L. No. 101–508 §§ 4206 and 4751, 104 Stat. 1388-115 to -117 and -204 to -206 (5 November 1990), codified at 42 *U.S.C.* §§ 1395cc(f) and 1396a(w).

14. The provisions were included in Title IV of OBRA (Omnibus Budget Reconciliation Act), ("Medicare, Medicaid, and Other Health-Related Programs") in Section 4206 ("Medicare Provider Agreements Assuring the Implementation of a Patient's Right to Participate in and Direct Health Care Decisions Affecting the Patient").

15. A. Meisel and K.L. Cerminara, *The Right to Die: The Law of End-of-Life Decisionmaking,* 3rd ed. (New York: Aspen, 2013), § 7.04[c].

16. 42 *U.S.C.* § 1395cc(a)(1)(Q); 42 *U.S.C.* § 1396a(a)(57); 42 *U.S.C.* § 1396r(c)(2)(E); 42 *U.S.C.* § 1395i-3(c)(1)(E); 42 *U.S.C.* § 1395bbb(a)(6). The PSDA also applies to Medicare HMOs. 42 U.S.C. § 1395mm(c)(8); 42 U.S.C. § 1395w-22(i).

17. Many of these same duties are separately imposed by Joint Commission accreditation requirements or by state law. The Joint Commission, *2013 Comprehensive Accreditation Manual for Hospitals* (Oakbrook Terrace, Ill.: Joint Commission, 2013), § RI.01.05.01; N.J. Stat. § 26-2H-65(2).

18. 42 U.S.C. § 1395cc(f)(1)(A); 42 *U.S.C.* § 1396a(w)(1)(A). In the case of a hospital, this information must be provided upon admission. 42 *U.S.C.* § 1395cc(f)(2); 42 *U.S.C.* § 1396a(w)(2).

19. 42 *U.S.C.* § 1395cc(f)(1)(B)-(E); 42 *U.S.C.* § 1396a(w)(1)(B)-(E).

20. DHHS, "Medicare and Medicaid Programs; Advance Directives: Interim Final Rule," 57 *Fed. Reg.* 8,194 (6 March 1992). These regulations were later amended several times. DHHS, "Medicare Program; Changes to the Hospital Inpatient Prospective Payment Systems and Fiscal Year 1995 Rate," 59 *Fed. Reg.* 45,403 (1 September 1994); DHHS, "Medicare and Medicaid Programs; Advance Directives: Final Rule," 60 *Fed. Reg.* 33,262 (27 June 1995); DHHS, "Medicare Program; Changes to the Hospital Inpatient Prospective Payment Systems and Fiscal Year 1998 Rates: Final Rule," 62 *Fed. Reg.* 46,037 (29 August 1997); DHHS, "Medicare and Medicaid Programs; Religious Nonmedical Health Care Institutions and Advance Directives: Interim Final Rule," 64 *Feg. Reg.* 67,052 (30 November 1999); DHHS, "Medicare and Medicaid Programs; Religious Non-

medical Health Care Institutions and Advance Directives: Final Rule," 68 *Fed. Reg.* 66,710 (28 November 2003). "All CMS regulations related to advance directives are based in 1866(f)(3) of the [Social Security] Act." DHHS, "Final Rule: Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Visitation Rights for All Patients," 75 *Fed. Reg.* 70,831, 70,841 (19 November 2010).

21. 42 *C.F.R.* § 482.13(b)(3). This regulation provides that patients have "the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives, in accordance . . . 489.102." The substantive PSDA requirements are included in 42 *C.F.R.* § 489.102.

22. 42 *C.F.R.* § 489.102(a)(1)(ii).

23. Interestingly, one bill proposed the partial repeal of the PSDA. H.R. 566, 102nd Cong., 1st Sess. (1991) (Donnelly).

24. H.R. 1003, 105th Cong., 1st Sess. (1997) (Hall), enacted as Pub. L. No. 105-12, § 7, (30 April 1997), 111 Stat. 26, codified at 42 *U.S.C.* § 14406.

25. S.M. Wolf et al., "Sources of Concern about the Patient Self-Determination Act," *New England Journal of Medicine* 325, no. 23 (1991): 1666-71; E.J. Emanuel et al., "How Well Is the Patient Self-Determination Act Working? An Early Assessment," *American Journal of Medicine* 95, no. 6 (1993): 619-28; A.M. Capron, "The Patient Self-Determination Act: Not Now," *Hastings Center Report* 20, no. 5 (September/October 1990): 35-6; M.A. Refolo, "Patient Self-Determination Act of 1990: Health Care's Own Miranda," *Journal of Contemporary Health Law and Policy* 8 (1992): 455-71.

26. L.P. Ulrich, *The Patient Self-Determination Act: Meeting the Challenges in Patient Care* (Washington, D.C.: Georgetown University Press, 2001); G. Duke et al., "The PSDA 20 Years Revisited," *Journal of Nursing Law* 13, no. 4 (2009): 114-23; A.W. Foster, "Bacon, Eggs, and Advance Directives: The PSDA 20 Years Later," *University of Houston Health Law Perspectives* (May 2011); O. Ben-Shahar and C.E. Schneider, "The Failure of Mandated Disclosure," *University of Pennsylvania Law Review* 159, no. 3 (2011): 647-749; E.H. Bradley et al., "Institutional Efforts to Promote Advance Care Planning in Nursing Homes: Challenges and Opportunities," *Journal of Law, Medicine, and Ethics* 25, no. 2 and 3 (1997): 150-59.

27. R.E. Shugrue, "The Patient Self-Determination Act," *Creighton Law Review* 26, no 3 (1993): 751-83; L. Rutkow, "Dying to Live: The Effects of the PSDA on Hospice Care," *NYU Journal of Legislation and Public Policy* 7, no. 2 (2004): 393-435.

28. C.J. Jones, "Say What? How the PSDA Leaves the Elderly with Limited English Proficiency out in the Cold," *Elder Law Journal* 13, no 2 (2005): 489-518.

29. T.M. Pope, "The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act," *Health Matrix* 9, no. 1 (1999): 139-202.

30. *Patient Self-Determination Act—Providers Offer Information on Advance Directives but Effectiveness Uncertain,* GAO/HEHS Doc. No. 95-135 (1995).

31. See Meisel and Cerminara, note 15 above, § 7.04 fn.222.

32. D. Leahman, "Why the Patient Self-Determination Act Has Failed," *North Carolina Medical Journal* 65, no. 4 (2004): 249-51.

33. See Larson and Eaton, note 7 above, p. 284.

34. *Resolution 106A, Adopted by the American Bar Association House of Delegates* (6 August 2012), *http: //www.abanow.org/2012/06/2012am106a/,* accessed 3 June 2013. The resolution further encouraged requiring "the annual Medicare wellness examination, or other periodic doctor-patient interactions, to include both an opportunity to engage in and assistance with have resource options available relating to advance care planning for health decisions."

35. American Academy of Nursing, "Policy Brief: Advance Care Planning as an Urgent Public Health Concern" (15 April 2013), *http: //www.aannet.org/policy-brief—advance-care-planning-as-an-urgent-public-health-concern—2013-,* accessed 3 June 2013.

36. H.R. 5785, 102nd Cong., 2nd Sess. (1992) (Roybal).

37. S.2556, 103rd Cong., 2nd Sess. (1994) (Danforth).

38. S.3684, 112th Cong., 2nd Sess. (2012) (Warner).

39. H.R. 3253, 111th Cong., 1st Sess. (2009) (Levin).

40. Advance Directive Incentive Act, H.R. 2705, 111th Cong., 1st Sess. (2009); Personalize Your Care Act of 2010, H.R. 5795, 111th Cong., 2nd Sess. (2010) (Blumenauer); Advance Planning and Compassionate Care Act of 2009, S.1150, 111th Cong., 1st Sess. (2009); Advance Planning and Compassionate Care Act of 2009, H.R. 2911, 111th Cong., 1st Sess. (2009) (Blumenauer); Senior Navigation and Planning Act of 2009, S.1263, 111th Cong., 1st Sess. (2009) (Warner); Senior Navigation and Planning Act of 2009, S.1251, 111th Cong., 1st Sess. (2009) (Warner); Senior Navigation and Planning Act of 2009, H.R.

3172, 111th Cong., 1st Sess. (2009) (Baldwin).

41. Christopher's Law, H.R. 5458, 111th Cong., 2nd Sess. (2010) (Adler).

42. D.B. White and T.M. Pope, "The Courts, Futility, and the Ends of Medicine," *Journal of the American Medical Association* 307, no. 2 (2012): 151-52. Until Vermont legalized physician aid-in-dying in May 2013, no U.S. state had done that through legislation. The Death with Dignity Acts in Washington and Oregon were enacted through ballot initiatives. Montana legalized aid-in-dying through a court decision. P. Span, "Vermont Passes 'Aid in Dying' Measure," *New York Times,* New Old Age Blog (14 May 2013).

43. *In re Jane Doe,* 45 Pa. D. and C.3d 371 (1987).

44. 42 U.S.C. § 1395x(ww).

45. H.R. 6331, 110th Cong., 2nd Sess. (2008) (Rangel), enacted as Pub. L. No. 110-275 (2008).

46. 42 *U.S.C.* § 1395x(ww)(3).

47. America's Affordable Health Choices Act of 2009, H.R. 3200, § 1233, 111th Cong., 1st Sess. (2009) (Dingell).

48. C.P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," *Milbank Quarterly* 88, no. 2 (2010): 211-39.

49. G. Kessler, "Sara Palin, Death Panels, and Obamacare," *Fact Checker* (27 June 2012), *http: //www.washingtonpost.com/blogs/fact-checker/post/sarah-palin-death-panels-and-obamacare/2012/06/27/gJQAysUP7V_blog.html,* accessed 3 June 2013.

50. Pub. L. No. 111-148, § 4103.

51. 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).

52. 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 Secretary Kathleen Sebelius (14 March 2011).

53. 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).

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

55. H.R. 1173, 113th Cong., 1st Sess. (2013) (Blumenauer); 159 *Cong. Rec.* E300 (14 March 2013).

56. The bill would amend 42 *U.S.C.* § 1395x(s) by expanding the definition of "medical and other health services."

57. I comprehensively covered recent legal developments concerning POLST in T.M. Pope and M. Hexum, "Legal Briefing: POLST (Physician Orders for Life Sustaining Treatment)," *The Journal of Clinical Ethics* 23, no. 4 (Winter 2012): 353-76.

58. *http: //www.polst.org,* accessed 3 June 2013.

59. Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH), Pub. L. No. 111-8 §§ 4101, 4101-04 and 4201, 123 Stat. 115, 467-94, codified *inter alia* at 42 U.S.C. § 1395w–4(n)(-(o).

60. 42 *C.F.R.* §§ 495.2 to 495.370.

61. 42 *C.F.R.* §§ 495.6(g)(2) and 495.6(m); Centers for Medicare and Medicaid Services, "The Official Web Site for the Medicare and Medicaid Electronic Health Records (EHR) Incentive Programs," *http://cms.gov/regulations-and-guidance/legislation/ehrincentiveprograms/*, accessed 3 June 2013.

62. *http: //www.whitehouse.gov/the-press-office/presidential-memorandum-hospital-visitation,* accessed 3 June 2013; 75 *Fed. Reg.* 20,511 (15 April 2010).

63. DHHS, "Proposed Rule: Medicare and Medicaid Programs: Proposed Changes Affecting Hospital and Critical Access Hospital (CAH) Conditions of Participation (CoPs): Credentialing and Privileging of Telemedicine Physicians and Practitioners," 75 *Fed. Reg.* 29,479 (26 May 2010).

64. DHHS, "Final Rule: Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients," 75 *Fed. Reg.* 70,831 (19 November 2010).

65. Centers for Medicare and Medicaid Services, "Survey and Certification Letter 12-47," 27 September 2012, *http: //www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-47.pdf,* accessed 3 June 2013.

66. DHHS, Medicare and Medicaid Programs; Hospital Conditions of Participation: Patients' Rights, 64 *Fed. Reg.* 36,070 (2 July 1999).

67. Centers for Medicare and Medicaid Services, "Survey and Certification Letter 11-36: Hospital Patients' Rights to Delegate Decisions to Representatives; New Hospital and Critical Access Hospital (CAH) Patient Visitation Regulation," 7 September 2011, *http: //www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-11-36-Part-I.pdf,* accessed 3 June 2013.

68. Centers for Medicare and Medicaid Services, "CMS Manual System: Pub 100-07 State Operations Provider Certification: Transmittal 75," 2 December 2011, *http: //www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R75SOMA.pdf,* accessed 3 June 2013.

69. Centers for Medicare and Medicaid Services,

"Survey and Certification Letter 13-16: F tag 155—Advance Directives-Revised Advance Copy," 8 March 2013, *http: //www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-16.pdf,* accessed 3 June 2013. Around this same time, CMS released updated interpretive guidelines to CMS state survey agencies and CMS regional offices clarifying the obligations of ambulatory surgery centers to honor advance directives.

70. See Survey and Certification Letter 12-47, note 65 above; see also J.K. Feldkamp, "Four Recent Releases by CMS for Nursing Facilities," American Health Lawyers Association, December 2012, p. 1, *http://m.babc.com/files/Publication/d17cf251-c6ae-49ba-88b4-391f51ad6246/Presentation/PublicationAttachment/27ac985a-877d-43c7-bf47-ad2950933457/LTC_Dec12.pdf,* accessed 3 June 2013.

71. *Scheible v. Joseph L. Morse Geriatric Center,* 988 So. 2d 1130, 1132 (Fla. App. 2008); *Turner v. Jackson Park Hosp.,* 264 Fed. Appx. 527 (7th Cir 2008); *Asselin v. Shawnee Mission Med. Ctr.,* 894 F. Supp. 1479 (D. Kan. 1995).

72. S. 686, 109th Cong., 1st Sess. (2005) (Frist), enacted as Pub. L. No. 109-3 (2005); 151 *Cong. Rec.* H170 (20 March 2005).

73. While patients and families have no cause of action under the PSDA, they can often sue under other laws such as state healthcare decisions acts and state common law. T.M. Pope, "Clinicians May Not Administer Life-Sustaining Treatment without Consent: Civil, Criminal, and Disciplinary Sanctions," *Journal of Health and Biomedical Law* 9, no. 2 (2013): 101-84.

74. DHHS, "Medicare and Medicaid Programs; Hospital Conditions of Participation: Patients' Rights," 64 *Fed. Reg.* 36,070 (2 July 1999).

75. *http: //www.hospitalinspections.org/* (searched "advance directive" and "tag A0132"), accessed 3 June 2013.

76. *http: //www.hhs.gov/dab/,* accessed 3 June 2013

77. *http: //www.hhs.gov/dab/decisions/index.html* (searched "advance directive"), accessed 3 June 2013.

78. Kentucky Cabinet for Health and Family Services, "Health Care and Long Term Care Applications," 10 January 2011, *http: //chfs.ky.gov/os/oig/ltcappls.htm,* accessed 3 June 2013.

79. Ky. Rev. Stat. Ann. § 216.530.

80. R. Mullman, "Nursing Homes Ignorant of DNR Purpose and Policy," *S.C. Nursing Home Blog,* 25 May 2009, *http: //www.scnursinghomelaw.com/2009/05/articles/regulatory-enforcement/nursing-homes-ignorant-of-dnr-purpose-and-policy/,* accessed 3 June 2013.

81. "Resuscitation Orders Not Always Followed in Kentucky," *Independent Online,* 22 March 2009, *http: //dailyindependent.com/local/x1192779354/Resuscitation-orders-not-always-followed-in-Ky,* accessed 3 June 2013.

82. DHHS Centers for Medicare and Medicaid Services, "Survey of Consulate Health Care of Woodhaven No. 105998," 2012, *http: //www.medicare.gov/nursinghomecompare/SurveyReportDetail.aspx?ID=105998&SURVEYDATE =June%20%208,%202012&AspxAutoDetectCookieSupport=1,* accessed 3 June 2013.

83. *http://projects.propublica.org/nursing-homes/,* accessed 3 June 2013.

84. DHHS Centers for Medicare and Medicaid Services, "Survey of Consulate Health Care of Woodhaven No. 105998," 2012, *http: //www.medicare.gov/nursinghomecompare/SurveyReportDetail.aspx?ID=105998&SURVEYDATE=June%20%208,%202012&AspxAutoDetectCookieSupport=1,* accessed 3 June 2013.

85. *Evergreen Commons v. CMS,* No. CR2372 (20 May 2011), *http: //www.hhs.gov/dab/decisions/civildecisions/cr2372.pdf,* accessed 3 June 2013.

86. 42 U.S.C. 1395cc(f)(1)(A).

87. *http: //www.hospitalinspections.org/report/1734,* accessed 3 June 2013.

88. *http: //www.hospitalinspections.org/report/964,* accessed 3 June 2013.

89. See Larson and Eaton, note 7 above.

90. DHHS, "Final Rule: Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients," 75 *Fed. Reg.* 70,831, 70,836 (19 November 2010).